## 

Hadley Presents

Reading 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 explore options for reading after vision loss. Our guest is Hadley learning expert Steve Kelley. Welcome to the show, Steve.

Steve Kelley: Hey, Ricky. Thanks for having me.

Ricky Enger: Yeah, great to have you back. For those of you that don't know you, maybe this is their first episode, why don't you just give a quick intro and tell us a bit about yourself?

Steve Kelley: People may have heard me on one of three discussion groups that I'm a part of, Get Up and Go is one, Crafting Circle, and Book Nook. I'd love to see anybody who hasn't already heard those join in. Then my day job is working with you in the tech group, which I absolutely love.

Ricky Enger: Yeah, we have a fantastic time and I think it's interesting that you are a co-host on Book Nook, and I think that experience will certainly come in handy for our topic today. I know that you've done some work in the field with people who have experienced vision loss, and you have some personal experience with that too, so just really looking forward to diving into this topic because there's a lot here to cover. What we're talking about today is reading after vision loss, which is a pretty broad topic and there are so many different things that we can cover because there are lots of different ways even to think about reading. Are you reading for pleasure? Are you reading because you have to? Once you decide that, then how are you reading? What's available? What techniques can people use? I think a lot of people just don't know what's available, so that's why we wanted to have this discussion.

I guess we'll start with what happens when someone is starting to lose their vision. Maybe it's gradual or maybe it's very sudden, but in either case, there's probably some change in how they're reading. Maybe they're trying to read in the same way they always have, but it's not as easy as it once was. So, there's this adjustment period. What kinds of things do people try when they're in that period of figuring out, hey, I still want to read but I'm kind of struggling?

Steve Kelley: Oftentimes, when I was working as a vision rehab therapist, I would often show up and somebody would pull out grandpa or grandma's handheld magnifier from the 1930s or something like that. They oftentimes were not having a whole lot of success with it and just weren't sure why. I've just seen all kinds of other things like that. Sometimes there's stuff in the TV that we see, or you walk into a box store and there are some handheld magnifiers there. Unfortunately, a lot of times, they don't work as well as people think they're going to. The reason is because one size doesn't fit all. There's just all kinds of different things out there. Handheld magnifiers are great device, don't get me wrong, but you want one that fits where your vision happens to be. That's where I saw the failure in that method happening, was people just weren't really having an assessment and figuring out which one was going to be the best one.

Ricky Enger: Well then, how do people know? I'm sure this too is not a one size fits all. I think there's this feeling that if I just try hard enough, I can make this work and maybe I'm the problem or I'm not using it right or maybe this will just get better if I keep at it. How do people know then when it's time to investigate some other technique that might be a little more successful?

Steve Kelley: One of the things that I've observed both personally and with clients in the past is that none of us likes change. Maybe I should just speak for myself, I certainly don't like change. So those of us who have spent most of our lives reading with our vision, that's what we want to hang onto, and we are going to hang onto it tooth and nail no matter what happens.

Let me just give you a quick story. When I started a master's degree about 18 years ago, I showed up on campus and we had done some reading beforehand and I was woefully behind in my reading and that's not really who I am. But at the time, I was doing my reading with a handheld magnifying glass because I had always read visually and highlighting and putting notes in the textbook, the printed textbook, which by the way, was just in regular print. It wasn't working. I knew it wasn't working, but I wasn't willing to do anything differently because that's the way I had always done it.

One of the students who was blind in the workshop seemed like she was all caught up and knew all of the answers and everything, so I finally said to her, "How are you doing this?" And she said, "Well, I went to the Office for Students with Disabilities and I got the text on a CD and I'm just using my computer to do the reading text to speech,” which is where the computer or whatever device you happen to be using is just reading everything on the screen out loud to you. And I'm like, "Oh, the Office for Students with Disabilities."

Here's the thing. I did not see myself as somebody with a disability, but because of the frustration and also being concerned about my grades and all of that other stuff, that's where I was the very following morning at eight o'clock filling out the paperwork and getting my CD with it. Then I put it on my computer, and I started using the text-to-speech, which I had some familiarity with.

It wasn't smooth and it wasn't seamless, and I didn't get it at first. It was a bit of a struggle, but it was a heck of a lot better than what I was doing with the handheld magnifier. I just kept at it because that's what I needed to do in order to succeed in those classes. I don't think that I'm not that much different than a lot of other people. I have to remind myself to be mindful about efficiency and trying things differently when things aren't working.

Ricky Enger: Yeah. I guess it really does take some kind of motivator because change really is hard and perhaps you have to have something that you're trying to accomplish that's just become too frustrating to ignore that may get you to that point. Perhaps you're proactive and you're learning things before you necessarily need them, which may also make that transition easier. I guess it's different for everybody.

Steve Kelley: You bring up a really good point. I should say, I just spoke to somebody on the phone within this last week who was being extraordinarily proactive. She's an 85-year-old writer. She has things that she needs to write, and she was checking in with vocational rehab and learning how to use the iPhone and then VoiceOver on it so that she could master it because she wanted to continue doing those things. She still had some functional vision, so she was being very proactive, and I just really applauded that personality type. It's just not mine, but there are people out there who do that and that's wonderful.

Ricky Enger: I guess there are, well, I guess at least two types of reading. There's reading because you want to, curling up with a good book, reading for pleasure, and then there's reading because you have to. I want to know which mail is junk mail or how do I cook this thing or what medication is this. Why don't we talk about ways that people can do that necessary reading. Are there devices or products that are available that are really well suited to that kind of reading?

Steve Kelley: This is a great distinction that you bring up because that piece of mail that just came in or that quick short note or label that you need to read, a lot of those things can be quickly and easily done with a good handheld, for sure. In fact, my go-to magnifier is just a 5X Bausch & Lomb magnifier that I have in my right pocket every single day. It's really not a great magnifier because there's no light on it. In most situations, I can do what's called spot reading with it. I can see enough of it to know what's going on. That's the low-tech approach. The other go-to thing is I've always got my phone on me. It's a smartphone. Oftentimes, I open up the camera, use the magnification gesture on that to make things a little bit larger, again, for spot reading. You're not going to read a magazine article or anything like that.

Then when you have something that you really want to read for pleasure, like a magazine article or a book or something, then you have a whole new set of tools perhaps in your toolbox. I always think of it in terms of a toolbox because there's not just one device that's going to do this stuff. You might have a pair of reading glasses. You might have that handheld magnifier. Or maybe you’ve got a desktop video magnifier where you’ve got a platform and you put your cookbook or other reading material right on the platform and above that is a camera that takes a picture of the text and puts that up on the screen, so then you can zoom in or magnify and it makes it easier to read. Again, for me, if I'm doing research, then I completely switch to text-to-speech almost entirely. I just use something on the iPhone or my computer that reads the text on the computer screen because I can always pause it and go back and that sort of thing.

I too make a real distinction between what I'm reading, say for pleasure, or what I'm just reading real quickly like the mail or something like that and it's something that's a little bit more complicated or more in-depth. I know that you read in different ways too, and I suspect that you too have a way that you'd prefer to read something that's a little bit more in-depth versus, say casual or pleasure reading, right?

Ricky Enger: Yeah, definitely. I have no vision, so if I'm reading something that's the equivalent of spot reading, I too am going to use a tool on my smartphone. Whether it is something like an app called Seeing AI, and hey, we have information on the Hadley website about that. So, there's Seeing AI. There's an app called Envision. These are apps that allow you to get just a quick and not always super accurate, but accurate enough idea of that text, enough to figure out, oh, this is junk mail, oh, this is that business card that I wanted to call the person back to come mow my lawn or whatever. Those are the kinds of things that I would use for spot reading, either that or I would get some visual assistance. Now that could be someone in my home or more often than that, I will choose to use a visual interpreting service. This is a thing where you can call somebody up using your phone with a camera.

Generally, they're smartphones, but there are a couple of less smartphones that also have this capability where you can, again, call the person, they can see what's happening through your camera, give just that quick spot reading for you, and then off you go about your day. That's what I do for spot reading. Then for something that's a little more involved, whether it's pleasure reading or something that's going to take a lot longer to read, then I'm probably on my computer or perhaps I'm reading it in braille, lots of different ways to go about reading that longer text. Why don't we talk then about that? If you're doing some research or you're reading a long article, or again, if you're curling up with that good book for pleasure, what do you tend to use?

Steve Kelley: If I'm pleasure reading, I will probably get something that is narrated by a human being. These days, if I'm pleasure reading, I am going to go to Audible where you've got a human-narrated book, or actually I'm first going to check to see if it's on Talking Books. If it is, then I'm going to download it because that's a human-narrated book. It's enjoyable. I just really love reading that way for pleasure. Although oftentimes, I'm not reading for pleasure, and in that case, then I'm going to download the book as digital text. Usually, I'll use something like Bookshare, but not always. I might just download something off the internet or whatever and then I'm going to use text-to-speech. It's usually my iPad. I'm either going to have VoiceOver read it to me or I'm going to use a Voice Stream Reader or one of the other apps that will read it because I want to be able to go back to reread certain sections. I want to be able to put a bookmark in. I still like to highlight, and I like to add notes, and you can do that with all of those different apps. That's definitely the distinction between the two for the most part and I definitely have a preference, for sure.

Ricky Enger: Yeah. I'm much like you in that there are those same tools in my toolbox. We mentioned talking books, that's the NLS BARD service and we'll have information about that in our show notes, of course. Bookshare, another service that allows you to download texts. But in all these cases, we're reading them, in your case, you could use magnification on your computer screen or again, text-to-speech. It just feels more efficient, especially if you have a situation where you have vision that is only good for so many hours. If your eyes are getting tired, you want to use that vision for something that you don't have an alternative for. So, reading in text-to-speech could be a lot easier on your eyes whether or not you can still see that large print. I think it's interesting that we do, again, have the same tools in our toolbox. It's audio, whether it's text-to-speech or whether it's a human narrator. Did you have any techniques that got you more accustomed to not looking at that text as it was being read?

Steve Kelley: Yes and no. Again, it wasn't really anything that I can take any kind of credit for. It's one of those things where it came down to efficiency. When you start realizing that your efficiency using your vision is really slow, it becomes a lot more appealing to listen to it. That's part of that transition where maybe you might be frustrated at the time and gosh knows I was and still am sometimes. As you start making progress with some of these other alternatives and you start realizing, oh, my efficiency with this is getting much higher if I turn on text-to-speech or if I get that narrated book to keep up in my book club or something like that, that I think is what moves us along, is just recognizing that this new path is a little bit easier and is a little less frustrating and we're actually getting the things done that we want to get done. So, I think that's part of the process for those of us who aren't a little more proactive. The proactive people are going to figure this out logically and make steps in that direction.

Ricky Enger: Well, I guess it's no surprise that braille is going to come up on a Hadley podcast. I think it's the first thing that people think about when they start losing their vision. In some cases, it's the only thing they think. So, there's probably this huge sense of overwhelm, like, "Okay, I am struggling to read print, so I have to learn braille. I have to learn it now and it is going to be the only method by which I'm ever able to read anything forever." It's a little more complex than that. Is there a way that braille can fit in and have a logical place and yet there are some other techniques as well? Are there reasons that people might learn braille that don't involve reading everything in braille forever more?

Steve Kelley: When I first realized that what was going on with my vision was progressive and that I would get perhaps to a point where I was having trouble reading print the way I normally did, it was like the very first course I took at Hadley once I figured out my way and it was bumpy. But I got a braille course because I assumed exactly what you said. Oh, gosh, my only opportunity is going to be braille. I was actually pleasantly surprised when I took the braille course, which was just the alphabet in braille. It was actually simpler than what I thought and at the same time, I thought, "Now how am I going to read a book in this?" because that piece of it was quite challenging. I think where braille fits in really well for somebody with low vision is for labeling, putting a quick label on something in a letter or two that you just touch and right away, you know "Oh, this is the Advil," or "This is the cleaner that I want," or whatever, especially in places where it's dark, underneath the cupboard or maybe in the freezer.

There are plenty of places that braille can be used on a regular basis for somebody with low vision. They're probably not going to be literary braille readers, but if that's something that they wanted to pursue, of course, yeah. The other thing that people don't realize is you've got a whole world of braille with braille displays connected to the computer. A lot of folks who are real readers or real literary people may actually, even with low vision, want to learn, get to that place where they're literary braille readers with their braille displays because again, it might be more efficient or more enjoyable for them.

Ricky Enger: Wow, I love that, just a whole spectrum of ways to use braille. We do have courses for learning braille, both visually and tactile braille that still can involve some of your vision if you still have it. Those initial lessons will engage both your eyes and your fingers. If you're looking to learn braille, you've come to the right place and Hadley's got you covered for that. But we have talked about not just braille, but magnifiers, text-to-speech, smartphones, talking books, digital books, this huge list of things, and all the different types of magnifiers. If somebody's sitting there going, "I heard a lot of information and some of it might apply to me, but I'm feeling really overwhelmed just thinking about this. Where am I even supposed to start and what do I do?" How can someone figure out where to start? How do they try some of these options without just shutting down and feeling like it's too much?

Steve Kelley: I think the very first thing that I would do, and we'll put this in the resources, I'm sure, I would get a hold of the National Library Service Talking Book program, and here's why. The reason I'm suggesting the National Library Service is one, it's free, two, the talking book player is probably one of the easiest machines that you ever learn how to use. You can literally pick it up and use it in the minute you get it. There's no charge for it. You can get library books. You can get magazines.

And here's the plug for Hadley too, of course, you can also get many of our workshops right on the talking book cartridges that play in the machine. The reason that I'm suggesting that as priority number one is because it will take you to the next steps whatever those next steps happen to be. You may not use it later on, but it will help you get to those next steps. So that would be priority one.

The second thing, Ricky, I would suggest is I would suggest people get in touch with their state vocational rehab agency or their department on aging, and every state's got one. Those are the places where you are going to find some additional training, maybe some demonstrations for some of these devices. The quickest and easiest way I can think of to do that is to call me, and I do this on a regular basis, and I'll look it up for you and give you that information as well. But the reason I'm saying that is you want to get an assessment for some of these things. So many people, as I mentioned before, have that magnifier that's not working. It's in the top drawer. They don't use it and they don't use it because it was the wrong one.

Get someone from one of those agencies to come out. There's usually no charge for it. Have an assessment. Figure out what it is that's going to work best for you and also find out about that broad spectrum of stuff that's out there that will keep you reading. There's a bunch of it and they know more about it than you do so you can learn something from them.

Ricky Enger: That's really well said. It's great to know that there are so many resources because I think that's one thing that people struggle with is they know that they're having trouble with something, but now what? Where am I supposed to go? What questions do I even ask? I don't know what I don't know.

Steve Kelley: I think half the battle is just figuring out what some of the options are and knowing that you do have options.

Ricky Enger: Well, Steve, thank you so much for sharing your experience and just the ideas that you have about things that people might try. The show notes are going to have a ton of information for you to check out if you're wondering where to start. If all that is maybe a little bit much, Hadley's always here to point you to the right things. We'd love to have a conversation with you, so do give us a call, and again, happy to point you in the right direction.

Steve Kelley: Oh, it's always great chatting with you, Ricky. Thank you.

Ricky Enger: Thanks so much, Steve. 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.