Hadley

The Not So Straight Line to the White Cane

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, content creator Dorrie Rush joins us to share her journey in coming to grips with using the white cane. Welcome to the show, Dory.

**Dorrie Rush:** Hi Ricky. Thank you so much. It's good to be with you.

**Ricky Enger:** Absolutely. And it's good to have you back. You joined us a couple of years ago. You were talking about OE Patients, which is just this amazing collection of online resources. There are blog posts, articles, podcasts, all relating to various aspects of vision loss. We'll have that link in the show notes for people to go back and do that. But for people who don't know who you are, give us just a brief intro of who you are and a little bit about your vision loss.

**Dorrie Rush:** Sure, thank you. The OE Magazine as it is often referred to now, thanks to you, and the title of that podcast that we did a few years ago. It is indeed a magazine and I'm the editorial director. I was diagnosed at the age of 33, which is 31 years ago with Stargardt Disease. Stargardt Disease is an inherited retinal disease that impairs central vision. It's mostly concentrated in central vision, and it is similar to macular degeneration. So, people who are going through age-related macular degeneration, my progressive loss is very similar, mostly in the center.

At the time, the changes were very slow. I will say that my vision has always been changing, but relatively slow. I've only had a few significant, really noticeable, meaningful changes, and one was recently during the pandemic. I was thinking about this before because I know a lot of people with Stargardt disease, I know a lot of people with macular degeneration. This is part of the work I do. And so, I encounter people all the time. Everybody has a different trajectory and a different way of dealing with the loss.

**Ricky Enger:** And it's ongoing. You never know, even from day to day sometimes, what your vision is going to be like, and what your emotions surrounding that, what that's going to be like. You recently wrote a blog post for OE Patients about your journey, and ultimately deciding to use the white cane. I think there's a lot to unpack there and I'm so glad that we have a chance to talk about this, because vision loss is not new to you, but the cane is. So, what was that? What drove you to finally make that decision to say, "Well, I think maybe I should try this?"

**Dorrie Rush:** It was definitely a long time coming, and frankly Ricky, I know so many people can relate. I hoped that day would never come. I really did. And one of the best doctors that I ever had and went to for many, many years, the first thing he ever said to me was, "I can promise you you'll never need a cane or a dog." And that helped me see past all the things I was worried about. And I believed that, and I don't fault him for the misinformation today, but I don't think anybody ever really knows where you're going, or where you'll end up, or how you'll deal with it. I know a lot of people with central vision loss, and most people frankly don't use canes. I pretty much thought you can navigate the world. You see what's all around you, what you lose is the detail in the center.

So, reading and identifying faces, I have no facial recognition. That is very difficult. But walking around the world is usually something that you can do. Maybe it's not smart to do it without some assistance, but you can do it. So, I did it for a very long time and I had no problem. I was encouraged to use the cane, and I was even sometimes shamed into ‘why aren't you’, and ‘you should be’, and ‘it's not smart that you don't’. I always thought that I would know when I needed a cane. I knew I would know. And I actually also knew that it would have to do with not being able to navigate the streets safely. So that's what happened. During the pandemic, I noticed everything was weird and changing, and our lives were so different and isolated. I remember the day that I noticed, first in the street and then when I was in a supermarket, that things were really looking very different, that my vision had changed.

Now, just like everyone, when this happens, we all say, "Well, I hope this is just a moment," but it's usually not a moment. It's usually a significant change. So, I knew that it had changed. I went for two exams and there was really no explanation, or no reason could be found. But obviously I have a retinal disease and I'm aging and, okay, it happened and I'm going to have to address it. So I knew it was time for the cane. But honestly, even though I knew, and even though I am a professional in this field, and even though I give great advice, I don't always take it.

I was resistant, to be sure. And it was for me, a borderline, a boundary that I knew I had to cross it, but I still didn't want to. Interestingly enough, I had written a post at the very beginning of OE in 2017 and I just read it this morning. In November 2017, I wrote a post titled, Considering the Long White Cane. I don't usually say my writing is perfect, but it was perfect, the best advice. And when Neil and I moved into a new home in a condominium building where there were a lot of new people and a lot of new staff, he noticed, even back then, that I was having difficulty adjusting to all the new people. And without eye contact, I can't recognize faces. He came home from work one day and said to me, "I read a very interesting article today about the White Cane, and it was on OE."

I just looked at him like, "Okay, what are you getting at?" He said, "I was so surprised to see you were the author." And I said, "Yes, I know that article. And it is a very good article, and thank you for pointing it out. I should really read it again." I said to him exactly what I just said to you, "I do give very good advice and I don't always take it." He said, "Well, I was thinking, maybe now it would be helpful because people don't really realize that you are visually impaired and they think that you are just not friendly."

**Ricky Enger:** And that's actually an interesting aspect of this to talk about. There was actually a quote that you mentioned in your latest article, and it's a quote from another blogger and she basically says, "If I use a cane, I'm going to look blind and people are going to stare at me." So can we talk about that, not just the practical aspects of what does blindness mean exactly, but also that whole stigma around disability that still certainly exists?

**Dorrie Rush:** Oh, there's no question. Stigma is a word that really came. Actually, I received many notes from people mentioning that this would remove stigma, and I hope that that's true. But yes, I was absolutely impacted by stigma, as was Maria Johnson in her blog post. I read that and it's so sad. I think so many of us feel it, and maybe we just don't articulate so easily. She said, "If I use a cane, I'll look like a blind person. People will think I'm a blind person. I'm not really blind." "I'm just," I'm paraphrasing, "sort of blind.” “I can see enough to get around. I don't need the cane." And then she ended with, "And my friends will whisper when they see me with the cane. Oh my God, Maria's really blind now and she needs that thing." And honestly, I didn't really feel so much that I was worried about my friends. All of that is something that hopefully you can articulate and communicate.

But what I was told about the cane was, it's so great because people help you, people come and help you when they see you with the cane. And I was like, "I don't want people helping me." And then I've also heard over the years, and I'm sure you have too, of how many people with low vision using a cane, justifiably. And people say, "Well, do you really need that? You can see." I still think that the cane does say to the general population that you are blind, and their expectation of blindness is that you have no sight. And it's unfortunate because I feel it's my responsibility, as well as the medical community, as well as all organizations that serve people with vision loss, to do a better job in explaining and communicating the spectrum and the complexity of vision loss. Because it's a lot. I think people would rather be more educated about it than to be thinking, "Well, everyone who's using a cane is blind."

**Ricky Enger:** Exactly. And I think that it does at least help with some things. I remember standing in front of somewhere trying to figure out the restroom signs or whatever, and it at least says to people, "No, I'm not being a creep. I'm just looking to see what the sign is." So, it does answer some questions, but it also raises some questions because people just don't know blind means this whole spectrum of things.

**Dorrie Rush:** Exactly. And that should be better understood. I think it has changed over the last two decades a lot, because I think the word blindness is used for impact. It represents, really, truly, in the public understanding, represents only about 15% of the population of people who have vision loss. That might even be just people who are legally blind, and legally blind is also a confusing term. But I think that what you're saying is right. I was the most surprised with all my resistance. And I knew it was coming, and I knew I had to do it. And as I say in the article, I got a cane, I reached out to see if I could get some training. It was complicated, and it was a wait. Eventually I did get on the phone and got a cane. I talked to other people who used canes sometimes or always.

I certainly have plenty of resources for that. I got on the phone, I got the cane, and the woman was amazing and really helpful, and I got the cane I needed. But on the day I put that cane in my hand, and honestly, Ricky, I can't even recall ever having a cane in my hand before that. We were going out for a walk on this path that we go out to just enjoy nature. It's beautiful here. A week or two before, we had been on the path, and I was very uncomfortable walking on the path and I thought, "Ugh, I don't see the colors that well anymore. And now I can't even walk on the path so comfortably." I was realizing that, little by little, I was shrinking down my world of independence. That was the worst thing.

So next week we were going, and I took the cane and I opened it up in my bathroom, and I came out and said, "I'm taking the cane on the path." And he said, "Oh, this is great." I wanted to use the cane and I didn't want to sweep it, I just wanted it to be quietly in front of me. The woman on the phone said to me, "Yeah, you can't do it that way." Neil and I walked maybe half a mile toward the path, which is about three quarters of mile. I was fighting with the cane. I thought, "This doesn't, it's not really working. It's not really working."

Neil said to me, "Can I try to show you something?" He showed me why you have to scan it back and forth. In the next half mile, I would say I was amazed at what a difference it made for me, so quickly. So quickly. The confidence and the security, the sense of security that it gave me back lifted all of the stigma and the concerns about what people would think. And it didn't matter anymore, because I found something that was so empowering again for me. And it really changed a lot in a very short time.

**Ricky Enger:** Wow, I love that. And it just took the right time for you to make that decision.

**Dorrie Rush:** That's right.

**Ricky Enger:** I think that's something everybody struggles with. We've mentioned the word resistance a few times here, and that does happen. If the vision loss is gradual, where you start out and you're not using a cane, and eventually you do, there are people along the way saying, "This would be really helpful, you could be safer if... there's this article that was written that really, really describes how great this is," but you have to make that decision. So can you talk about how you did that in a way that really felt authentic to you and not just, okay, okay, I'll do it.

**Dorrie Rush:** Absolutely. I really do support this in everything, because in my work at the Lighthouse, I did a lot of technology and a lot of iPhone training, for example. Some people weren't ready to do it, and some people just weren't ready to use a screen reader or not ready for whatever it was. I would say, "You are not going to be able to do it until you're ready. You have to want to do it, and you have to be ready." I give myself that ability to say, "I will do this when I'm ready." And I do trust myself in that way. I know I'll be ready. I knew the time had come for the cane because I did fall a few times in the street, and I knew I couldn't keep doing that. Also, the long-term ramifications of an injury are just not worth it.

I knew I had to do it, and it was a place I didn't want to go. I didn't want to go there. It was an advancement into a place I hoped to avoid. But once it was in my hand, and once I understood on that path, for example, the walk I had taken there a week or so before was so different now with this cane in my hand. I didn't have to worry about holding onto someone or walking behind someone so I could see what was happening. I just had to walk with this cane and accept the information it was giving me. I have no regrets. Would it have been smarter and better if I had been more compliant, if I had done it earlier? Of course. And I'm not telling anybody to hold out, but I think that we all have to get to these places in our own time and our own way, and no one can push you when you're not ready to go.

**Ricky Enger:** So it's always going to be that unique journey that you take, and you're going to have the support of people who care about you, but ultimately it is your decision.

**Dorrie Rush:** Yes. And you have to allow that. Listen, I also thought about all the people, and there were many, some very close to me who had gone through this transition of taking on the cane and how much difficulty they had. Now, I was just quiet and resistant. But some people were very emotional and had a great deal of pain in doing it and getting it and tears. I knew people who would hide it from their doormen and their neighbors. They didn't want them to see all of that. I did not go through that. We live in a small city, and there's a city hall nearby we pass, and some court buildings have these grand staircases in front. Staircases for a good while scared the hell out of me. Going up and down was so hard for me.

But with the cane, I got right away how it just gives you a gauge. I went up and down a set of stairs in an office building three or four times. I couldn't stop. I was so happy with the ability to do this and not to worry and not to be looking for the banister. I was back in control of my steps, and it was really good. So I took to it after all of these years of resistance, or certainly this last year of resistance. Once it was in my hand, I took to it.

It sits at my front door, open and ready to go. I don't go anywhere without it. I was resisting or hesitant on my trips to Manhattan, and I was nervous, walking very gingerly and slowly and whatever. But the first time I went back there, it was amazing. As I mentioned, I learned very quickly about the kindness of strangers and the thing that I thought I wanted nothing to do with. People in such a sweet, kind, quiet, unobtrusive, helpful way, said things like, "The light is changing. Let's wait here. I'll let you know when the light changes," and it was all so just kind and nice and not weird, and I actually so appreciate it. It gave me something that I literally thought I didn't want and really didn't know anything about, and I love it.

**Ricky Enger:** Wow, that's fantastic. I love that as well. You're fairly new to this, but you've really taken to it. And I would bet that there is at least one person listening right now who is struggling with this. So they're where you were a year ago, and they're like, "I don't want to do this. People are telling me I should, and maybe I know I should, but I'm just not there yet." Is there something that you would tell that person who's still kind of wrestling with this decision?

**Dorrie Rush:** Yes. I would say that, based on my own experience, and perhaps it could be yours as well, that the fear factor and all the things that you conjure in your head about it, a lot of it is just not factual, and you may be surprised. And I've read, and you probably have too, Ricky, there's so many articles online about people's experience with this and how, just like my story, how they resisted it and they hid it and then they came around to it.

I talked with a lot of people also who used it sometimes only when they had to and whatever. For me, it's not sometimes, it's just all the time now. It's just like I feel so much better with it. I felt a little embarrassed that I might appear so ignorant that I didn't want to do this and that I work in this field and I know what it's supposed to do. I just didn't want it to do that for me. But once I did, again, put it in my hand for the first time and worked with it a little bit, all of that stigma and resistance and fear, sadness, dissipated from me very quickly. And what I've gotten back is so much more powerful than what I was afraid I was going to lose.

**Ricky Enger:** Yeah, that's really well said. Just pick it up, see what it does for you, and let go of the things that are holding you back. Because what's on the other side might just really surprise you. And you say that in the article of just how surprised you were that it was helpful for you, even though you knew intellectually. It's just that difference between knowing something and feeling it yourself.

**Dorrie Rush:** Yes. I think people do fear, like I said about friends of mine who didn't want their doormen to see. I've read stories. People have written this in their books. They don't want their neighbors to see. They went for their cane training outside of their neighborhood. I have been using the cane now for three weeks, and I have seen plenty of people. I walked through a building that has doormen and concierge, and everybody knew about my vision loss, and this was a pivotal moment, but no one has said a word and now they notice it.

There's a little bit more kindness and sweetness, I think a better understanding, perhaps. It’s interesting, people call out, "Hello," because they're not just assuming I see them. And so I have found, even in that, I see people responding. I see people reacting. I see people moving out of my way, which I appreciate. I see people, I think people are much more vocal now because they're understanding that I'm not seeing them or I don't know who they are when they pass me. There's been none of that, "Oh my God, you have to use the cane." None of that. None of that. Not one. No one has said that to me. I'm actually excited to tell people that I'm using it. I've told everyone, my family, everyone, and everyone is so happy that I got to this place and so am I.

**Ricky Enger:** That's so cool. You're all in now, and it only gets better from here. You still get to do some training with it, so you'll learn even more.

**Dorrie Rush:** I do. Exactly. And I will do that. I will. I have to say, I was holding out also for a while, thinking I had to be formally trained, and I'm not the only person. I heard from a lot of people who never had any training and do use it when they need to use it. We should all have professional training, absolutely. But that doesn't have to be something that you're also waiting for. You can try it out, and it's really not as complicated as we might have thought.

**Ricky Enger:** That's great advice. Thank you so much and thank you too for just stopping by and sharing your journey. I know sometimes it's hard for people to talk about having gone through something, especially if it's kind of brand new. I just appreciate your sharing that with us and being willing to talk so openly about things. Thank you again for joining us, and it's been wonderful having you.

**Dorrie Rush:** Thank you. Always a pleasure. Thank you for having me back.

**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@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.