Hadley Presents

Becoming More Socially Confident After Vision Loss

Presented by Ricky Enger

Ricky Enger: Welcome to Hadley Presents. I'm your host, Ricky Enger, inviting you to sit back, relax, and enjoy a conversation with the experts. In this episode, we discuss communicating effectively without visual cues. Our guests are author Hannah Fairbairn, interviewed by Hadley Learning Expert Elyse Heinrich.

I'm really excited about today's topic, but before we jump into that, I'd like to learn a little about each of you. So why don't we get a quick intro?

Hannah Fairbairn: So I'm Hannah, I'm a senior and I am legally blind. I can see colors really well and read absolutely huge print. And I'm a retired teacher of the visually impaired.

Elyse Heinrich: Hi, everyone. My name's Elyse Heinrich, a Learning Expert with Hadley. I teach a variety of courses, as well as co-host on a few different discussion groups. I'm so grateful you could join us today.

Ricky Enger: In this episode, we're talking about something that I wish had been talked about more. In my own experience, it's something that doesn't come up often. For other blind and low vision people I meet, they too indicate that this is something that is really difficult to find information on. Not only has Hannah written a fantastic book that we'll be talking about just a bit in the episode, but also she, of course, has her own personal experiences with this to share.

Hannah Fairbairn: I was born, as you can probably hear, in Britain, way back. When I was growing up, there was no support for partial sight in school. I was born with congenital cataracts. So as the print got small, I didn't do so well, and I didn't end up going to college. Instead, I trained as a chef and became a partner in a London restaurant. When I was just about 33, the retina in my better eye detached, and overnight I became legally blind, which was, of course, a massive shock.

Then just skipping forward, later on, I married my boyfriend who had most loyally and kindly stuck around through all the trauma. We have two daughters, and the younger one inherited my eye condition, although we'd had genetic counseling that said, "No, it wouldn't happen." So the reason I'm mentioning this, is of course then I got a whole lot of opportunity to give my daughter the advantages and the support that I hadn't got.

Both our daughters have done equally well. And of course I, myself, got a huge training in how to advocate for vision loss through my daughter. And then we moved to the US, where my husband had grown up, in Massachusetts. It was then that our younger daughter got very good support in the school system there. And then once she was sort of launched a bit, I started work again at the Carroll Center.

Elyse Heinrich: Can you talk a little bit about, I guess, the Carroll Center, and then did that sort of jumpstart you to the low vision, blindness field?

Hannah Fairbairn: Well, in fact, I jumpstarted before that because when I was really very new to vision loss, very new to being legally blind and still pretty stunned by it all, I was invited to contribute to the BBC, the British Broadcasting Corporation. They have a weekly radio program called In Touch, which is for blind and visually impaired people. I was invited to contribute about, of course, cooking, since I was a chef, and cooking and household equipment that worked well if you couldn't see properly. I was so impressed by the presenters who were all either had low vision or were blind. I was so impressed by their easy, cheerful, friendly manner, but also very determined and firm to get the results that they needed. So that was my first wake up call.

Elyse Heinrich: So I guess when I think about communication and speech, one of the big parts of it, to me, is more of that face-to-face, and even the non-verbal cues, that eye contact or even some head nodding?

Hannah Fairbairn: Yes, indeed. When I got to the Carroll Center, I found that ... I was teaching personal management, and I found that it came up again and again with my clients, my students, who were pretty much all adults new to vision loss, that they found face-to-face, ordinary, everyday interactions were much more difficult. And that they had lost social connections, even a few friends, also independence, because they didn't understand why talking to someone had suddenly got so difficult.

So that was really the motivating factor for me to start thinking hard about this. And with the help of many of my students, and we had a focus group to work out what it was that so difficult about face-to-face communications. Of course, the thing is, as you were just mentioning, that you think that when you're talking to someone it's about the talking, but in fact, people connect with their eyes first. They always, always do. Especially with short interactions, like checking out at a store or you're checking in to a medical appointment, or maybe even a hotel.

People, they connect with their eyes, and then when they've got the attention of whoever it is, they start to speak. This is also very true at what ought to be an easy, comfortable event, like a church coffee hour, or going to a family party, which people often find really awkward and even painful because they can't make contact with people the way they did. That was when I began to think personal management ought to include how to talk to people.

Elyse Heinrich: Oh, for sure. So did you work on some different trainings and different experiences on how someone with a visual impairment could talk or act in more of a positive, assertive way?

Hannah Fairbairn: Yes. So I was very supported by the Carroll Center seniors, the head of rehab and the head of counseling were very helpful and often co-taught with me, especially in the summer with the kids, the teens and young adults, who also, of course, have this problem, often in spades. What we worked out was that if you had just a very small group of adults with vision loss getting together in a room, just three or four people working out and then role playing difficult situations, like how to line up at the pharmacy, or just the most ordinary things, how to find someone to talk to at a party, that we could role play the different ways or just talk about it, if we didn't want to role play, and gradually, and sometimes very fast, people would come up with great answers. There's nothing like a small group of people who have the same problem to come up with great solutions.

Of course, you have to practice because the main part of this is ... And this is not different from what you probably already do at home if you live with other people. Because when you are living with other people, if you walk into the kitchen in the morning, you don't start by making eye contact. Person will have their back to you, and you'll say, "Hi, good morning. Have you got the coffee on?" Or whatever you say. But you don't wait. And so you need to adopt that exact attitude of speaking up in a cheerful, confident way, nice and clear, but definitely positive, and you make the request.

This is really hard to do at first. You feel like such a lemon speaking into the void, but that's the way forward, is to speak up. What you're going to try and cultivate is a tone of voice, a manner, that is like those first people I met on In Touch, the blind and low vision presenters. You want to be firm, determined, positive, and then with this nice, light touch, so people don't feel, "Oh, what's going to happen next?" They feel you've got it, whatever you feel like inside. Because often you feel really uncomfortable inside to begin with.

Elyse Heinrich: Yeah, yeah. I'm just thinking about that. You keep the skill and practicing that and coming up and developing it within yourself to feel more confident that you could actually go to a real-life social setting and to practice that. But really, would you say that's what effective communication look like, that being confident within yourself and being firm and assertive, but not overly pushy?

Hannah Fairbairn: You want to have a, as it were, a smile as you do it, so that the other person, whoever you're speaking to, the assistant, the clerk at the drugstore, whatever it is, feels good about you, doesn't feel that you're going to be a problem. But I do want to say a little more about how to do it. This is going to sound really tricky, but once you've practiced it a few times, it becomes just what you do. And that is, when you go to a store, and the same goes for going to a medical appointment, and presumably we'll all start doing this sometime or other, first of all, you need to mention as lightly and in a throwaway manner, the fact that you have a vision problem. I know people hate doing this, but it makes such a difference to the other person. So you're going to just say something very throwaway like, "Recently I've had a bit of problem with my eyes. I don't see so well these days," whatever you ... You want to practice in the shower to find what feels most comfortable to you. So you just say that. So then the assistant knows, "Oh, this is about not seeing clearly. This is about not being able to find things." And it also means, so this applies, even if you're carrying a white cane, which I know most people don't want to, but it means that your assistant knows that it's okay to speak about it. That they can say, "Would you like me to tell you which aisle we're in," or whatever.

The next thing is, which I've already spoken about, so it's having this confident, cheerful manner, whatever you feel like inside. And then thirdly, and this is the tricky bit, this is the bit you're going to practice quite a bit with whoever it is, you're going to coach your helper in how to do it. Because let me tell you, they haven't a clue. Whoever you're talking to, you may very well be the first person with vision loss they've ever met. I only once in all my time have had an assistant who knew about sight loss. I once had an assistant in a grocery store who was moonlighting from a job at the Perkins School for the Blind, and suddenly it's like we were up and flying because she knew so much. But it's never happened again.

So you have to coach your assistant. And you're going to do it, again, in this light, easy way, but very definite, and you're going to say whatever you need, "Can I take your elbow over to the dental aisle or over to checkout?" Or you might say, "Can I follow you? Can you show me where the restrooms are? I can follow you," or something like that. Or you say, "Just let me know if there are any steps." So you need to coach them in what help you need.

And then the last bit, is you need to tell them when the help will end. So you say, "I need you to stay with me right through the checkout, please. Once you've shown me to where the pants section is in my size, I'll be fine. I can do it from there." And this stops the person, your helper, either disappearing on you or sort of hanging around when you don't actually need her anymore. Same goes for a medical appointment. As you check in and you've got the person's attention you want to say, "And when Dr. X is ready to see me, I will need someone to show me which is her office door. And then I may need help too in finding my way out, so can you keep an eye out for me?"

So that's what you do in those kinds of situations. You want to start there, where people are paid to help you, paid to help anybody, but that's a good place to practice. And then after that, you may start socializing yourself, going to things. When you're new to vision loss and you want to go to some social things or you have a second disability, or you're just not feeling very well, you want to stick with, what I call, the three Ss, which is seated, simple and small. So if you can be seated around a table with just three, four, five, or even just one other person, and choose something simple to eat or drink, you're much more likely to enjoy yourself. Indeed, most people I know who live with vision loss, prefer to socialize with a small number of good friends to anything else. Big groups, not that we're doing that right now, but big events feel more like work.

The second thing is once you're more confident, once you're more ready, then you can move on to the three Ps, which is prioritize ... Think, do you really want to go to this wedding? Why are you going if you can't see the bride? Or whatever it is. Work out what you can get out of it and how much planning it will take, and then do the planning and then do a lot of phoning, so you get well-supported. The bigger the event, the more support you'll need. So those are the basic first steps. As you get more confident then ...

I mean, one of the people who joined the focus group for writing my book, said, "Before you lose vision, you don't have to be so organized, but once you lose vision, it's you have to plan. You have to be organized." And this means doing the stuff ahead of an event. As I said, the bigger the event, the more planning you have to do. So first you decide, maybe you're going to an event because you'll have a lovely long ride with your daughter and you can have a great catch up, or maybe you're going because you've arranged to meet a dear old friend you haven't seen for a year or two and you want to plan to eat with her or him, and you're going to sit down somewhere, so you plan all that ahead. You never leave ... If you go to an event that you haven't planned for on the phone and got people who know you're coming and are looking out for you, it's odds on that you're not going to have a good time. So you do have to plan. And then you first you phone your host and your real question is, "Who else is coming?" So you know who you can phone, who you already know. And then your second question is, "What kind of an event is this? Is it indoors or out? Is it a buffet? Is it a sit down meal?"

You need to know all those things because actually, oddly, it's much easier to go to an event where it's very structured, where you have maybe a seating plan with your name at a certain seat, and then you can ask who's on either side of you, and you can have a nice conversation, than to go to a casual event. Casual events, where people are standing up and moving around, they're much more difficult to manage well. People do it and people can do it, but you have to be much more confident.

I want to tell a little story here. I had a great client, called John, who thought that having a barbecue at home would be just the best. He thought it was just a family, extended family, and a couple of old friends, but it was really awful for him. He tripped over the cooler; people didn't talk to him much. He just had a horrible time. And he came up with the great phrase, "It's the unstructured events that kill you." And this is absolutely true. If it's an unstructured event, you have to make it structured for you. You have to plan it so that you will have people to talk to, so that maybe you have a little job at it.

The other great story I want to mention, is I had another client, Anne, who was well in her 60s, and she'd gone to a family party, which of course people think will be great, and it isn't. Her host, and this happens pretty often, wanted to seat her somewhere so that the host felt safe that she wouldn't trip or anything. And then she said, first of all, it was great. Somebody brought her a drink and she thought it was wonderful. But then everybody else went somewhere else. And so her piece of advice was, "never allow yourself to get parked." You always want to stay with the group, and only sit down when you're with a group of people who are sitting down. Again, the bigger the event, the more you need one or more friends to be alert and give you a hand here and there. Fix someone you're going to eat with, fix someone who's keeping an eye out for you, this kind of thing.

Elyse Heinrich: So it sounds like these are really some good strategies for us to learn to speak up for ourselves, and to be assertive, and to plan ahead of time before going to a doctor appointment or a family barbecue.

Hannah Fairbairn: And people feel awkward approaching you when they haven't made eye contact with you, and they don't know what's wrong. They don't know very often that it's the eye contact that's missing. So that's why you have to speak up, just like you would at home, "Hey, here I am. How are you? Who's that?"

Ricky Enger: I was just thinking about this, as well, in listening to you talk about having people that are looking out for you, and you may have one person who that you're going to sit with, and you may have a group of people that you've decided you'll be talking with. Do you feel like it makes it a little bit less awkward for a stranger, once they see you talking to someone else who might be familiar, and that person is relaxed with you? Do you think it's a little less awkward for the stranger to then approach you and break into conversation?

Hannah Fairbairn: That is absolutely true, isn't it? You're not seated in some little island all by yourself seeming rather distant and difficult to approach. If you're with a group, then somebody who doesn't know you feels much better about sitting down beside you and having a few words. They realize that you're, by the look of it, you're easy company and that's very important to establish.

And of course, it's very hard when you're new to sight loss, you don't feel like easy company at all. You feel like it's such a grieving thing. So really, when you begin on this whole speaking up thing, the first thing you have to do is allow yourself to recognize what a serious thing has happened to you, that this is very difficult to handle, and to be compassionate towards yourself. We tend to be self-critical as humans, and you have to be really ... Think if this had happened to a dear friend of yours, how much you would feel for him or her, and have that attitude towards yourself and give yourself time to feel all the grief about the loss of really good sight.

And then you can begin to make these adjustments, once you've admitted the loss to yourself, and got a tiny bit more comfortable with it. It does take a long time. Then you can begin to feel better and to start to know that you're a very valuable person in the community. So many of us in the population have a disability of some kind, and the more we can speak up for ourselves, the more that other people with disabilities are helped to be part of ordinary life.

Ricky Enger: I think that's fantastic advice. I know that you discuss this and more in your book, which is, When You Can't Believe Your Eyes.

Hannah Fairbairn: The book is called When You Can't Believe Your Eyes. And the second half, the subtitle is, Vision Loss & Personal Recovery. You can get it in print, and also as an accessible e-book. With kind donations, I've made copies of the accessible e-book free of charge. There's a very simple form on my website. And it's also on Talking Books and on Bookshare, When You Can't Believe Your Eyes. But if you want a family member to have a copy, please do apply for a free copy.

Ricky Enger: As we reach the end here, we'll start with you, Hannah, do you have any final thoughts that you'd like to leave our listeners with? I know that the advice you gave about just giving yourself that room to grieve and feel compassion toward yourself, and you do come out the other side, that's excellent words of wisdom. Do you have anything else you'd like to add?

Hannah Fairbairn: I do want to say that, please do, when you're ready, ask a family member, or maybe a cousin you talk to on the phone once a week, if you can practice on them. Practice this assertive speech, practice asking help at a grocery store, that kind of thing. And then practice by yourself in the shower, so that you get that tone of confidence and ease and you feel better about it. Once you are easy, the person you're talking to feels much more comfortable.

Ricky Enger: Elyse, how about you? Do you have any final thoughts?

Elyse Heinrich: Don't let your low vision take your communication and your confidence away from you. And just like Hannah was saying, it comes with practice.

Hannah Fairbairn: When we've all a little bit less social distance, if you do go to a low vision support group, perhaps you can pick out a couple of people and have lunch together afterwards or before or whatever, and talk about this together. You'll find that with three or four of you, you can come up with such great solutions to how to do this.

Ricky Enger: I'd like to thank you both so, so much for joining us today. I love the information that has been shared here. So for people who'd like to contact one or both of you, how can they go about doing that? Let's start with you, Hannah.

Hannah Fairbairn: So you can contact me at Hannah, and it's H-A-N-N-A-H @vlprblog.com. V-L-P R, meaning vision loss and personal recovery, blog.com. Hannah@vlprblog.com. And if you would like to talk to me on the phone, Elyse has kindly offered to funnel calls to me. So she will give you the number to call her first, but I'd be very happy to talk to you.

Ricky Enger: Fantastic. And Elyse, how about contact information for you?

Elyse Heinrich: Please reach out. My email is elyseh@hadley.edu. I'll spell, E-L-Y-S-E-H @hadley.edu, or toll free is (800)-323-4238. Just ask for me.

Ricky Enger: Thank you both so much for joining us and thank you all for listening.

Got something to say? Share your thoughts about this episode of Hadley Presents, or make suggestions for future episodes. We'd love to hear from you. Send us an email at podcast@hadley.edu. That's P-O-D-C-A-S-T @hadley.edu. Or leave us a message at (847)-784-2870. Thanks for listening.