PODCAST EPISODE 1

TALKING ABOUT VISION LOSS:

KYLIE

INTRO: This is an audio resource produced as part of a peer support program, Chatter Paws, by Guide Dogs New South Wales/ACT’s connection services. Connection services exists to foster the power of peer support. It’s produced by Guide Dogs’ clients for clients. This particular miniseries focuses on all things adjusting to and talking about vision loss.

JESS: Hello, you’re listening to the Guide Dogs Chatter Paws series talking about vision loss. I’m Jess Nelson, and I’m a Guide Dogs client and volunteer. This is a series that’s part of a real-life discussion about the sensitive topic of how we talk about vision loss, and particularly about how we talk about it with friends and family. This is part one of a three-part series, and today we’re talking to Guide Dogs client and volunteer, Kylie, about her experiences. Hello, Kylie.

KYLIE: Hello, Jess.

JESS: Please tell us a little bit about yourself.

KYLIE: Okay. My name is Kylie. I am 48 years of age, and I’m from Sydney. I have an eye disease called uveitis, which is basically the information – it’s an information disease, and it produces swelling and destroys the eye tissues in the eyes, so my eyes are red and quite painful and I’m really sensitive to light, and I have little floaters that float around in my eyes, and, yeah, causes vision loss. I have a wonderful, beautiful Guide Dog that assists me. That’s a bt about me, Jess.

JESS: Yeah, sorry, name of the dog?

KYLIE: Oh, my lovely Guide Dog is called Lyric.

JESS: Lyric.

KYLIE: Lyric.

JESS: Kylie and Lyric. You started to lose your vision and you were affected early in your life, weren’t you?

KYLIE: Yes, it started when I was 10 years of age.

JESS: Okay, a lot of experience there. How did you feel when you were approached by Guide Dogs to join in this discussion about talking about vision loss, because it can be a really personal topic.

KYLIE: To be honest with you, when I was first approached I was like, “Yeah, this is cool, you know, I wish this was around when I was starting to lose my eyesight.” And then I sat back and thought about it and I was like, “Whoa, this is something deep. This is – I have to, like, talk about myself and my emotions and things like that.” And I had a chat with my family and friends and they were like, “You can do it, and just think about how this could support others.” So it’s a pretty emotional rollercoaster in opening up, but I’m here to do it.

JESS: Good for you. Thank you. We appreciate it. Now, you also work. You do quite a social job. You work in hospitality, yeah?

KYLIE: Certainly do.

JESS: So when you’re working, do you get a lot of interest from customers about your vision impairment? Do you find yourself answering a lot of questions?

KYLIE: I do have to answer a lot of questions, because it’s – in the way of I can walk my Guide Dog out for a toilet, her toilet break, or walk into the building with a Guide Dog, and then they see me in my work position and they’re going, “Oh, so you’re training”, you know, “I just saw you training the dog. That’s really great,” and I’m like, “No, she’s actually mine,” and they’re like, “But you’re working here.” I’m like, “Yes, I have” and then it’s part of an educational thing of explaining, you know, “I have vision loss and you don’t have to be completely blind to have a Guide Dog and I’m still quite functional. I can do things. Like, you wouldn’t have even known unless you saw me with the dog,” sort of thing. So it’s a lot of education that goes into explaining who I am, I guess.

JESS: Well, yeah, that’s good for you, because, I mean, I’m a bit of a grump personally, so just doing a forward-facing job, I’m very impressed. Is there certain ways that you can answer people’s questions and be friendly while answering their questions but it’s not taking up all your time? Do you have any advice for people?

KYLIE: I look at how busy I am and the situation and who’s around and how they’ve made a comment. Like, I’ve had a few customers say to me – because I can’t see properly, I get closer to the till to see, and they’ve gone, “Oh, you need glasses, love,” sort of thing, and I’ve just kind of like, “Ha ha ha, yeah, thanks for that,” and laughed it off. Whereas other times when I’ve got the time, or the tone that they’ve used, or whatever, I take the time to sort of just explain a little bit. “Oh, thanks for pointing that out, but yeah, you know, I’ve got some vision loss and I’ve actually got a Guide Dog and everything.” So I sort of choose my tone of what has been approached towards me and try and be positive about it, but I admit inside it can be quite emotional and you’re just like, “Oh, here I go again. I have to explain myself again. I just want to be me. I just want to be Kylie, not Kylie the visually impaired person,” you know.

JESS: So there’s a little bit of personal forgiveness sometimes…

KYLIE: Yeah. Yeah.

JESS: …when you don’t feel like you’re in a position to advocate for vision impaired blind people.

KYLIE: Yeah, because I think, just when I don’t want to advocate, I sort of laugh it off and go, “Ha ha ha, yeah,” sort of thing. But there’s other times where I’m like, “Okay,” and I’ll explain who I am and, you know, why I have the dog and everything else.

JESS: Yeah. So do you find that when you are out with Lyric, it’s – you get – you feel like a bit of a different person than when you’re just out by yourself without any mobility aids that would identify you as vision impaired?

KYLIE: Yes, especially at work, because Lyric goes into her little room, because I don’t need her while I’m working, because I’ve worked there in those premises for 21 years, so I know my way around, and when I’m at work and I’m in my position, I’m just Kylie. I’m not Kylie and Lyric. I find when I’m with Lyric everyone talks to the dog first, and they’re like, “Oh, hi,” you know, “nice dog,” and I’m like, “Whoa, I’m up here too. I’m a person.” Or they go, “Oh, hi Lyric,” and I’m like, “I’m good if you want to know,” you know, “ask me how my day is going,” sort of thing. So you become Kylie and Lyric, and that’s fine, but sometimes I just really want to be me.

JESS: Yeah. Yeah.

KYLIE: And I mean I love my dog, and she helps me a lot, and she’s awesome, and I can understand why people always see the dog first, but it does emotionally get to you.

JESS: Yeah, well, I – as a crazy dog lady, I apologise on behalf of all of us. So when you’re at work, I imagine – I mean, when I’ve been in jobs, I have a tendency to make lots of friends at work, and I imagine you’ve got lots of friends at work. Is it a little bit more difficult when you’ve got friends at work, because you’ve kind of got to train them how to work with you? Is that part of your experience?

KYLIE: Yes, having to explain to new staff that come in, or if I’ve had a change in my vision, or, “Okay, guys, I used to be able to do this, but my vision’s a little bit worse today, or I’m having problems. Can we adapt it this way, or that way?” I think having to educate them that, “I need structure. I need things put back in the same place. I know it’s going to be a hassle for you guys, but we need to work as a team.” And you know what, they step up to the plate and they’re absolutely awesome, and they’ll, you know, if a new product comes in, it will be, “Wait till Kylie comes. She can work out the way that she would like it done,” and everything.

And educating them in the sense of, you know, I had one person that used to throw some keys at me when I used to go in and ask for them, and I was like, “Okay,” and I didn’t say anything. They’d land on the floor. I’d spend a few minutes digging around on the floor trying to find them, and, “Okay, thanks,” and walk out. And then in the end it sort of got to me, because it was eating me up inside that I couldn’t open up and say to him, you know, “Hello, this is a thing that’s ongoing. We need to adapt to the situation.” So he had a sense of humour, which was good, and he threw them to me one day and I just turned around and said, “You threw them, you find them,” and he just went, “Oh, okay, where did they go,” and I went, “Yeah. Yeah, how’s that feel,” sort of thing.

So I think you’ve got to sort of dig deep in your emotions and go, “I’m the only one that can change this,” and work out how to handle it with that person, how to approach them. Like, do they handle humour? Am I going to have to be upfront and honest, or – you know, it takes a lot of guts to do it, because you’re like, “How is their reaction going to come back towards me? Is it going to be positive or are they going to go, oh, okay.”

JESS: Yeah, well, I mean, so it’s an ongoing thing, really. Do you have any sort of examples of times where you have kind of tried to get somebody to come around to your way of thinking and doing things and it hasn’t really gone that well, and what did you learn from that?

KYLIE: Yes, I – yeah, I’d have to say I did have a situation, and it was at work, and the person changed the products in the fridges because they thought it would work better this way, and they sort of – I came in and I was like ready to have a meltdown, because I couldn’t faunction and everything else. And I’d spoken to that person and said, “Oh, did you, like, change this and this,” and they’re like, “Yeah, I always put them this way,” and I’m like, “I don’t want to upset the apple cart or whatever, but I really need it this way, because I can separate the products, as in the shapes and the colours and things like that, because I do have low vision that I can still see certain things.” And they were quite upset and said, “Well, that’s the way it is. I’m not changing it back.”

So I then had to go to my manager and sort of go, “I don’t want to cause trouble, but this is where I’m at,” and they’re like, “Okay, well, we’ll just have a chat to that person.” So, you know, there’s times where it has gone a little pear-shaped, and I like to try and approach that person first and try and sort it before I have to, you know, take it a little bit further.

JESS: Oh yeah, absolutely, and it was great that you had that support there for you.

KYLIE: Yeah, definitely.

JESS: Yeah, because it’s really not a lot to ask. So, I mean, you do need to sort of advocate on your own behalf. It’s not just about the wider community. Sometimes you need to advocate for your own situation a lot of the time, and that probably – it probably takes a little bit more strength, and maybe it can get a little bit tiring. Do you have any advice for people who are newly diagnosed and newly finding themselves in a situation where they’re vision impaired or blind? Do you have any advice for them on how to sort of claim your space?

KYLIE: Do you know what? It can be so exhausting some days, absolutely exhausting, because you just – you’re trying to do the best you can. You’re trying to get through the day, and you’re adapting to all this new stuff and everything. Your head can go into a mental overload and it can be exhausting. And you just – you build it up and you’re like, “I’ve got all these emotions. I don’t know how to deal with them. Like, who do I talk to? Where do I go? Do I try and explain to my family, but I don’t want to burden them and show them I’m not coping.” You know, “where’s my avenues to turn?” It can be so overwhelming.

JESS: So where do you find those supports in life?

KYLIE: I think it’s really awesome to be able to talk to someone that doesn’t know me at all, doesn’t know my family, doesn’t know my friends, or anything, and I can sit down and talk to them and have the private conversation and know it’s confidential, and that is a psychiatrist. And I think it’s important because that’s my time. That’s where I can say, “I am so annoyed,” or “This happened,” or, you know, “My family’s in my face all the time,” you know, “I know they love me and want to help, but I need space.” And they can give you adaptive ways to handle things, like, you know, take a breath before you speak and different other things, you know, what works for you at the time.

JESS: Yeah, yeah. I mean, I personally, I get a lot – this Chatter Paws that we’re doing now is a special series, but I don’t know whether listeners will know this but Guide Dogs runs regular Chatter Paws peer support groups. I personally love mine. It’s a great gang. I get a lot of support just talking to other vision impaired people, too, so that’s a good possible outlet as well as, you know, a psychiatrist or psychologist, I think. Do you do peer groups?

KYLIE: Yeah, it’s awesome, because you’re talking with people that have the same sort of situation. So sometimes you can’t get into the psychologist, and you can lean on these guys and just say, you know, “I’m having a bad day today,” or just talk about anything and just be yourself. Or if you’ve got a situation happening, they can suggest different ways how they do things. You learn so much from other visually impaired people, and tapping into that is an awesome thing as well.

JESS: Yeah. And on that note, I mean, you’ve been dealing with vision impairment for, well, nearly 40 years by my maths, so obviously you’re a Guide Dogs client and volunteer, because you were about 10 when you first realised you had a vision impairment.

KYLIE: Yeah.

JESS: Did you get involved with them straightaway, or was it later in…

KYLIE: I got involved with Guide Dogs later on, when I was a lot older. Basically, because I could still – I had enough vision to be able to drive, and when I had to hand my license in, that’s when it became the time, “Okay, I’m going to have to look at some aids to help me,” and everything else.

So originally I started off with the cane, and I found the cane to be – out in the area that I live, the foot paths aren’t even and everything, and I was bending and breaking it and it was digging into me and everything else. And then someone said to me, one of the trainers, “Kylie, have you thought about a dog?” And I’m like, “Oh, a dog. Um, yeah.” I said, “I do long hours at work. Is it fair on the dog to be sitting there?” And they’re like, “Well, Kylie, that’s what they’re trained to do,” and everything, and they said, you know, “Come out and have a walk with one.” I’m like, “Oh, okay.”

So I did, and I fell in love, because, being a dog. And then I got the benefits of using a dog, and for me it was great. I mean, dogs aren’t for everyone, but it was for me. My neck wasn’t hurting anymore when I was walking. I was looking up. I was walking around. I had more confidence. Yeah, my total personality just came back, from…

JESS: Wow.

KYLIE: …I went into my shell and now I was like, “Woo-hoo, I’m back.”

JESS: That’s fantastic. That’s fantastic. So, Kylie, what do you think is the most important thing that you’ve learned about yourself as a vision impaired person?

KYLIE: I think the major thing I’ve learnt, and I only discovered this the other day, and that is that I’ve become a very patient person in some ways, and very structured. It’s when I do things now, I think about things, like if I’m pulling something apart, I need to put it here and here and here so I know where it is again and things like that, whereas probably when I had more sight, I’d just be like, “Yeah, pull this apart, I’ll put this here. Oh, I can find this,” and everything else. So I think I’ve become more structured and I think more, which can be so exhausting. And I’ve become a bit more outgoing, because I’ve got the confidence again with the dog.

JESS: Great. I actually really agree with that. I used to be a very impatient person, and now I’m on time for pretty much everything.

KYLIE: Yes.

JESS: Yeah, reformed, much to the gratitude of my family and friends. Is there anything else you wanted to add, Kylie?

KYLIE: Just that, you know, if things get overwhelming, make sure you reach out to someone.

JESS: Good advice. Really good advice. Thank you for just being so open about it, Kylie. That was great.

CONCLUSION: You’ve been listening to an audio resource produced as part of a peer support program, Chatter Paws, by Guide Dogs New South Wales/ACT’s connection services. To find out more about how Guide Dogs can support you to reach your individual goals, visit guidedogs.com.au, or phone 1800 436 364.

Talking about vision loss can be tough. If this discussion has brought up concerns for you, please reach out to Lifeline for support on 13 11 14.

PODCAST EPISODE 2

TALKING ABOUT VISION LOSS:

OLIVIA

INTRO: This is an audio resource produced as part of a peer support program, Chatter Paws, by Guide Dogs New South Wales/ACT’s connection services. Connection services exists to foster the power of peer support. It’s produced by Guide Dogs’ clients for clients. This particular miniseries focuses on all things adjusting to and talking about vision loss.

JESS: Hello, you’re listening to the Guide Dogs Chatter Paws series talking about vision loss. I’m Jess Nelson. I’m a Guide Dogs client and volunteer with retinitis pigmentosa. This is a serious that’s part of a real-life discussion about the sensitive topic of how we talk about vision loss, and particularly how we talk about it with friends and family. This is part two of a three part series, so if you haven’t heard part one yet, make sure you go and have a listen to that one, too. Right now, though, we’re talking to Guide Dogs client Olivia about her experienceS. Hello, Olivia. Let’s start with a bit of an introduction. Please tell us a bit about yourself.

OLIVIA: Hi, Jess, yes, it’s Olivia. I’m 23 years old. I live on the northern beaches of Sydney. I’m pretty new to vision loss myself. I’ve only been experiencing it for about 15 months, having been diagnosed with a neurological condition called idiopathic intracranial hypertension, which has caused me to lose a significant amount of my visual acuity and all of my peripheral vision, so I sort of see vision as like a rough tunnel vision, and the vision that I do see is very blurry, yes.

JESS: Yeah, so it was a lot to take in for only 15 months ago.

OLIVIA: Yeah.

JESS: How was it initially when you heard the news that your vision was going?

OLIVIA: It was pretty confronting at the time. I had just finished university. I was 21 at the time, and I was working as an intern in marketing, which was what I studied in university, and I also worked in a café just to make some money, and I noticed while I was working at the café my vision was starting to become really blurry, and most of all I was having these awful headaches. These headaches were also impacting my vision and my ability to work. They were at the very front of my head, and they were just the most painful thing I had ever experienced. And it started to go on for a few weeks, and I really thought, “What am I going to do about these headaches?”

My mum’s a nurse and I spoke to her, and she works in the emergency room, so she sees it all. To her a headache is absolutely nothing, so it kind of seemed like I was making a big deal out of nothing, so I thought to myself, “I just need to power on and just get over these headaches.” This actually turned out to be a detriment to myself, because those headaches were the warning signs of the neurological condition that I have. Part of the neurological condition is that there is too much pressure, too much liquid in my brain, and it was crushing my optic nerves, which is what destroyed my vision. And eventually the headache just got absolutely terrible, and I noticed that my vision was actually becoming really strange. I was noticing warping in my vision. People’s faces started to become unrecognisable. So I thought, “All right, I’m going to bite the bullet and go to the doctor,” and that’s when the doctor told me, “You know what? I think you should actually go to hospital.”

I was in hospital for quite a few hours in the emergency room. They didn’t know what to do. At first they were quite baffled by the symptoms, and they nearly sent me home, just saying, “You know what? These are some migraines. We’re going to give you some migraine tablets.” But the director of emergency said, “You know what? Something does not sit right with me about this case,” and he looked further behind my eyes and he saw my papiloedema, which were extremely swollen, and that’s when he diagnosed me with the condition.

They looked at my papiloedema and realised how swollen they are, and when they started to investigate my case further, they realised it was actually one of the worst cases they had ever seen at Royal North Shore Hospital. And had I come in probably a lot sooner when I was experiencing those initial headaches, I could have potentially have saved some vision, but I was just thinking to myself, “What could they possibly do for a headache.” But now, looking back, that was the warning signs of this condition.

I ended up staying in hospital for nine weeks. I had roughly four surgeries on my optic nerves and my brain. I had a stent put into my brain, which will be in there for life. And, yeah, then I – while I was in hospital, I was just processing all of this. After I had the optic nerve surgeries, that’s when a lot of my vision actually started to deteriorate, because they had to perform these surgeries to relieve my brain of the pressure so I didn’t have a stroke, but it actually destroyed a lot more of my vision.

And while I was in hospital, I was just realising, “Oh my God, my vision is deteriorating even worse.” And after having surgery, it was like I was pretty much completely blind, and I felt almost incapacitated at times because I was having staff help me do absolutely everything from, you know, getting out of bed to doing basic things like going to the toilet, and when you’re a 21-year-old who’s just graduated university, you want to be out in the world experiencing things on your own and doing everything for yourself, experiencing independence, and all of a sudden you’re back to the beginning having someone hold your hand everywhere you go. It was really confronting. But while I was in hospital, it felt very contained to the environment. It felt like, “As long as I’m in this hospital, it’s not quite real.”

It all sort of came crashing down on me when I actually left hospital. As soon as I took that step outside of the hospital, I was like, “Oh my God, it’s real. I have to go home now and realise that this is my actual life now.” But fortunately I was very lucky to have some great occupational therapists in hospital who put me in connection with Guide Dogs, and that’s where my journey began with assisting myself in the vision loss community. And while it was a very bittersweet journey, it was the beginning of finding my independence again.

JESS: That’s an incredible story, Olivia, thank you for sharing that. I don’t know how much you know about retinitis pigmentosa, but it’s often a very slow degenerative disease, so to hear a story about a reasonably sudden onset is quite intense. So let me just try and get my head into where you’re at at this point. So you have gone home, and you’re trying to essentially learn how to live your life in a new way. How did you talk to the people around you about what was going on with you?

OLIVIA: Well, I struggled at first. I don’t think I handled it quite correctly, because the entire time I was in hospital I hid it from everyone because I was really embarrassed, even though I shouldn’t have been. I didn’t tell anyone except for my boyfriend that I was in hospital, and while this was at the very beginning of lockdown and people were still meeting up in small groups, people would ask him, “Oh, where’s Olivia,” and he knew I didn’t want people to know, so he would just sort of give some flimsy excuse, but people were starting to catch on that I was sort of missing.

Eventually I connected with some of my very close friends and told them this, and to just hear the final situation all at once was very overwhelming for them, but they were very supportive. It was mainly them realising that, while it was a big physical change, I’m obviously going through something quite big emotionally and mentally, and it was then that they realised as my friends and my peer support group that they needed to uplift me and support me throughout this.

JESS: So did they ask a lot of questions about what’s going on with you? Like, is that an ongoing conversation?

OLIVIA: It’s definitely an ongoing conversation, because at the beginning they realised that I was hiding it a lot. They weren’t quite sure what questions to ask me. And I think, just in general, when it comes to something like a disability, you never know what questions are appropriate to ask someone, with the added tension of the fact that I was very insecure about my status. But I was very quick to reassure them that they could ask me anything I [sic] wanted. What I prefer is people ask me questions about my situation rather than just assuming, so they learned that quickly, and we’re still having very long conversations about it.

When we go out, they’re always asking me, “Are you okay with this? Would you prefer if I guide you here, or is this the type of path that you can walk down.” Sometimes they’re like, “Oh, is this condescending,” but I much prefer open questions rather than just assuming, or them even just saying, “Oh, no, no, she can’t do that.”

JESS: Yeah, that’s what I always tell my friends. I’d rather be asked the question than you assume, and if I’ve got question fatigue I will just tell them, “Were’re done with questions for the day.” But I mean, you are very reasonably in terms of things – Kylie, who we were talking to in the last session, has been dealing with her vision loss for 40 years, so you’re still at the beginning, and you take me back to the time where I kind of struggled because my friends and family would be asking a lot of questions, and sometimes I actually just didn’t know the answer, because I was still learning about myself. Are you finding you’re getting a little bit more in charge of yourself, that you are better able now that you’ve been dealing with it for a while, that it’s getting easier to answer questions?

OLIVIA: Yeah, definitely, because at the beginning I think there were certain questions that maybe put a bad taste in my mouth, and I realise now that even though I didn’t particularly love the questions, people are always asking – well, if they’re a friend or a family member, they’re always asking from a good place.

And I think back to the time when I was first discharged from hospital, my mum actually kept asking me quite a lot of questions, like, “So what if we looked into doing this medical route,” or “What if we did this medical route?” It seemed like she was posing a lot of questions that would present me with the opportunity of, “Oh, if we did this there’s the chance that you might be able to gain some vision back.”

And at first I was really perplexed by this question, because it seemed to me like she was not okay with my new diagnosis, like, she wasn’t able to accept where I was and she was just almost like bargaining with where I was at. “Oh, but what if we did this? Don’t you think that maybe…” And while all these questions are still really valid and there are, I guess, maybe some things, even though I’ve been completely deemed, like, there’s no further progress for my vision, it’s not coming back, I realise now that she was just being a really caring mother. And it was almost like she was grieving at the time, like she was trying to figure out all the answers in her head. But from my perspective at the time, when I was a little bit upset, it seemed like my own mother wasn’t accepting me. How could this be? But she was just coming from a place of really wanting to understand the whole situation.

So now when strangers ask me, “Oh, do you think that, you know, this, maybe in the future,” I don’t get upset or anything about people trying to change me. I realise that they’re just trying to figure out the whole situation. Maybe I haven’t explained it entirely well. So I realise I am getting a lot better at answering questions, I think.

JESS: Yeah, it is quite a transition, and at first when you’re diagnosed you think it’s all about you, and fair enough, because it is, but it took me quite a while in my journey to realise that my friends and family were kind of sad about my vision loss on my behalf, and it wasn’t until I gave them a bit of space and let them have some conversations about what they were feeling in relation to my vision loss that I got a lot more feedback from them. Have you had some conversations that were hard but worth it?

OLIVIA: Yeah, definitely. I think the dynamic in my family has been a little bit difficult at times, just because I’m the youngest of three children, and I was at that stage of just about to get my life together, was just about to, you know, find the right career for myself, and all of a sudden this big shift changed in dynamic. I could sort of see it in my family at first, and while it was upsetting for me to sort of see my own image change in everybody else’s eyes, I was no longer the young, vivacious child of theirs, I was now this person that I could see themselves having sympathy for and thinking that, “Oh, she’s going to need so much help,” whereas before I was the one helping them.

It was really tough at first, but some time apart has actually done us really good, because I’ve since moved out of my parents’ house and they’ve realised that I can actually do quite a lot for myself, with obviously the assistance of others, but I can still be an independent young adult. And even though the dynamic is changing, it could be for the better.

JESS: Yeah, I think one of the most important things I’ve learned in the past five years since being diagnosed is that, actually, because I’m so fiercely independent, but actually being able to ask for help outside of yourself, and just put yourself out there, ask for a little bit of help, it can go a long way to making you more independent, and that’s what I’ve learned. And it’s early days for you yet, but what do you think so far is the most important thing that you’ve learned about yourself?

OLIVIA: I think I’ve learned that I’m very adaptable to situations. Even though I do take a little bit of time, I can suit new environments quite well and just make things work for myself.

I think it’s also shown me that I am quite emotional, because I think maybe compared to others it’s been quite a big journey for me emotionally, because I really didn’t like seeing myself change, because I really had this idea of myself growing up of what I was going to be, and having to accept that that’s not going to be a reality was quite huge for me, and I was very emotional about it.

I’ve always thought that being emotional is a bad thing, but emotions show us how we feel for a reason, and I was meant to take that time for myself to realign myself and realise, sure, I’m not going to be that extremely independent person who goes and has a full-time career in what I studied at university. But just because I can’t have that one image I had for myself, I can certainly create a new one and find happiness in that one as well.

JESS: Yeah, that’s true. Resilience is the key for a long and happy life. Thank you so much, Olivia, for sharing this story. It’s very emotional, very intense. I think it’ll help a lot of people to hear what you’ve been through and how you have bounced. So is there anything else that you would like to talk about? Any advice for people?

OLIVIA: Well, one of the main reasons I was really excited to do this project was because I felt so alone when I was going through what happened to me, so I thought if I could help somebody else in my position, that would just be amazing. So if anybody is going through, even anything similar to what I’ve gone through, or has been going through even their entire life, it’s just really nice to know that you are actually not alone, even though you may feel alone.

Through amazing programs like Guide Dogs, we can actually become connected and meet people who have very similar situations to yourself, and it’s actually quite liberating. Since actually joining the Zoom group we have, the young adult’s Chatter Paws, it’s actually been really refreshing for myself. It’s been the first time I’ve ever been able to speak to any other young people with visual impairments. And even though it was just something small like an online Zoom every fortnight, it’s actually made a huge difference to me to know that I’m connecting with other people who have the same situation as myself. So I think for other people, if they are experiencing what I am, it’s really important to connect with others.

JESS: I absolutely second that. I agree with every single word you just said. So, Olivia, obviously you’ve had to learn quite a few new skills real fast. You mentioned to me earlier that you use a long cane. How was learning that, because I struggled with it a little bit myself.

OLIVIA: Yeah, when I first met my O&M instructor, I think maybe after a few consults she brought to me the idea of using a cane, and I was still coming to terms with my vision loss and I thought to myself, “Oh, am I really the type of person who needs a cane? Is my vision that bad?” But she had one with her, and I just thought, “Okay, we’ll do just five minutes outside my house.”

And those five minutes, just using it in my hand, I was like, “Wow, this is really, really powerful.” The feedbac in the handle, all of a sudden I was like, “Oh, wow, I can see why someone with my type of visual loss would use this,” because I’ve just got that small circle and I was so used to staring at my feet every time I walked around, being really scared. All of a sudden, I could look up and stare in front of me where I was going and use the cane to guide in front of me and know what was happening in front of me without having to stare at my feet, and it was just so refreshing all of a sudden. So I was like, “Wow, totally. This is something I’ll definitely take on board.”

And that’s when I began training with my long white cane, and since then I’ve been doing lots of training around supermarkets and stuff, around my apartment block, and it’s just been really nice. It helps me with mobility, being able to get out, staring at my feet, which is insanely impractical and unsafe, or having someone guide me all the time. So it was really nice to be able to start using that.

It was just overcoming that stigma of sticking out like a sore thumb, because I was all of a sudden this young person and I’ve got this big white cane in the middle of the northern beaches, and you don’t really see people with canes on the northern beaches, and I’m walking around and I could feel the stares. Everyone was staring at me. I could hear little kids whispering to their parents, “What’s that,” and I just felt so embarrassed at first. But it’s something I have to overcome anyway, because either I have my cane and people stare at me, or I don’t have my cane and I’m falling over stuff and people are like, “Who’s that crazy lady on the floor.” So it’s something that you’ve just got to deal with, I think, anyway, and breaking the stigma is good because if I can overcome something like that, it can help me with any other sort of insecurities I have, and it’s been really nice getting to know the long white cane.

JESS: Yeah, you’re not Robinson Crusoe there, Olivia. I learned how to use the cane and be safe with the cane a lot sooner than it took me to overcome that sense of people looking at me, I feel really self-conscious. So yeah, you’re not alone there. Luckily I had my RP support group, God bless them. They were very encouraging. They all said, “It’s the same for us. Just keep trying. You’ll be fine.” And they were right. They were right. Thanks again so much, Olivia. That was really, really bold and great of you. That was so interesting. And yeah, I’m touched. I’m touched.

OLIVIA: Thank you so much.

CONCLUSION: You’ve been listening to an audio resource produced as part of a peer support program, Chatter Paws, by Guide Dogs New South Wales/ACT’s connection services. To find out more about how Guide Dogs can support you to reach your individual goals, visit guidedogs.com.au, or phone 1800 436 364.

Talking about vision loss can be tough. If this discussion has brought up concerns for you, please reach out to Lifeline for support on 13 11 14.

PODCAST EPISODE 3

TALKING ABOUT VISION LOSS

MATT

INTRO: This is an audio resource produced as part of a peer support program, Chatter Paws, by Guide Dogs New South Wales/ACT’s connection services. Connection services exists to foster the power of peer support. It’s produced by Guide Dogs’ clients for clients. This particular miniseries focuses on all things adjusting to and talking about vision loss.

JESS: Hello, you’re listening to the Guide Dogs Chatter Paws series talking about vision loss. I’m Jess Nelson, and I’m a Guide Dogs client and volunteer with retinitis pigmentosa. This is the final part of a three-part series, and now we’re talking to Guide Dogs volunteer and client, Matt, about his experiences. Hello, Matt. We’ve been starting these sessions with an introduction, so please tell us a bit about yourself.

MATT: Hi, Jess, and thank you very much for the introduction. I’m 50 years old. I’m a Guide Dog handler, and very lucky to be one. Thank you to New South Wales/ACT Guide Dogs for the precious gift that I have. Obie and myself are a team. We walk regularly and enjoy our life with the mobility that we have. I have cone rod dystrophy, so I have mostly blurred vision and quite a bit of night blindness and light sensitivity. I previously worked full-time, owned a business. I also play at sports and whatnot regularly. I was diagnosed approximately 10 years ago, so in that 10 years I’ve been through losing my livelihood, losing some of my sight, giving up driving, and numerous other things that go along the vision loss journey that we all are on. But, you know, you have to grow and build resilience, I believe.

JESS: Yeah, I do believe that is the key. I think a lot of people hearing you introduce yourself can really, when you were going through those milestones of loss, could really relate. I think a lot of people relate to the losing of your drivers licence. I think we’ve all got a story that involves tears of going in and having somebody chop it up. So have you ever had any formal support to talk to people about when you feel loss? Do you feel that it’s an okay thing to talk about? What’s your outlet for feeling these emotions around these milestones?

MATT: I guess that was probably another big part of my journey in the last 12 months. So only recently I’ve engaged the help of a psychologist earlier this year, And that was probably the final step in my journey to really start to become to understand where my grieving actually began and how to manage that. Prior to that, I thought I was doing fine, but last December my family told me otherwise, which was really sobering, and I think – you know, I took it the right way and I thought, “You know, this is really time to make a difference.” So I started a new journey at the start of 2021, and it was the quest to be my best, and it’s going pretty well so far, so, yeah. But, you know, I definitely took on some professional support, and I don’t believe you can do that until you’re ready.

JESS: That’s really great that your family felt that they could talk to you about it. It might be a bit personal, but is there some insight that you can give us to how that conversation came round? And why do you think you were so receptive to listening to them?

MATT: Look, it is personal, but I’m happy to share. I was a bloke that enjoyed a beer, and I was probably having too many, and that sort of was the thing that really started to bring it to a head. More often than not, you know, I was having it just because I could, and there was no reason behind it otherwise. So on 19 December last year I stopped drinking almost completely, and then, so, like, I have not bought a carton of beer since that day.

JESS: wow, good for you, and in lockdown, too. That’s a challenge.

MATT: Yeah. No, all I’ve done is have some, you know, social drinks with friends, and we travel with a caravan, so, you know, I have drunk, but I’ve only had one beer since May this year.

JESS: Congratulations.

MATT: Yeah, thanks, Jess. And look, it was a massive step to starting that journey. And I knew before they spoke to me, but, you know, they needed to – the hard conversation had to be had, and I promised them that I would make amends and do what I had to do to make things right and get on the right path so I could be the best person for myself, and also the best person for the rest of my family. And that’s sort of where I’m at now. I’ve lost 25 kilos this year in this process as well.

JESS: Very cool.

MATT: So I turned from a person that was fairly casual to someone that is now visiting a personal trainer three times a week and walking up to 25, 30 kilometres a week with my Guide Dog, and I’m really enjoying that part of my life now. I was the sort of person that would, “Walk? Geez, I don’t even walk to the fridge if I don’t need to.” So ideally you would say that I’ve completely changed.

JESS: Wow, that’s really, really impressive, Matt. It must be good to know that you’ve got the support and honest feedback of your family. Has it always been like this? You mentioned, you know, sort of 10 years of vision loss. What was it like in the early days? Has it changed a lot?

MATT: My vision loss has changed a lot from a reading perspective in that 10 years, quite a lot, and from what I – you know, I see everything but it’s all blurred, so my ability to do quite a few things is altered. But I still push on to try and make sure that I’ve got that independence, and I’ve found ways with technology or whatnot to help me through that. But, yeah, look, the last 10 years have been difficult. I was starting a new relationship, and then she could have quite easily have said, “You know, I didn’t sign up for this. This is all too difficult,” but she didn’t and we’ve been married two years now and she is just the most wonderful person in the world. I thank myself every day, my lucky stars, for having Tanya in my life, and her children, and then my older children. They’ve been the cornerstone of support, but you know, you didn’t realise they were there until things started to come together.

JESS: Yeah, now you mentioned your family. I think a lot of people who would be listening to this also have family around them, and it complicates things a little bit because you’re not marching to your own drum. What sort of challenges are you facing, just on a practical level even, having them around? Because you mentioned you go camping a lot. I mean, I get very mad if somebody doesn’t put my scissors back in the same place. I can only imagine what it’s like in a very packed camping van or a car. What’s that like?

MATT: Well, I predominantly pack everything, and the caravan and everything is packed by me, so I know where everything is. The girls are really quite good now. It’s been a real progressive thing for me, so they’ve – as they’ve gotten older, they’ve gotten better at realising, “Put things back,” and there’s a reason behind putting things back, which helps everybody, and it helps me, so I can just put my hand on it again next time. But that was a difficult time to try and organise and manage.

And we actually did a three month trip right up into the Gulf of Carpinteria with our first caravan. My wife does all the driving, so she’s a pretty special person when she’s hardly ever towed anything in her life, and then hooked up a caravan and off we went for three months with the kids and a Guide Dog.

JESS: Very cool. Very, very cool. So what’s the most important thing that you’ve learnt about yourself as a vision impaired person?

MATT: I certainly found out who my friends are.

JESS: Right. Tell us a bit more about that.

MATT: Look, I’ve got a couple of very good friends that are still good friends and that will never change, but then there was a lot that distanced themselves, you know, because it was just a bit all too difficult. Or you didn’t get asked to go and play golf any more because it was a bit hard because they always had to help you find the ball, and those sorts of things. So there was a lot of life-changing events that were associated to it that made me grow.

One of the other things I learned about myself was I’m still the same person. And by no means should you lose anything from the person you know you are because of any sort of disability. It doesn’t matter whether it’s vision loss or if you’re in a wheelchair, you know, you need to be the **[0:10:37 inaudible]** person that you are and stick to that. And yes, it’s taken me a long time to understand that, but I knew I was still always the same person. But yeah, you’ve got to stick to your moral values. You’ve got to stick to your strengths and try to make sure that you are doing things that do make you happy, and your family happy, and everything else should be okay, you know. It doesn’t matter then, does it, as long as you’re happy and your family’s happy.

JESS: Yeah, exactly. Now, Matt and I have talked in the past, and he is one of those people who is a good advocate for the vision impaired blind community when people are talking to him in public. So when you’re out in public with Obie and somebody wants to ask you all the questions about what it’s like to be vision impaired or blind, how do you manage that? Do you have advice for people? Have you got an example of a situation that went right?

MATT: Yeah, I’ve got lots of situations that, especially when we travelled, there was a lot of situations where quite often, because of the residual vision I have, I can help my wife park the caravan and things, and then set up the camp and do all of those sorts of things, and then put Obie in harness and walk off to the toilets, and people would go, “Hang on a minute. Didn’t he just help his wife park that van and set it all up, and now he’s trying to say he’s blind.”

JESS: People get easily confused by that, don’t they, because there tends to be an idea that if you – you have to be able to not see at all to be vision impaired.

MATT: That’s right, yeah. So I try to turn any of those types of situations into positives. And it usually – it always revolves around kids, I find, Jess. Children are the best catalyst to start the conversation. Whether I’m in a shopping centre or if I’m at a caravan park, I find that if a young child comes up and asks to Pat Obie and he’s in harness, I usually find – in a shopping centre I’ll just say, “No, he’s working,” but if I’m outside the front of the shopping centre I’ll say, “Yeah, sure, just give me a minute. We’ll move over somewhere and I’ll take him out of harness and you can give him a proper pat.”

JESS: Perfect.

MATT: And then I can sort of start the conversation with the parent or a caregiver or whatever that’s there, so it becomes a positive. And that’s what usually happens around the campsite sort of thing, too. Obie will be on a cable, and then somebody will be walking past and they’ll sort of go, “Oh, can I pat your dog?” “Yeah, no worries, he’s not working now.” And then they’ll sort of go, “Oh, we saw you with him in a harness. Are you training him,” is the question I get quite often, and I go, “No, he’s mine. He is my Guide Dog. I’m vision impaired.” Then I can open that conversation up. And it always tends to go right. I’ve rarely had any real negatives, and I guess it’s because I do like to give. I think the future generations are our kids for understanding vision loss and for understanding disabilities. If we don’t treat the children growing up the right way, they’re not going to treat people with disabilities the right way.

JESS: Thank you, Matt, for – that was so insightful, and thank you so much for sharing so much about your family life. It’s insight that is very valuable and we don’t get it that often, so it’s really, really appreciated that you gave us your time today. Is there anything else that you want to add? Any particular general advice for people who are trying to navigate family life as a vision impaired blind person?

MATT: Yeah, don’t sweat the little things. Try to, you know, try to make sure the small things that might be annoying you don’t become the things that annoy everybody, because they’re not necessarily what really matters, you know. The little things, yeah, sure, they might matter to you, and if the sauce is not put back in the right spot or something like that, it’ll get there. Just keep putting it there. Keep trying to make sure that people see you go and change it, or something like that, because by making a song and dance over it, it’s not going to make anybody feel better. So definitely don’t sweat the little things, and be the person that you know you are. Enjoy your life, and enjoy your families.

JESS: Great advice, map. Thank you very much. Thanks again.

MATT: Thanks, Jess.

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