Torch Trust

Sight Loss 101

in conversation with Philippa Lomas

Hello and welcome to this episode of Sight Loss 101 where I, Tim Jeffrey, the chief exec of Torch Trust, have conversations with people who are blind or partially sighted as part of helping me to understand, as a sighted person, what's it like to live in their world today.

I have a great pleasure of talking to Philippa Lomas and Philippa is somebody who has, I understand, been blind from birth. Philippa welcome and it will be lovely just to hear a little bit about your story and how your life has unfolded thus far and how sight loss has featured in that.

So I was born blind with a condition called bilateral anophthalmia which basically means that my eyes didn't develop in the womb and so I have plastic eyes. Obviously that was a massive shock to my parents. They’ve got six other children and my mum, all the way through the pregnancy, knew that something was wrong, but everything on the scans was clear and they couldn't understand why she felt like that, so basically when I was eventually born, they had to back down and say, no you were right, there was something wrong. So it was huge shock but they really wondered how I was going to live a normal life and they're very strong Christians. They always sent us to Sunday School. They have a very strong faith and they were really wondering what God would bring out of this situation - how he make it good. But they fought for me to be sent to mainstream school. They treated me just like they did any of their other children, so I played with my brothers and sisters. I was responsible for things around the house, little jobs like you are when you're young.

But what number were you in the order?

I was the baby and I have 4 sisters and 2 brothers.

Wow!

So they were a very noisy household but it was a lot of fun.

So that you must have been, as well as being the baby one that they all looked after, I suppose with the sight loss as well, that must have added an extra sort of protective layer to how they engaged with you.

It did but they very much treated me like one of them, very much normally and didn’t let it stand in the way. If they were riding bikes, I rode my trike along with them around the garden things like that things. When we were playing we used to be very naughty; we used to get in sleeping bags and slide down the stairs because the front door was directly in front of the stairs, so we used to be able to slide right out the front door if we got a good enough run up – a good enough momentum. I did that along with them. It wasn't oh she can't do this, she can't do that because she can't see. There were things they did slightly differently, like they would bring me things to feel, they would show me things. They would for quite a long time say, well Ben's just going to go and do this and that was because I needed to get to know them and their voices and who they were. So saying their name in the sentence gave me that ability to learn who they were. So I would say I had a very normal childhood and certainly because I went to mainstream school although I didn't go after lower school because we're in a three tier system, so after lower school I didn't go to the same school as my siblings. I did still go to mainstream school, but I went to the school that had a blind child before and then I went to a more local school after that for my GCSEs and things but it still meant that I went through the same sort of things as they did.

And how was school for you? That's wonderful you managed to stay in mainstream school. How well did they differentiate for you?

Lower school was fine. I always had a team with me so they taught me to read braille at age 5 when other children are learning to read print and I was very reluctant to learn braille. To me it was really boring and it was just a load of dots with nothing to break it up really and I think I really struggled with that because I just wasn't interested but I learned to touch type at the age of 6 and again that was a skill I was just like, why are they teaching me this. But now you're looking back, braille and touch typing are the things that I really couldn't do without, things from my education that I use every day. So after lower school it got a bit harder because the workload was harder. The children weren't children from my local village, they were from quite a big town near us called Bedford and it was just different there. I went from a school with probably about 50 children max to a school with sort of 250 children. It was a big jump and then from that to go to a school that's probably got, I think, was about 600 pupils, it's massive and the school premises were massive and I found it difficult to get my way around. I could do it but I was very self-conscious. I didn't really want to be the one that stuck out, I didn't want to get lost, I didn't so that sort of aspect was difficult for me and the fact that teachers really didn't understand that they needed to give the work to my support team in advance for it to be brailled. So I’d get to a science lesson and there'd be a worksheet with a diagram that hadn't been produced in a tactile format because the teacher hadn't given it in time and then I’d get told that I wasn't putting the effort in and I said to the teacher, ‘well how would you expect me?’ I actually asked her once, how do you expect me to put the effort in when you don't put the effort in? She was like well that's a fair enough question! So I actually did find it really hard work especially GCSEs. I didn't particularly enjoy school. I did all right in my subjects apart from Maths and Science but I didn't particularly enjoy it. But there were teachers that made it better, like my art teacher. I took GCSE Art because she was all about making it work for me. So I’d have different mediums to work with, like plaster of paris or paint with stuff mixed in it or shiny paper or whatever, it was all about textures and things that worked for me so, in fact, she pulled me out of a class once because the teacher who was teaching the class, was doing reflections and she said this is absolutely ridiculous, how on earth do you expect a blind person to sit there and talk about reflections, in a mirror and paint the picture from the reflection in the mirror. No this is wrong.

Amazing that. It strikes me the kind of creativity that some people bring, thinking about how do I make this work for somebody who has got either a visual impairment or some other disabling condition and how the creativity that people come with. That sounds wonderful, that art teacher.

Yeah absolutely! It's brilliant.

It's a real lesson isn't it for the rest of us I guess. Let's really use our sort of God-given creativity to find ways of making things work.

It's very much about people's attitudes and willingness to think outside the box and if they're not willing to think about it, if they just think oh well this won't work or I’m not going to do anything different, I don't know what to do that could be different, it's not going to work. I had a teacher like that who would just say, well that's what your support team are there for. But it wasn't; they can't read me every aspect of the lesson, there needs to be some communication beforehand so I really did struggle in school in a lot of ways. But I’m glad I went to mainstream school. I think for me, I’m not saying this is the case for absolutely everybody, but for me I think had I gone to a school for the blind, a residential school, I would have missed out on family life. I would have not really had a clue how hard I would find it when I came out because the working world is not much different.

Can I ask you a very practical question Philippa? That is I’m just putting myself in your shoes and thinking, going from a small school to a big school, a new building with lots of rooms and corridors and outside spaces, how do you do that when you're blind? I mean, do you build a map of it, do you get somebody to guide you around? How does that work for you?

So a bit of both. The mobility teacher or rehab worker as they now called, will come in and they will find out which classrooms you need access to and then I’ll take their arm, and walk through the corridors. They'll point out various landmarks so it could be this corridor has a glass door, this corridor has a wooden door, or there's a jutting out piece of wall here and when you get to that you need to turn down the next corridor, things like that. Well there's a piece of carpet here. When you get to that carpet you need to go straight ahead to the next door and point out the landmarks. And then walk it through with me using my long cane.

And so do you can create a map in your head?

Yes, that's how you do it. You build it up and eventually you get to remember your routes, but it was fine when the corridors were empty but I used to absolutely hate it when 50 children were coming the other way. They used to let me leave a little bit early from lessons so that I could just try and make it to my next class before the rush.

Thank you. I was just fascinated to know. My family say that I have got an internal sat nav because I just seem to know which direction I’m facing and so it makes me think, how when you have a new building or you go into a new church or something or new home how do you do that and how do you create that kind of internal map?

Well for me it was all right inside but I didn't like things like taking buses, going on public transport. I was very self-conscious and I was very scared of becoming lost with no one to help me and of course back in those days we didn't have mobile phones all the time and things like that. I was very conscious of that which made me really wary of doing routes in my hometown and things like that and because we lived in a village I would have had to get on a bus and to go into town and the problem with the buses around here is that if they don't see you waiting at the stop they won't stop the bus. They won't just stop and wait, so if I wasn't standing in the correct place the bus could have driven past or sometimes they'd think well I’m not going to drive down to that stop because there's no one waiting so I’ll stop at the stop before and it's just that uncertainty made me really panicky and unwilling to sort of break out of the box. I had a couple of bad experiences in shops when I went and tried to ask for help, so it really put me off. It wasn't until later on when I had my children and moved into my own house and my children I needed to walk around my local town, needed to take them to school but I’ve always been told by the blind community that independence is getting on public transport but because I couldn't do that my argument was, well actually now I’ve moved I live right over the road from the shops, I live walking distance from the school, it's all going to be on foot, it's all something I can do, so now that's happened I’m a lot more travel independent.

Fantastic and so sorry I interrupted your fascinating story. So what happened after school?

So after school, I did stay on and do my A levels which I actually wish I hadn't done because of the extra stress but before I left, the headmistress asked the school reception to give me 6 months’ experience on the switchboard. So that was really good. I learned a lot there and then I tried to apply for jobs and things like that. And various knockbacks like being told you're a health and safety risk so you can't really come and work here. I volunteered for hospital radio but it was, well we've got to get someone to lead you around, so that wouldn't be practical - things like that. Various knockbacks and I was wondering really what God wanted out of my life and maybe that I just need to be - because I’ve got loads of nieces and nephews - maybe I just need to be a babysitter for them. And then my uncle who owns an auction centre in Bedford, he rang me and he said, ‘I’m looking for somebody to come and do a couple of days’ work, answering the phones while the others are typing up the lots for auction.’ I am interested so I went and found out about that and I actually worked there for 3 years with support from Access to Work and really learned a lot there and eventually as well as answering the phone, I got able to type the lots on for sale and help with the cataloguing and things like that. So that I really enjoyed that job and it was brought to a bit of an abrupt end because Access to Work which is the company that funds all the specialist equipment and things, they had done my claim for 3 years and because I had taxis to and from work and because I was working part-time, it should have only been for one year, so they did it wrong and then when I came to the end of the claim it was, ‘well we're not going to renew it because you’re not supposed to have any more support for 12 months’, so I basically lost my job overnight because I couldn't pay the taxi costs to get to and from work. So that was a bit of a shock. It was kind of God saying, well that job's come to an end.

But to go back a bit, I was always very much aware that God existed and I remember from a really young age talking to him and asking him to forgive me, right from when I was in lower school. I very much remember having conversations with God and I went to the Sunday School in my local church in Potten which was where my family attended and that church were absolutely fantastic. They were really inclusive and still are and the pastor's wife at the time, she learned braille along with my parents so that she could braille out hymns or Sunday School lessons for me.

What a commitment!

I know, it was brilliant so I was always really involved in church.

And church leaders take note of that one!

Absolutely, it was brilliant. It was really good and people would like the teachers at the Sunday School, they would make things, for example, we did once the story of the woman of washing Jesus’s feet with her tears and pouring oil on them and I had a pair of cardboard feet and a bottle of perfume and it was just accessible, really nice, so I’ve always been really involved in church and because I’m fairly musical and I do a bit of singing, so I was singing in church and things, so I’ve come to know God at an early age and I was baptized at 12.

What difference do you think being a Christian has made in your life and particularly as a blind person, in terms of coming to terms with that, with dealing with that every day? What's the difference it's made?

A massive difference. I really think had I have not been blind I wouldn't have relied so heavily on God and I know that the first face that I will ever see is going to be the face of Jesus and that to me is so important. I mean throughout my life there's been so many times when everything has changed and everything's been uncertain and I’ve really taken comfort from the fact that God never changes. You know, he's always the same and that really helped. People have asked me why I haven't got enough faith to be healed but it's not actually about that, it's about the fact that God wants to bring something about from me being blind rather than, yes it would be a massive miracle for him to heal me and he could do it right now but that's not what is in his plan. His plan is to use me as I am, to reach out to other people and that's really how I got involved with Through the Roof. I went on a trip with them to Guatemala. I was their ambassador out there to say that basically people with disabilities should be included and shouldn't be ostracized just because they've got disabilities and that was voluntary and that came about because I’d had a really bad relationship and it had really knocked my faith and my trust in God and I’d come back to God and said to him, ‘what do you want me to do for you because I really want to do something for you now that I have come back to you’. And my church had just changed their hymn books and they had swapped the hymn books to Praise and Christian Hymns and Christian Hymns wasn't available in braille, so they said to Torch Trust how much would it cost to transcribe and I think the cost was about £1,000 and the church funded that. And it was around about the time that the Baptist Times were doing some articles on braille in churches and so I got interviewed for one of those and from that the CEO of Through the Roof saw my article and got in touch and said, ‘would you like to come on a mission trip?’ So that was that was amazing and I can honestly say it's one of those times in my life when it's just been I knew that God was sending me and I knew that I should go and he was there almost close enough to touch and it was amazing. I went 3 times, 10 days each year for 3 years and that was when I was still working at my job at Peacock's auction centre. And then in I think it was 2011 when my job ended, it was what do I do now and then the opening for a youth ambassador came up at Through the Roof as a paid job which I applied for and I got that job. I worked there for 3 years and during that time I was going around churches basically doing what I’m doing now and sharing my story and trying to show that just because people in your churches have disabilities or people in your family have disabilities, there is a place within the church, there is a place for them in life, there's a place for them in school. It’s all about adapting your attitudes, your way of working. You can include these people, they can bring valuable contributions to everyday life and to church life and I did that for 3 years. During that time I went to Guatemala for the third time and then while I was working with Through the Roof in 2012, I was asked to go on a Torch holiday and share my story and was going to do it for one day and then I decided to go on the holiday because it looks quite fun. So I said to my mum, she's ’oh, you never know!’ I said, ‘no if you I’m going on this holiday to meet someone I’m not going. Okay I’m not going.’ So I went on this holiday and there was this man there called Will who had not really much time for God. He'd been brought up catholic and it’s fine; he's sitting opposite; he can hear every word I’m saying so it's all good. Beeb brought up catholic and not gone to church for a long time and then come on the holiday because it was an adventure holiday and was brought to know the Lord during that holiday and we came back a courting couple basically and were married in 2013. And we have two children.

Tell us, how has it been being a blind and being a parent? How do you manage that? I think of my own experience of parenting and all the challenges that there are and trying then to think of that without sight is just, well is amazing, so I’d just love to know what have been some of the challenges? What are some of the ways in which you’ve managed to make it work really well?

So I’ve always been around children. I’ve got loads of nieces and nephews. I think the last count I’ve got 27 nieces and nephews and 6 great nieces and nephews, so I’ve always been around children and I knew that I could look after a baby. It was basically about proving it to other people. I had my mum and dad's full support. The first 6 weeks were very hard, like they are for any new parent because although you know how to look after children when it's your own and you're solely responsible for this little person, it's totally different, whereas when you can give them back, it’s you're not responsible for final happenings of the day if you like, so the buck doesn't stop with you I suppose basically.

You fall back to pass them back to!

Exactly! So when I had Carys in 2014, for various reasons struggled to feed her and so I’ve learned a lot through that, not because I couldn't. It wasn't anything to do not being able to see but because of a medical condition. I couldn't breastfeed to the way I wanted to which really upset me because then I had to learn how to make up bottles and things like that. Instead of using a buggy I would use a sling which kept her close. It meant I had two hands to do housework or to use one hand with my cane and walk around with her, so I use the sling a lot and when she got to walking I used bells. I put bells on the back of her dress and squeaky shoes so I knew where she was, but she was always very vocal and very good at telling me where she was and if she wanted to show me something, she'd grab my hand and she'd pull me to it and so she learned from a very young age to be really adaptable. If I took a buggy out, I would take a buggy that I could pull and so I would be pulling the buggy with one hand and using the cane with the other. It has its challenges - I think it has a few more challenges than sighted people - but I think you just have to think of different ways around them. Obviously we can change nappies, we can prepare bottles, we can breastfeed, we can feed, we can feed solids, spoon feed and take the baby out for a walk. It's all doable and so it's just finding different ways of doing that. I remember distinctly once, I’d got Carys out of the bath and the health visitor was due. I just dressed her when the health visitor came in and she said, ’oh I need to weigh her.’ Right, okay. She said, ‘have you bathed her all by yourself?’ I was like, yeah actually, and they were so shocked that my mummy wasn't there holding my hand but I think it taught them a lot. Certainly, my health visitor, from being a little bit unsure and not knowing how I would cope, after that became very supportive and really brilliant. So it's a learning curve for professionals just as much. I know there were things that I really struggled with, like when they were first walking and wanting to walk along the road. It was things like, how do I know where they are and so we had things like wrist straps or harnesses that had a strap on, so I can actually hold on to the strap rather than keep holding onto the handle and things like that. And I would say that really the challenges started when it was time for them to learn to write their names and things like that. That would be my sort of take on it because things like spoon feeding with Carys - I did a mixture of both, a spoon and baby led weaning so I used to spoon feed her and she got to the stage where she would either lean towards the spoon or she would take my hand and guide my hand to her mouth. She did that from a very young age but I used touch her cheek and then put a spoon to her mouth but it just makes a bit more mess. It does get the job done but it's a challenge. What I used to panic about was whether I’d cleaned her face before I took her out or if I’d got to feed her in public would everybody sort of say, ‘oh that person is making a right mess, that poor child.’ Again, it's like when I went to a toddler group and it was a learning curve for them as well as me. It was very much but I thoroughly enjoyed it, those early days and obviously now I’ve got two, ( people have double buggies don't they normally) but I used to double carry, so I had one on the back and one on the front. I must have walked around I must have looked like a three-headed monster but it was just easier because then I had my other hand free. I could take a buggy but it was much easier just to take the sling. And you just adapt and learn - it's a learning curve and now I actually volunteer from an organization called Blind Parents UK and we teach, well we don't teach people to look after children, that's the wrong way to say it but we give Zoom sessions on birth and early days and we have a sling consultant so that she can teach them how to tie their slings independently.

That's Blind Parents UK. Is there a website?

Blind Parents UK. Blindparents.uk. We were originally Blind Mums Connect, but we've just changed to Blind Parents UK. So we give feeding advice, we give buggy advice, so like the best buggies that are pullable and we we're really about peer support, so people that have been in the same position as someone else and we've got a very active Facebook group and a very active community and quite a few expertise in various different areas. At the moment because I’m now a fully trained breastfeeding counselor I do all the feeding support and early days stuff as well as the buggy things.

That's amazing. It's so good to hear about that and the creativity and things available. I’ve got one last question for you and it's asking you for a top tip. So out of your experience, for me as a sighted person and other sighted folk watching this, what would your top tip be to us about how best to engage with folks who are blind or partially sighted? What's the most helpful thing we can do or be, as we engage together?

I think treat us as you would treat anyone else and there's only a few things that you need to change. So if you're speaking to a blind person for the first time, if you know their name then say their name so that they know you're talking to them. Quite often I get this on the school run that somebody will say good morning and I’m never sure whether they're saying it to me or to the person that's walking down the other side of the road. So if you know their name then say it. If not, make them aware that you're talking to them, maybe a light touch or something like that and just be normal. Don't ever assume that just because we can't see at all or can't see properly, that we won't have a very full active life and be able to cope with things the same way sighted people will. And we basically want to be treated the same as everybody else. There are going to be a few exceptions, there are going to be a few adaptations needed but basically just be yourself and let them be their selves. I’m the main administrator now for our church so I will contact all the preachers and things like that and by my emails even if they don't know me, they don't know that I’m blind, it’s not until they come to church because it's irrelevant in a lot of ways. It’s just that I contact them for the information or I contact them to make sure they're still okay to come and things like that, so it’s a level playing field and it's just about being who we are as people and letting us grow in that way that God wants us to.

Absolutely. Philippa that has been absolutely wonderful. You have made my day. It's been really lovely to speak with you and to hear your story and it's incredibly inspiring, so thank you so much for sharing with us.

thank you for joining us on Sight Loss 101

for more information on Torch call 01 858 438 260.