Torch Trust

Sight Loss 101

in conversation with Marilyn Baker

Hello and welcome to this episode of Sight Loss 101.

I have really hit the jackpot today because with me I have Marilyn Baker, the one and only. This series is about for me, as a sighted person, seeking to be part of a charity working with blind and partially sighted people, to understand what's it like to walk in their shoes. Now many of us will have read a lot about Marilyn's life especially the recent “The Beautiful Tapestry” book. So there's an awful lot to talk about here. So Marilyn it's wonderful that you could make time for this in your busy schedule.

Oh thank you for having me Tim.

That's lovely. Many of us as I was saying, will know something of your story. I wonder through that story, maybe over the different decades of your life, what are some of the things that you've found most frustrating or hard about being blind? What have been some of the biggest challenges for you?

Well, I think I’ll go back to the beginning. You see my parents didn't know that I was going to be blind and so everything seemed fine. I was premature. I say it's the only time I’ve ever been early! But anyway, the thing is that when I got a squint they took me to the hospital. They kept me in and that was a bit of a shock to my mum, but when they told her - just out of the blue that I was never going to be able to see and that I would lose my sight - the sight I had, she was devastated and my father went into a sort of depression. There wasn't the support either then to help people so much, and so over the next 18 months or so, I had lost my sight and apparently she saw me trying to strain to look at the last bits of light I was catching and I think she found that very heart-breaking you know. So I don't remember seeing; I don't remember seeing anything, but actually to be totally blind these days is unusual. An awful lot of people were blind at the time I was born and the reason is, you see, they gave us too much oxygen in the incubator. Now they didn't know then that that was the case. They found out a few years later what was the cause but there were a lot of children became blind and depending on how long you were in the incubator, that made the difference to the way you were blind, if you know what I mean. So I’m totally blind and apparently there's only about 4% now in our nation that are totally blind. Most people do have some light sense.

But you have none, you have none whatsoever.

None whatsoever. Nothing, nothing at all.

Do you remember anything about sight from when you were so tiny?

Not even a tiny bit, I don't and that's why things like colours are difficult for me. If I’m going to wear clothes, I mean it's quite important for me as I’m a singer and a songwriter. I need to look nice and I haven't got the slightest idea. I don't even remember what colours go with what, they're just words for me. I’ve got a very good friend in the lady that helps me on the road, Tracy and she loves clothes, she loves makeup, she loves colour and all that, so she can really help me. But to be honest, it wasn't anything even that bothered me much and you know, because another thing this might sound strange, about blind people, when you're totally blind you don't see other people's gestures. You don't see facial expressions and some blind people can actually, now this does sound a bit hard but look a little bit expressionless if they've never seen. I mean that's just a fact or they can rock or put their head down, and all that is because we're not really aware of how people are looking at us. We don't think too much about it perhaps. I’m sure some do, but I remember when I was about 13 somebody said to me, “when you're talking to somebody, look at them” and I said, “look at them but I can't see them anyway. I’ve got my ear to them.” She said but that's not the point, if you turn your head towards somebody, it makes them feel that you are paying attention to them. And I thought, gosh, I never even thought of that.

No of course.

And then the other thing that was interesting, they said, “you know, learn to smile more.” I said, “smile more! Well I’ve got laughing in my heart.” She said, “yes, but let it express itself on your face. It makes all the difference to your communication skills.” I love communication and perhaps some people think, how silly to have all that told you, but really it helped me quite a lot.

Well I have to say, in engaging with you, particularly in zoom conversations and stuff I love your smile. Your whole face lights up with you.

Well I hope that's a natural expression. They say the eye is beautiful, nothing of the soul but anyway there you are, windows of the soul. So that's a good thing. So my parents, in a way my dad, was too depressed to cope with my blindness and what happened was he kept on saying things that made me feel totally excluded and that was a disappointment. Things like you'd say, oh you wouldn't understand that because you can't see and he'd explain things to my friends, what he was doing, like making something in his workshop or whatever and then I’d say, What's that Dad?” “No you wouldn't get it." So I didn't feel believed in. That was a hard thing actually growing up. And you know, I think that was quite a difficult thing for me because I so wanted that affirmation from my father. Being a Christian has helped me because my heavenly Father. I know how much of an encourager he is and you know, my dad couldn't help it. He was kind of orphaned himself so he didn't know how to make relationships very well but my mother, she did believe in me. I went to a school for blind people when I was five and I know that some of the people telling their stories on your show said how hard it is to leave your parents and that when you're five and I felt that I missed my family very much but then I went to a boarding school near London. It was a grammar school and then I went to the Royal College of Music. Now that was interesting. I’d never mixed with sighted peers.

Okay, I suppose being in blind schools from the beginning.

Yes. I didn't have any brothers and sisters and I went to this hostel where I lived. I had to learn my way. I was very sure that God (because I’d become a Christian when I was about 16), I was sure that God would give me a place in a hostel that was very close to the college but they wouldn't take me because I was blind and so I had to go and learn a walk which was quite complex to a hostel quite a long way away, but in the end that served me well. One thing you wouldn't know about this type of blindness that I have, they used to give it a long name I think it's got a different name now, Retrolental Fibroplasia it used to be called, but anyway the thing is it affects your spatial concepts. It does something to the brain. It's not just the eyes and the longer you're in the oxygen, the worse it affected, so I was always the bottom of finding my way around in the school. I could never learn the walks and they actually explained it to me and they said that this is something to do with the reason you blind. People with this kind of blindness have much poorer mobility skills often. So that's interesting because you know that meant I needed more help. Anyway as a result of having to do this walk and it was a big struggle for me but in the end I got quite excited about travelling on the tube and I used to travel quite long distances on the tube and get excited about my new independence.

Wow! It sounds to a sighted person, Marilyn, it sounds so brave that you could do that and I can't imagine going on the tube and through all the escalators and tunnel ways and stuff with all these signposts ...

Yes, I used to get guided and I used to ask people for help and I did have a guider at one time. I can't even believe it now, but we used to have to carry our guide dogs on escalators.

Good grief!

I don't know how and no wonder I’ve got a bit of a bad back. It was a heavy dog and I used to get members of the public to give me a hand with the dog, who would scrabble around in our arms and things like that.

Gosh. And how in terms of asking for help because we British, are not always very good at that. How has that been for you?

Well I’m quite an extrovert person so I don't really mind asking but sometimes you can ask and you don't know why they're not watching you or looking. You see, you haven't got the eye contact. I think that's another very important thing about being blind, if you're in a crowd you can't pick somebody out; you can't spot someone across the other side of a room and say, hey, glad you're here at church or whatever. You're much more reliant on them coming up to you and that makes communication in the crowd more difficult - you haven't got the visual cues as to when you can join in the conversation.

So how do you cope with that? So when I’m public speaking I feed off an audience and I make eye contact with absolutely everybody I can and try and draw them in. I can't imagine doing what you do and being so effective at it without. How does that work for you? How do you kind of navigate that kind of public - worship - speaking ...

Well, you know what, I have got this theory that if we talk to somebody we've always got to, whether it's one or a thousand. you talk to them as if there's only one of them. I’ve always felt that really each person needs to feel personal with you somehow and so I’ve just had to trust. I mean there's no other way of knowing. If you're in a live event then if they clap or they laugh with you - I love having jokes with my audience. I think audiences are great because you can have fun with them and you can make them laugh and sometimes I plan a programme and then I think, this audience is a bit too serious I need to do something else and so I changed my programme, thank goodness, at the drop of a hat. I never mind doing that. That might be one of the things that I can do. I like spontaneity. But I think really the key is making sure that you are communicating things that you find interesting, I suppose,, and hopefully they will too. And putting your heart and soul into that communication, but I can't guarantee that they're paying attention and it's very disconcerting on zoom because if I’m doing a concert and, of course, we mute everybody when it's a real concert, I’ve finished there's no feedback. I’m saying things like, well I hope you like that. Silence. No I can't but then later the man who helps me with our internet programmes, he says, “Oh Marilyn, they were all engaged, they were clapping and singing at home; they were looking excited.” And I thought, oh it's nice to know but we lack the feedback, so that's why I think it's very important when someone who can see, is with a blind person, that you don't presume they know things. Of course you know you could presume too much or you could give them too much info and if the person's a bit kind of feisty and a bit of a bad move - so don't tell me that I know that already! Well that's unfortunate if they're like that, but it's better to be more verbal, it's better to say things. If I’m in in an area - I was walking around Eastbourne the other day and I said to my friend, “well are there any shops around?” “oh yes,” she said as if to say, "don't you know?" I thought, no I didn't really I didn't know whether there were shops or whether it was just residential housing. I didn't know, so when I’m with somebody I like to take their arm and I like them, if they've got a lovely view for instance, now I can't see a view, but on the other hand, if somebody's enamoured by a view and they say, oh this sunset it's so wonderful, now I love to feel how they're loving it because that somehow gives me a sense that I can love it as well. I can't love it in the same way as they can but something about that communication. It doesn't make me bitter. The other thing I think about being blind, actually, is that I’ve learned, and believe me, I’m sure many have whether they can see or not see, but the detail of God's care. Now like if I lose something on the floor or whatever, it is if nobody's around, who do I talk to? I chat to Him my wonderful Father God and I say, “You know Lord, I’ve lost this. Now where could it be?” Now I can't say that every time I find it, but often I do. And you know I remember just recently, Tracy my friend, had a problem with her computer and I can't read her screen actually because I haven't got any talking software on her computer and she was saying, I’ll have to call the computer man and all that and in my heart it was like God's Holy Spirit, you know he's a wonderful friend and he said, “go and help her.” I said, “how can I help her Lord?” He said, “you'll sort it.” I said, “will I?” So I went in with great confidence, I said let me have a look. What do you mean have a look? I said, well I’m going to just sort it for you. I don't know how, so I said look. She said, I can't close this window so I gave her a key command that usually works for me. Believe it or not, it all closed and she sorted it and I thought, isn't that wonderful Lord? You know, I love the detail, so what it means Tim, when I write songs I put this kind of thing into the songs; not about Tracy's computer but I’m putting the fact that God cares about the detail, that he loves to be our greatest encourager, that things that really are on our hearts, that we really care about, he totally cares about and I’ve proved it through the reliance of being blind. Like when I’m wanting to cross a road; I’m praying about crossing a road; I’m talking about being safe - to Him and maybe He'll send someone to help me or whatever. But he's a friend to me in my blindness, you know.

And it sounds like the trust that you've had to develop and the reliance both on other people and therefore on God has actually been a real bonus to you.

I think it has. I would say that that's tremendously true for me, I mean the trust. I’ve learned a lot. My father wasn't trusting, he couldn't be and he always kept telling me to look after number one and that nobody would help me if I didn't help myself but I had to unlearn that lesson and I think that's why I love reaching out to people because I want them to feel that they can trust me, but most of all, that they can trust our wonderful God who loves them and loves me and has shown me that in some of the plights I get in and different things, that he's alongside me every moment and there's a verse actually which some people will know. I wished I could find it and whether I will be able to. It's in Isaiah. I think it might be Isaiah 46 but it's about the Lord leading the blind in ways that they do not know and of course you could take that as spiritually blind or you could take it as literally blind and in "The Message" version it's even more amazing. I’ll just see if I can find it. No I don't know that I can, sorry.

I think we've got the gist of it.

Yes that's right but it will lead them in unfamiliar paths. It will guide us and he'll put light in front of us and he'll make paths level and I think that's such a fantastic promise and as I say in modern translation "The Message" he says, I won't leave you for a moment. And I think, great okay, Lord. I’m taking that. That's it, Lord you now it says these are the things I will do for them and I will not forsake them. That's it so that's my trust. I don't mean it's never hard being blind. I think there are times when I just think, gosh I wish I could drive; waiting for a bus drives me mad when it doesn't sort of turn up and you know, just wanting to go out for a walk . I haven't got a guide dog and I’m not good with a long cane so I’m stuck at the moment. I have to rely on my friend to take me and really I think sometimes when people get sad or they get frustrated, they go out for a walk or they can get away from a situation. I remember once getting into a temper in the recording studio, recording one of my albums and I stamped my foot. I didn't like what they were doing. I said I really don't like this and they said, well we do, and I said, well I don't and it's my song and I was getting very hoity toity, you know, and I was doing this and in and I said I said, right well I’m leaving the room and I went to the door and I walked out and then I suddenly realized, where can I go? I don't know where to go and of course, all I managed to do was cause a bad atmosphere and I couldn't go very far anyway, so I thought, stop getting on your high horse you know so there you are.

Oh bless you. Marilyn, I wonder after so many ... forgive me if this sounds rude, but so many years in ministry and ministering to other people, whether you've sort of got clarity about what is it that is the core message you think God has given you for the world?

Oh what a question, Tim. I think the core message is terribly simple but how he is reaching out and loving every individual. How they respond to that love is another matter but I believe he sees the gold that he's put in everybody because we're made in his image. That image got marred but he wants to restore us back, you know what I mean, and he's reaching out and so my mission as it was to help people understand that he is looking for them, loving them, wanting to be their greatest encourager. And issues of forgiveness. - we meet a lot of people who feel they're rubbish or feel that they're not worth anything much and well I just love this sense of trying to help them see how worth they are, because I think when God points out things that are wrong in our lives, like the sin in our lives, he does it with great respect for us actually and gentleness and yet conviction of course, but he's not looking for reasons to withhold from us.

And can you see how your sort of view of God, your understanding of God has changed over the years?

Absolutely. When I first became a Christian I was extremely black and white. Everything was - you do this and you don't do that and it was all to do with performance as well. If I did well as a Christian, if I had my quiet time every single day and did everything, then God would love me and forgive me because we live in a very performance orientated world, don't we? But the thing is, that I’ve come to understand not that these things aren't important and spending time with God etc but that doesn't constitute why he loves me and I think that is what has changed about me really and my understanding of him. I don't want to become sloppy and over liberal but I do want to become flexible even more in his hands and try to see things from his perspective.

Yes that's so true isn't it? I weep when I see older folks who are increasingly brittle in their attitudes and stuff.

That's right. Brittle.

And the beauty of people who have spent a lifetime with God being moulded and mellowed and are just beautifully gentle loving people. You're on my list of those.

Oh that's very nice to say. I love it when people spend time with the Lord like that and they really know him, they're what I call comfortable people.

That's nice. Yes, comfortable to be around

Yes, that's right.

That's lovely, So Marilyn, just to end - what would your top tip be for me as a sighted person as I work alongside befriend folks who are blind or partially sighted? What would you say is the thing that I most need to know?

Well I think the key thing is connect with them. You won't have the eye contact but we love friendship. You know sometimes in church people will say, okay sit down and we'll get you a coffee and that's very nice and then they leave you to it. What I might prefer more is if somebody would take my arm and say oh so-and-so is here today, is anyone you particularly want to chat to or shall we go and have a talk with so-and-so or you know, connection is all important. And you know, describing things - we've already talked about that and it's not so different getting to know a blind person as from anyone else, the only thing is they can't see what you can see, so you can convey those things but they might be able to see things that might shock you, things inside or underneath. I feel I know people even if I can't see them. Do you know people say, oh you can't see me. Okay but I actually can see something quite different, I can see hearts. Mind you, I’ll tell you one funny thing; I was with a lady once and she was sort of joking with me, she said, well at least I knew you were coming each other I won't have to dust when she comes or something like that; I won't have to make it look tidy and I joked backwards and I said, ah but I can smell dust. I was being naughty you know, I’m glad people don't feel they've got to get all dressed up and all sorted for me, but you know the thing about it is, we're just the same as anyone else but connection is the one thing that some of us may lack because we don't know who's in the room, sometimes. We don't always know what's going on and so do your best to connect and be friendly and if people don't particularly want to be, well they'll show you that and don't think, oh that's because they're blind. It's just because they're them; it's who they are more than being blind.

Marilyn, such a joy to speak with you. Thank you so much for sharing with me and I’m sure on behalf of anybody who watches this or listens to this, thank you for all that you are and all that you continue to do.

It's been a great joy speaking to you Tim. Thank you very much and everybody else.

Thank you and God bless.

Thank you for joining us on Sight Loss 101.

for more information on Torch call 01 858 438 260.