Torch Trust

Sight Loss 101

In conversation with Niall Geddes

Hello and welcome to this episode of Sight Loss 101.

I’m Tim Jeffrey, the chief exec of Torch Trust and one of the things I’m doing as part of my induction into Torch and into the world of sight loss, is talking with various people who themselves experience different levels of visual impairment and for me to find out a little bit from them, what it's like to live in their shoes with their sight loss. So these conversations are being recorded so that other people can also benefit from the wisdom and the insight that comes with my guests.

So today I have the wonderful pleasure of introducing Niall Geddes and Niall works for Torch and has got a fascinating background, so I’m really looking forward to hearing a little bit more.

 Niall welcome and maybe you could start off by telling us a little bit about your sight loss journey and how that sort of wove into your life. When did you first know that there was something up?

My sight loss journey is, I think, like most people with sight loss a bit unique because I thought I had relatively good sight when I was born.

I had to wear glasses growing up as a kid. It was when I was around about 10-11 years old that my dad was then registered blind and then he went off to an ophthalmologist to check his eyes. They told him he had macular dystrophy at the time, which is quite a common eye condition but has so many different variants and so many different strands, and the question was asked, well is it hereditary, will it will my kids have it? The ophthalmologists clearly stated, not a chance - 1 in 250,000 chance of your kids having a visual impairment. They tested all three of us, myself and my two brothers and we all had it.

 Wow.

Unfortunately we don't know if it's a male dominant gene because I don't have any sisters to be able to tell, but I was around about 11 years old at this time, being told I have a visual impairment, not knowing the level of sight that I actually had, to what I have now. So then we didn't really make any adjustments to what I did as a kid because my dad was my hero essentially, and if he can live with the visual impairment and if he can go on day-to-day life as “a normal person” then so can I.

So we were against the world to say, we can do whatever we want to do, we can do what a sighted person does.

And so has your sight then stayed the same or has it deteriorated ? What's the evolution of it been like?

Over the years my sight has got worse. As a kid at secondary school I remember I used to be adamant I would sit in the back row of the classes because I was a smart kid, so I did my work. I didn't want attention, so I sat at the back, did my work, carried on like normal life. Only a few people knew about my eye condition and it was normally the person I sat at the back with. So I let them know that I couldn't see the board and I could copy their notes, so they just wrote a bit bigger for me at the time. The teachers didn't know because I didn't want any extra help. I was a bit stubborn and then over the years my eyesight did get worse; to walking into a few things now and again; night time became harder because the light wasn't there to go into the eyes, so I was walking into a lot of bins at night thinking they were people and apologising!

There’s a bit of a clue there!

Yes, and you know you've got to be quite British sometimes. You got to apologise, you never know if it's actually a person or not. But it got it got worse over the years and then I was registered blind and I just got committed. I just thought, well, I got to a certain age where I just realised that there might be other people like me not accepting help, but need the help and if I’m big enough to admit this, that I have a sight problem and I need help, maybe they will as well. So I decided to be an advocate for those people losing their sight at a young age.

Fantastic. And so help me understand, what sight have you got at the moment? What does it look like looking out of your eyes? How can I understand what you see or don't see?

So my sight level varies on day to day. It varies on environment, so if it's a really sunny day it's hard for me to see. My normal sort of vision, I would have is between 5-8% vision, so if you think of you're looking at an eye chart as a sight person and you can see the top letter on an eye chart. A top letter on an eye chart is 6/60, so that works out at 10% vision. So for me, I can't see that - it’s just a blur, until I take a few steps forward.

I also have a reduced peripheral vision which is slightly different from my family, my two brothers and my dad, because they have their peripheral vision. So when I talk about peripheral vision, that is vision around you, so for an instance, I have around about between 30-20 degrees for my peripheral vision. So that means if I put my fingers out to the side, the moment I see them is when they get to about here [his fingers are just in front of his eyes], so from there onwards I can't see - it's all blurred. I can't see details so it's hard for me to see things around me.

Is that it now? Are you stabilised in that or is it continuing to reduce? What's the prognosis for you?

Eye conditions, they're so different, so my main thing I judge mine on is how my dad's doing. My dad is 62 this year and I’ll be 30 this year, so I kind of judge his eyesight to where mine will be. So if my dad's still got around about between 4-5% vision at his age, I’m hoping that I do as well but that's not saying that mine will, so the easiest answer to the question is, I have no idea! Sometimes it can stay stable but who knows, who knows? Everybody is totally different.

I know that you have played sport at an extremely high level and I’m sitting here thinking, how on earth? I know you're a big guy, you're a tall guy, you've done basketball and things. Tell us about some of your sporting history and quite how that's worked. How do you play basketball when you have that much reduced vision and such limited peripheral vision?

I class myself as a sporty person. I’ve been lucky enough to be in the right situations at the right time, a lot of the time to be scouted for certain sports. So I grew up as a basketball player. As you mentioned I’m a taller guy, so I’m 6’ 6”. Ideally I was set for basketball; I was long and lanky as a kid. I grew up and again, my dad was my hero. My dad was a great sportsman, he was a footballer, a football referee at a really high level and an army champion boxer as well, so I wanted to be like my dad. Not in the same sports because footballwise I wasn't that gifted. I could defend on the football pitch but I couldn't really do anything at my feet with it. I’ve got size 14 feet so it's kind of hard to wrap a ball around it sometimes but basketball captivated me because it was a mix of flair and fundamentals and style and just being able to express yourself out on a court and that's what I loved. For me, growing up playing it was all about feel. Again, like I said, you can express yourself, so it's how you feel out on court is to how you put your yourself onto it. It's like a pen or a paintbrush on a canvas, sometimes, you just have to have in your memory where the hoop is and you base all your movements off memory. I’ve been lucky enough to have a good memory, so I’ve been able to kind of fluke my way through a lot of things, especially in basketball. So I played for the Leicester Cannons as a youngster, in a junior national league and then as an 18-year old I was lucky enough to represent Leicester in the under-18s England all-star game. For basketball in the UK, it's a very small sort of market, but there's a lot of teams and as an under-18 your pinnacle you can do, unless you go on to play for national team, is to be selected as an all-star at the end of the season. So it was the top 20 players in the country, a lot of players a lot better than I was, there were a lot of 7’ guys who I had to defend throughout the year, that I got to compete against and they were off to America the following year and I was in that limbo where I don't know what I want to do. Just after that I was really fortunate enough again, to be in the right position at the right time. One of my basketball coaches found out about my visual impairment.

They didn't know before that?

 So my 2nd year of sixth form, my basketball coach Dave Greenaway and my other basketball coach John Stonebridge, great coaches in my life, they found out because I had to go to an ophthalmology appointment basically, just because I had a check-up - I just had a normal eye check-up and I had to miss a practice. So they asked what are you OK? And then I told them I’m registered blind.

What was the reaction?

They were shocked. They asked me how I followed plays because we got given a playbook with really small plays every year and they were fantastic with me. They made adaptions for me so instead of the playbook we did walkthroughs, so we walk through the play so I could use my memory to remember where I had to be, at what points I had to set a screen or run off a screen or get the ball to find the open man, so I had a play going on in my head the whole time. So my basketball coach John Stonebridge, after I finished juniors, he actually submitted my details to Paralympics GB which is the governing body for all paralympic sport in the UK. He submitted my details that he just basically said my weight, my height, my age, my disability and a couple of sports called when I was actually away with some friends at a camping holiday. Without me knowing about it, I answered a phone call. Normally I don't answer phone calls that I don't know, but just on this occasion I did, and it was the talent scout for Goalball UK at the time, that invited me to "give it a go day" they said. But I thought "give it a go day" was with other novices but this was with the GB men's team.

That's a bit of a deep end experience!

 I had no idea what the sport was. I had to go home after the holiday because in 2010 it was a bit of a different time. You couldn't just YouTube on your phone - that was only just starting. So then I YouTubed it. I showed up with not the right amount of kit and with a Mcdonald's breakfast in my hand, thinking this is going to be like a basketball camp that I’ve been to in the past. Totally different! And I was invited back and from 2010 to the end of 2014, I was a part of the GB men's Goalball team.

And so you were in the Olympics in 2012, the London Olympics, the Paralympics?

I was so it was an incredible experience. So when I look back at it now that I’m out the sport and I can really appreciate it, at the time I was disappointed because we didn't do as well as what we wanted to do, but then we got to take in the atmosphere. The whole team feeling of, we all have a disability in this venue or in the Paralympics, but we have that never-say-no-attitude and never-give-up attitude, that everyone would have said to us at one stage in our lives. If they knew about our disability, they would have stopped us playing sport. I know so many Paralympians that weren't allowed to do PE in their secondary schools, but they were part of a national team set up when they left school or whilst they were in school, because they were deemed a risk if they did PE, but yet they're flying off to a country at the weekend to compete for their country.

Doesn't that say something about our general attitude in this country towards disability and folk who've got different needs?

It's just amazing. What would your message be to young people who maybe have a similar visual impairment to you or other disability? What would you say to them?

If someone tells you, you can't do it, do it to prove them wrong. That's the biggest thing you can do is prove people wrong, because how do they know you can't do it? They're not in your body, they don't know what you know, they don't know all the things you've had to go through, just to get up in the morning, just to come to grips with your disability.

That's amazing. I have to ask you one more thing particularly and that’s I found out that you're a bit of a chef and that’s a big thing in your life. Tell me about cooking and chefing and again, as a sighted person, I think I know I’m chopping onions or vegetables or stuff. I mean, I use my sight so much in cooking. How does it work for you?

For me, I’ve always loved cooking. Again, I’ve mentioned about basketball being able to express yourself, cooking is exactly the same. I’m not a good painter, I’m not a good draw-er, but everyone can express themselves in different ways and to me cooking is one of them. I fell in love with cooking mainly because my parents were horrible cooks.

So your dad isn't a hero cook as well as a hero sportsman?

Definitely not! My dad's idea of a dinner was crispy pancakes with ham and cheese inside and some chips and beans. He was born in the late 50s; he's born in Scotland, so we can forgive him for that!

They’re not deep fried Mars Bars then?

Oh I think he's had a few in his time, but I would try things in the kitchen and to me, when you talk about chopping things, I compare myself to some - well, I don't compare myself that's too big headed - I look at some of the best chefs in the world and you learn their techniques. If you look at a really good chef, they don't look when they chop, they feel what they're doing.

Interesting.

So my whole thing about cooking and is my tag line as well, is you don't need eyes to cook, you just need your feel, you need your taste, you need your smell if you don't have eyes, use your other senses. Don't get me wrong, sometimes I burn things because I can't see it is burning, but I can smell it sometimes. If one of your senses go down, use the others and that's my whole thing, is about breaking down stereotypes as well, that blind people can't cook; that people with visual impairments they can't do that; it's the whole thing of someone telling you, telling me you can't do that. I wanna just say, wait there a second, I’ll prove you wrong.

Good man, so you've started something of a sort of cooking, a career, I hesitate to call it a career, but you've got a YouTube channel is that right? And you're working on some possible ways of taking the cooking a bit further.

I’m trying to put together enough stuff to launch one. The main thing I upload onto currently is Instagram, so I upload recipes, I upload step-throughs on a lot of things and a lot of meals. I prepare in the week so I might put last night, for instance, I made some burritos from scratch, which I had again today for lunch, which worked out quite well, especially that I’ve got a really great support network at home so I’ve got a really great wife that loves to eat my food.

So she's delighted that you're a good cook?

Oh that's the only reason she married me! That and I get cheaper theatre tickets!

So now, just to end with what’s for me as a sighted person beginning to get used to and dealing with more visually impaired folks, what would your message to me and people like me be about how we think about, engage with, work with folks with a vision impairment?

The main thing I would say is, go in with no judgment. People judge people with visual impairments that they might think we're slower, just because we can't see. A lot of the time it, doesn't mean we don't process things just as quick. Just treat us like normal people, whatever normal is, and try not to tell a blind person they can't do anything, unless it's like driving, then that's an obvious - we don't want the health and safety hazards on our hands!

Now you are an inspiration that has been so fascinating and I just take my hat off to you in the way that you have just pushed through and decided I’m going to do things and show people. So that is hugely inspirational and I hope other folk listening to this will feel the same level of admiration for you and inspiration over what you've shared. So thank you and I hope and pray that your ongoing sporting and cooking careers are enjoyable and successful. Thank you for being with us. Bless you.