Hadley

Services You Should Know When New to 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, Steve Kelley and Eric Boklage join us as we discuss vision professionals you should know about. Welcome to the show, both of you.

**Steve Kelley:** Hey Ricky, hey Eric.

**Eric Boklage:** Hi Steve. Hi Ricky. Thank you very much for inviting me to join you today.

**Ricky Enger:** It is so wonderful to have you both here. Steve, you are on the tech team here at Hadley and Eric, you are a participant in our discussion groups frequently. We've even named you a Hadley Hero, and I know you've learned from our workshops as well. Again, so happy to have you both here. We're going to be talking about professionals if you're new to vision loss or maybe you have been experiencing it for a while, but you just don't know what is out there. What are these different types of professionals and what can they help me with?

I thought both of you would be perfect to talk about this because you have experienced this from both sides so to speak. You've been the person who's new to vision loss and you're out there learning what's available to help you, and then you made that transition at some point and decided to be the person on the other side of the desk. So you're helping people who are going through what you once did. Before we talk about these different professionals and what they do, why don't we just go through a couple of quick intros. Steve, we'll start with you. Take us from the beginning, where you started with this and how you ultimately decided to work in this field?

**Steve Kelley:** Yeah, I had a vision loss and I got the thing from the doctor saying, "Well, there's not much more we can do for you and there's the door." I went home and I panicked, am I going to lose my job? How am I going to take care of my kid? What about my mortgage? All of that. Fortunately, it wasn't like an overnight thing. So eventually I stumbled into vocational rehab. They kind of took me under their wings and the biggest thing was showing me zoom text and also introducing me to some people who had low vision and who were blind, because it's almost embarrassing to say this, but at the time the whole notion of blindness and vision loss was so anxiety-provoking because I didn't know. I assumed if I lost my vision or had low vision, I was not going to be able to work. I wouldn't be able to pay my mortgage. All of those things. Just had no clue that there was any support.

And to make the sad story a little bit shorter, let me just say that I was in the office of the assistive technology person and was surrounded by computers and tech and was talking with her, she was doing an assessment, and at some point I looked around the room and I thought, I know computers, I know technology. I'm comfortable in this room. And I thought, I can be doing this woman's job. And that's when things just kind of clicked and fell into place. So that's kind of the shorter version of how I got here.

**Ricky Enger:** Wow, I love that. And what you said about just that anxiety and not having any familiarity with vision loss before you were experiencing it yourself. It's such a common thing. Eric, how about you? How did you get from where you were to where you are now?

**Eric Boklage:** My story is a little bit different in that my vision challenges really started in my mid-forties. Over the course of the following 10 or 15 years, I had three retinal detachments and repair surgeries for those. Cataract surgery in both eyes, et cetera. And I was given a false sense of security because after each one of those surgeries, they'd have me read the Snellen eye chart and give me some corrective lenses and I was still able to read those charts. So I came away with some really good clinical outcomes, but I ended up with some optic nerve damage and lost some peripheral vision. I now have glaucoma and despite if you will, the false sense of security, I was still struggling. I had other kinds of vision issues that were associated in particular with optic nerve damage. Things like photophobia where you're sensitive to glare and staring at those computer screens or not having enough contrast.

I was fortunate enough to get a referral to a low vision clinic and one of the first things they did was to prescribe for me to wear dark glasses all the time because those dark glasses are tinted in such a way that they helped me to deal with both the glare and improve, if you will, the lack of contrast. They give me some sensitivity to contrast that I wouldn't otherwise have. And I ended up in a situation where I contemplated retirement after a 40-year business career, but then I decided you're not going to be comfortable doing that. You need to find something.

So I now have a new sense of purpose and that's vision rehab. After a four-decade hiatus away from, if you will, academia, I went back to grad school, I'm now studying to become a certified vision rehab therapist and a certified assistive technology instructional specialist. Long words. But the bottom line is that I'm currently studying so that I can become someone who can work with others who have vision rehab needs. In the meantime, not only have I learned a lot of things that I can use to assist them, but it's stuff that will continue to help me as my own vision journey continues.

**Ricky Enger:** What a great benefit. You're learning to help people, and, in that process, you are learning things for yourself as well, whether you were intending that or not, it is a nice bit of icing on the cake. So we've used this term a couple of times, we've said vision rehab or vocational rehab, and we never really talked about exactly what it is. When people think about rehab, they might be like, oh yeah, I went to the rehab facility after I had my knee replacement, and we did physical therapy and whatever. So is this a thing to make my eyes stronger? What are we talking about when we say vision rehab? What is it? What is the purpose of it and what does it encompass?

**Eric Boklage:** So to me, vision rehab is all about helping people to adjust and cope with what their remaining vision may be, regardless of what that is because some people end up with very severe blindness and others have other low vision related symptoms and implications. We initially meet with people and we talk to them and find out what are the parts of their lives that they're having difficulty with and trouble with. Then we work with them to find ways of modifying what they're doing or how they're doing it, in order to let them continue to be able to do all the things... Let me retract, not all the things, but many of the things that they want and need to do. We can help with a lot of the other day-to-day activities and doing everything that they might need to do throughout their daily lives.

**Steve Kelley:** Eric, you're exactly right. I think about it in terms of function. There's a bunch of research out there that shows that when we lose one of our major life functions, which could be driving, it could be reading, it could be anything, recreation, whatever. When we start losing one or two of those biggies, there's a really good chance, I think like 30%, that will fall into a clinical depression within a couple of months. And I feel like the vision rehab therapist or anybody in our profession, what we do is we get in there and we try to figure out some way to get that person back to accomplishing those goals in a slightly different way. And that's the importance of vision rehab, I think.

**Eric Boklage:** And it may take them longer to do what they used to do, and they might have to be more careful about the way they do it, but they're still able to accomplish much of what they wanted to do and need to do.

**Ricky Enger:** Yeah, I think that's so important. Many people who are new to vision loss may feel that they are the only ones dealing with this. I don't know anyone else who's had a vision loss. Anything I have picked up might be a negative stereotype that really has no basis in reality. So we know that people are feeling that anxiety that you talked about. How am I going to pay my mortgage? How am I going to take care of my kid? All of these things.

I think that knowledge is power and if we know, okay, who do I go to and what do they do, that helps to solidify some of those things, and you get those answers of how will I do this or that or the other thing. Why don't we just go down the line here and start with when you walk out of that office and the doctor says, there is nothing medically that we can do. If you still have some remaining vision, who's the professional who's going to help you get the most out of how your remaining vision works?

**Steve Kelley:** There's a whole group of specialists, and I'm just going to list them, and we can pick up on these later. You have the vision rehab therapist that we've been talking about. You have a certified low vision therapist who sometimes works with the low vision doctor. You have the orientation and mobility specialist, and then you also have the assistive technology specialist. All of these people oftentimes work for the state agency, and that's kind of like the ticket to ride, so to speak, or to find out a little bit more about those folks.

**Ricky Enger:** Absolutely. So let's break this down a little further then. We have this pile of professionals, thankfully, that can assist you, but each one does something a little bit different. So if you're going to your state rehab agency and they're referring you to various other people, let’s kind of give names to each of those types of professionals and what they do? So if you're looking for what glasses should I wear or what's available for handheld magnifiers? What can I do around the home to address my lighting situations? Who's going to be the best person to take that on?

**Eric Boklage:** I'll jump in and say that in most of what you just described, the kind of generalist that's going to deal with the vision rehab needs, it's going to be a vision rehab therapist. The acronym that goes with their little, the alphabet soup behind their name if you will, is CVRT, which is for Certified Vision Rehab Therapist.

**Ricky Enger:** Awesome. And then what about those things that we often call daily living skills? The challenges that you face when you get out of bed in the morning, how do I figure out which clothes match and organize my closet? How do I pour my cup of coffee so that I don't burn myself or make a big mess? What about keeping my house clean? Things like that. Who is teaching those kinds of skills? And I'm also kind of curious, how do people get those skills? Do people come to your home? Do you go to a center? What's the whole process there?

**Steve Kelley:** The vision rehab therapist, oftentimes they will come to your home, but you can also participate in a center-based program. For example, the National Federation of the Blind has several center-based programs that a person could go to if they were so inclined. And local communities also have them through their vocational rehab. I think a lot of it really depends on what the person is looking for and even perhaps the severity and suddenness of the vision loss. Again, it's one of those things that might come up during the assessment process.

**Ricky Enger:** Right. What about technology? Steve, I'm finding it interesting because you have all of these initials after your name, you have CVLT and CVRT and this next one too, talking about assistive technology. Who's helping with that?

**Steve Kelley:** Well, that one's a really, really interesting one for me because I want to say traditionally, that too has been the vision rehab therapist or maybe the low vision therapist as well.

**Ricky Enger:** Is there a difference between those two?

**Steve Kelley:** There is a low vision therapist. Their certification has more to do with optical devices, not necessarily refraction of glasses. That's the doctor for sure. But it has to do with optical magnification and stuff like that. You may find them also specializing in some of the electronic devices as well. But it's one of those areas that broke off of the vision rehab therapist. So you had people who were a little more comfortable, say with technology than they were with daily living skills like matching clothing or cooking or something like that. And now, Eric, you'll have to remind me, there is that certification for the CATIS, the Certified Assistive Technology Instructional Specialist. It's a mouthful, but basically, they're the folks who are comfy with technology.

**Eric Boklage:** You're right, Steve. It's less than 10 years that there's been this little offshoot from the VRT scope of practice that includes the additional or more expansive assistive technology aspects of things. That is partially in response to what's been going on in the real world. There's been an explosion of technology. Fifteen years ago, people wouldn't have had anywhere near the kind of technology in your pocket that we have today with our smartphones, right?

That sort of explosion in technology has really been a driver behind this new classification of specialists who are there for assistive technology. Because like you said, it's a different comfort zone than working with people to deal with day-to-day things such as their laundry and cooking and what have you.

**Ricky Enger:** Yes, that makes a lot of sense. And not every person can be good at every single thing. You're going to have people who are great at showing you some of these daily living things. When it comes to technology, they're like, well, this is a necessary thing that I have to use. I don't feel great about it, and I certainly don't want to teach it. So it's good that there are professionals who do that.

What about when it comes to learning to get around? If you're losing your vision, you're getting around a little differently, and maybe that's using something at night that will help you see a little better if you're having difficulty with night vision. Of course, some of it is about learning to listen to traffic and whatever mobility aid you choose, that's part of it too. I think some of it is even, how do I get around safely in the house? How do I prevent myself from falling over things I didn't have to think about before? What professional helps with this transition of traveling safely and what do they do?

**Eric Boklage:** VRTs will do a number of things by helping people inside their homes how to navigate their home, help declutter, if necessary, in order to make walking paths easier to deal with, to reduce tripping options. They'll go over what's called human guide training, where you're literally taught how to work with someone who's going to be walking beside you or giving you guidance and assistance and how to turn that down when you don't really want it or need it. Sometimes people can get a little pushy if they want to try to help you across the street and you're not asking for it.

So, that is work that can be done and taught by both vision rehab therapists and orientation mobility specialists. When you start using a cane and you start dealing with the great outdoors and the world at large, the risks that are associated with navigating sidewalks and street crossings and things of that nature, that's when you really want the services of a certified orientation and mobility specialist or COMS. They're the ones who are really well-trained in how to help you stay safe in all of that wilderness of automobiles and street crossings and things of that nature.

**Steve Kelley:** I just want to also say that the orientation mobility specialist oftentimes shows up with a whole suitcase full of glare shields or sunglasses. It's not all about the white cane. It's meeting you wherever you happen to be. So, if your big issue is glare and you're not ready, willing, or open to check out a white cane just yet, then that's all that's going to be addressed is just the glare issue. I've had this conversation an awful lot, and there's a fair amount of anxiety around the idea of using a white cane, which is too bad because it's such a useful navigational tool. Don't let that prohibit you from talking about orientation and mobility and contacting that professional.

**Eric Boklage:** Yeah. One thing that I would add is that for those who are fortunate enough to live in a metropolitan area that has mass transit, a lot of the things that an orientation mobility specialist will do is to teach you how to access and understand those schedules. How to use the available information that's out there sometimes through a smartphone app and sometimes through other means, to know when are the buses running or what's the train schedule and how do I get from point A to B safely, despite the fact that I may have challenges with being able to read the signs or not be able to see them at all. They're really well suited to help an individual figure out how to get there and what's the best way for me to get there knowing that there are a number of options.

**Ricky Enger:** Yeah, that's a really good point. Even things that you might not think about like, I've gotten on the bus, now how do I know when to pull the cord so that they will stop, and I can get off at my stop? It's not just about the white cane. As useful as that is, it's all of these skills that you're learning to get around safely, whatever your mode of transportation happens to be.

We've covered certified low vision therapists and certified vision rehab therapists, low vision specialists might've gotten mentioned here or there somewhere, orientation and mobility. So there's all these professionals, and you might go to your state rehabilitation agency to see if they can get you set up with them. Are there other ways that people should go about finding these professionals? If you’re still waiting for the state rehab agency to call you back. Are there other ways that you can find on your own to see one of these therapists or O&M specialists, whatever it is that you've decided that you need?

**Steve Kelley:** You know Ricky, the short answer is yes. I'd like this pass out the Connect Center phone number, and that's 800-232-5463. For somebody who just doesn't know where to go, I would suggest calling that number. Chances are they'll probably direct you to your state's Vocational Rehab or Unit on Aging, or just call us here at Hadley and we can do the same thing. What's cool about the directory that we'll be using, that directory of services that Eric mentioned, is there's oftentimes a nice long list of other local agencies, usually nonprofits, in the community where you might find some of these professionals housed. These folks are not medical professionals per se. It really doesn't matter. They're oftentimes located in nonprofits. The cool thing about that, Ricky, is that usually there's no cost, low cost, or a sliding scale, but it's not like you're going to have to pay a lot of money for these folks if you have to pay it all.

So, looking for them in a nonprofit is the place to go. And then of course, come to Hadley. We do have a lot of that training available as workshop series that people can take online or what with talking book cartridges, braille or large print, all kinds of different ways. Sometimes there are some great YouTube alternatives too, which is where some of these professionals talk about this. I'm thinking about Mike Mulligan's Blind on the Move, which is really kind of cool. Eric, I think maybe you can speak to some of the workshops that got you interested in learning a little bit more about moving forward, right?

**Eric Boklage:** Absolutely. My introduction to vision rehab came through Hadley. And the reality is, even though, for example, I can't drive, I'm not legally blind, so I don't qualify for a lot of those state required functions or the state available functions. There are a number of people who may fall into that no man's land like me. Hadley is an absolutely phenomenal source for those snippets of information that help you figure out an easier or better way to do what you need to do. They give you insights through these workshops that are curated by topics. So if you have a topical interest in how do I deal with preparing a meal, how do I deal with potentially fixing my phone so that I can hear what it's trying to say instead of trying to magnify it so large that I really can't see it. There's just a wealth and a breadth of information that's available in the workshops.

There're podcasts like these that are very good and the Hadley discussion groups. Something that goes back to what you said early on in this conversation, Steve. People who are going through vision loss often have a sense of isolation. It's not just what am I going to do and how am I going to do it, but it's grief. It's the loss of something that was a part of their life. The discussion groups that Hadley hosts, it's not like you're talking to a therapist, but you're talking with and interacting with others who are also going through vision loss. The discussion groups have topics that are of interest to different people, whether we're talking about Tech It Out, or whether we're talking about Hadley Growers for people who like to garden, or whether we're talking about Book Nook for those who like to read and or listen to their books.

There's a variety of different discussion groups where you've got other people that are involved who get it and they understand and they're somewhere along the same path that you're on. So Hadley is a phenomenal resource for being able to get some aspects of vision rehab available to you. And that's also important because there's a fairly limited number of people throughout the country that have these certifications that perform these services. The population is generally aging. We've got more and more people that are entering those age brackets that happen to have vision rehab needs because all of a sudden, their eyes aren't operating as well as they used to. They've got various conditions like diabetic retinopathy, or they end up having ocular degeneration. Those are age related from a standpoint of the more you age, the more likely you are to acquire those particular needs. Having resources to be able to get into sometimes can be a challenge because there may be waiting lists. When that's the case, Hadley is a wonderful source to help supplement all of that.

**Ricky Enger:** That's wonderful. Thank you. And if there's a waiting list, people don't want to say, well, I will just put my life on hold for the next 10 months until someone calls me back. They want to know immediately what can I do? So certainly at Hadley, you're going to find a wealth of information. There are other places. It's not just Hadley, although we're happy when you come to us. There are places like OE patients, that's a blog with various articles about things of interest to those with vision loss. It can cover anything from the journey to deciding whether a white cane is right for you, or a list of technology phone numbers you should be aware of. So, there is a lot of information there. Vision Aware, Eric, you mentioned that early in the show as well, the APH Connect Center where you can call and get hooked up with professionals in your area.

So a lot of resources, and we'll certainly have links to those in our show notes. This has been really informative and a lot of fun actually. I appreciate how you have both shared aspects of things that you've dealt with and then ways that you're helping other people and professionals that are out there to do the same. Any final thoughts that you have before we wrap up? Steve, we'll start with you.

**Steve Kelley:** My final thought is just to remind folks that they're not alone as they go through this. There are a bunch of professionals out there. You can just give us a ring and we'll remind you or point you in the right direction.

**Ricky Enger:** Absolutely. Eric, how about you?

**Eric Boklage:** Well, my final thought is going to be along the lines that if there are others who feel that they want to explore this as a potential act two or three for them, don't just throw that by the wayside. If I can do it after a four-decade hiatus from academia, then anybody can do it. There are a number of programs that are out there that would welcome someone who has some lived experience to participate. So explore it and maybe we'll include some information about that in the show notes as well.

**Ricky Enger:** Yes, indeed. Wow, wonderful. Thank you both so much for sharing a little bit of your time with us and sharing your experiences. I've had a great time. I hope you have too. I'm so glad you could join us.

**Steve Kelley:** Oh, yeah. Thanks for the opportunity. It's always great to chat with you, and Eric, I loved talking with you as well. Thanks.

**Eric Boklage:** Thank you both. I greatly appreciate the invitation to join you. It's been an honor.

**Ricky Enger:** 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@hadleyhelps.org. That's P-O-D-C-A-S-T at hadleyhelps.org. Or leave us a message at 847-784-2870. Thanks for listening.