Hadley Presents

Ophthalmic Edge Patients

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 OE Patients, a resource providing practical tips and encouraging advice for living with vision loss. And our guest is OE Patient's chief content officer Dorrie Rush. Welcome to the show, Dorrie.

Dorrie Rush: Thank you so much, Ricky. I am delighted to be here.

Ricky Enger: I am really glad to have you as well. I have seen OE Patients on social media and often Hadley and OE Patients sort of retweet each other's stuff and share those resources back and forth. It's wonderful to actually get a chance to collaborate on this podcast. You're a fellow podcaster and you do lots of other things as well. So really happy to have you on. Why don't we just start by talking about who you are and a little about what is OE Patients?

Dorrie Rush: I am Dorrie Rush, and I have been in the field of vision loss for 20 years and living with progressive vision loss for 30. At the age of 33, which was 30 years ago, I was diagnosed quite unexpectedly with Stargardt disease. Never heard of it. Had no idea. I noticed while I was driving that my eyes were not reflexing from light to dark, so I went to an ophthalmologist. Of course, at that moment, that was like a totally unknown scenario to me. Over the next 10 years, I continued in my work.

I was a sales executive in the apparel industry. Hoped that my vision loss would be very minimal. The progress was slow, as I say, especially for people with forms of macular disease. It's usually very slow and merciful. It gives you time to make the adjustments, but it did continue to progress. 10 years later, I had the great opportunity to move into a new field, and I joined the Lighthouse. I joined the Lighthouse in a position of fundraising, which was a natural progression for me in terms of same skillset.

I was with the Lighthouse for 15 years. I was director of major gifts. I was in fundraising. I ran the information and resource service, which was incredibly interesting. I had many roles in technology. One of the reasons I got involved in technology was because I really felt... It was the early 2000s and I really felt that... I felt I was being left behind by technology. I so wanted the same technology everyone else was using.

And although there were many options in assistive technology, I just always felt like I want what the other kids have. I was very vocal about that. The CEO at the time gave me the opportunity to move into technology and express my voice and my thoughts to see where we could go. So that's what I did. In 2016, I decided that after 15 years of Lighthouse, lots have been changing, certainly lots have been changing in fields of technology, I decided that I would move out and do something a little bit more independent.

So, I did do that. I left the Lighthouse, and I became an independent consultant. My very first job opportunity came, of course, from an organization very close to me. I have been on the board of the Association for Macular Diseases, which is an organization that was started in 1978, believe it or not, and has been going ever since. It's housed at Manhattan Eye and Ear Hospital in New York City.

We were about to embark on a partnership with Ophthalmic Edge, an organization website which is a website geared to physicians in training, free courses available on a number of ophthalmology topics from very prominent presenters. Dr. Yale Fisher, who is the founder of Ophthalmic Edge and a long, long friend of the association and a retina specialist. He wanted to develop a site for patient information and patient education. Perfect timing. Perfect timing.

They offered me the opportunity to steer this project and to help create it. That was in 2017. In 2017, we partnered with Ophthalmic Edge to create Ophthalmic Edge Patients. Now, the interesting thing is, as you said, Ricky, it is now referred to and our URL is also OE Patients because we shortened it.

Ricky Enger: And because nobody could say ophthalmic or spell it.

Dorrie Rush: Right, unless you were an ophthalmologist or in the field of ophthalmology, right? And somebody said that very early on and I really kind of just ignored it, but it was true. It's kind of fun though now, because we have developed ourselves as OE and I think some people know what that stands for and meet people know that we're connected with Ophthalmic Edge. But other people just... It's okay. It's an easy thing to remember and to say. So that worked out beautifully.

We began to develop a website and content for the patient population. And what we hoped also was, of course, we were developing content to help patients get information about living with vision loss and dealing medically and with medical developments, but really, we also hoped that we would have an opportunity to also connect with and educate physicians.

Ricky Enger: Talk a little more about those two things, because first of all, there are a lot of vision loss resources out there. There are certainly some things that make OE Patients unique, and I think one of them is this idea that you can educate healthcare professionals and that you can educate patients. Why don't we start with healthcare professionals and what do you think that OE Patients can really do well in that sense, because so many people talk about, "I went to the doctor, I got my diagnosis and the doctor couldn't tell me anything other than, well, people learn to live with it?"

Dorrie Rush: That is a very, very common experience. I do think that we have and hopes to, and we are continuing to work to develop the audience of professionals. Because as you say, Ricky, in some regard, everyone dealing with vision loss is a patient, right, of someone and in some way. It's natural for patients to look to their physicians and the professionals that's around them for guidance and advice about what to do next, right, even when it doesn't involve treatment.

And as we know, so much of the causes of visual impairment and vision loss are not treatable. We have to follow the advice of our physicians, and there are some good advice that doesn't have to do with treatment. But then there's more, there's more to it, and patients do expect that, and they don't really always get it. This is what we want to do. We want to keep this information going, and we do want physicians to know it, and we do want healthcare providers to know it.

We want them to be able to even if it's just give the advice of, "Take a look at OE Patients or Hadley."

Ricky Enger: Right. You have this ability to tell the physicians or the healthcare professionals, even if you don't know all of these tips on the site, you can still at least know where the site is and point your patients to that. What kinds of things then are people going to find? Let's say that they are a patient. They've gotten this information and they want to go check out the site. What are they going to find?

Dorrie Rush: We kind of cover the gamut, and I think that our website is structured a little bit differently from others. It's more of a magazine, news kind of a site. On our website, it's broken into four sections. But I should start by saying, obviously our website is also designed for people who are experiencing issues with their vision. We do have a lot of accessibility settings. The website is very cleanly designed. That was one of the most important things.

It's a simple article on each page, and there's not a lot of columns. It's very, very clean. I love that part. It's very clean. We have a feature that I'm so glad so many people have found. You and I might use a lot of the speech features and have an ability to use speech options in computers and tablets and mobile devices, but some people don't do that. We have a button at the top of our website that was so important to us to include it. It's called Listen. It's a read speaker technology.

You just click on the button at the top of the page, and it reads you the entire article, and it's fantastic. The website is broken into four sections, and all four of these sections are really they're all part of what we have to do to move forward and to do the things we want to do and to continue to lead our life as normally as possible.

The first section is called making adjustments. And in this section, of course, we're talking about things like how to adjust your home for vision loss, how to keep yourself organized. One of the most important things in adjusting is a willingness to make changes, because everybody has resistance. I don't want to do it that way. I want to do it the way I did it before. If you do something enough times, it becomes the new natural way you do it. It's so important. In this section, I'm just going to mention two of our big titles. One of our most popular articles on the website is the “Hottest Low Vision Gift.”

This was started one holiday season and every year we update it, and it remains always... I think it's in our top 10 on a monthly basis. It's very funny. I always say to people, if you have a gift, you want or you have a gift that you've received, that's great. Please let us know and we'll consider adding it to the list. The list, of course, has a lot of technology, but, but a lot of also very simple low-key kinds of things. Another article is “Try a New Approach to Menu Reading.”

People ask over and over again, "How do you need a menu?" A menu is one of those things that right away, it's really difficult. I still can't read a menu. Even with technology, I find it a rather cumbersome experience, but there are ways to focus in and get what you need and there are so many methods.

Ricky Enger: Yeah. I think that's such an important thing to recognize is that there is no right way to do things. There's always a number of ways that you can look at and find the one that works well for you, whether it's reading that menu and taking as long as you need to do that so that you've done it yourself or having speech read it to you or whatever. Love that there are articles with so many tips. Let's talk about then the other three sections.

Adjustment, I think, is absolutely one of the most important ones and it's something that people who are very new to vision loss or even people that may have been living with it for a while need to take a look at and just explore that portion of it before maybe they even feel ready to take a look at anything else. What are the other three then?

Dorrie Rush: The other three, accessibility and technology is the next one and this is really where the bulk of our information is I noticed this morning. It is the place near and dear to my heart, and I also think that it is a key factor in our independence and in our ability to go on and keep working and living and doing what we want to do and also being part of this whole social experience. In this area, one of the most popular is accessibility support phone lines.

I have found these incredibly, incredibly helpful. Because when you're stuck and you're a user of accessibility features, you can't always turn to your husband or your child and say, "What do I do with this?" You need some specialized tab and there are a number. We know Apple, we know Microsoft, Comcast, Verizon Wireless, they all have their own accessibility support lines and that's fantastic. You can get help at any time, but live support is something we still need and want.

It can all be done digitally. Another one is your smartphone is a comprehensive low vision device. I remember we used to walk around with a tape recorder and a magnifier and all kinds of different devices. And now it's all in this beautiful little phone. A lot of people do not know that. And once you know it, really it opens up a whole new world. Another article here that's very popular is five ways to make your computer at work easier to use.

A lot of people don't know how much is built into a Windows computer today, particularly when it's the early stages of vision loss and all the things that you can do to compensate so that you can still keep working. You and I both know that you can keep working through every stage of vision loss, right? As long as you are making the changes and you're aware. I love that article. My biggest advice is always make a friend with the guy in IT or the women, because they'll really help you.

The next section is health and well-being, and here we actually have a number of great contributors because, of course, we do have physicians writing for the site and some other nutritional and wellness experts. The article that really stands out here month after month in our analytics is written by Dr. Fisher. The title of it is “Doctor, Am I Going Blind?” This is the question for everyone at almost every stage, am I going blind? What does that mean to you? To what degree will I lose my sight?

Dr. Fisher goes through all the main causes of vision loss. Many, of course, we know are age related and the reality, what is the reality of really losing your sight completely. You're going to follow the care of a physician. You're going to keep a healthy lifestyle, and you are going to be okay, but still your vision is probably going to change, but not to the degree that... When you hear you're going to lose your sight, of course, people immediately think they'll have no sight.

It's all in a degree and it's good to know, it's really good to know where you're going and how you can have some control over that. That's what that article is about. It's very popular and I completely understand why. Another very popular article in this section of health and well-being is written for us by Michelle Milgrim, who is our nutrition and wellness contributor, and this article is titled “The Anti-AMD Diet.” Of course, the genesis of our organization is age-related macular degeneration, although now we've branched out into everything.

This is the leading cause of vision loss among people over 65. There's a component, of course, of lifestyle and nutrition that are very important here. And people really want to take action if they can. So, improving your diet, this is based on the AREDS study, which is a study from the NEI, from the National Eye Institute, on supplements, but Michelle took it and turned it into real food. That's what the supplements supplement.

The last one I'll say in this section is we have recently published two articles on treatments and development, one for AMD and one for diabetic eye diseases, and they both have a printable PDF that you can take to your doctor and talk to your doctor to talk about if any of these are something that you can look forward to or what the progress is on that today, because that's also something people want to know, what's in development? What are the treatments? What's coming that will help me?

The last section is Voices of Experience, and this is where the podcast is housed, and this is also where we write articles about people's experience people living with vision loss. I have to say, Ricky, and this one always in our top 20, for sure, every month. I wrote the article. The title of it is “The Frankness of Bruni.” I'm a New Yorker and a New York Times reader, and so Frank Bruni is someone I know. I feel like I know personally, of course. He's been writing a column at The New York Times for 25 years.

One day when I was reading his column on my iPhone in the morning, as I do, I couldn't believe the title, which was, “Am I Going Blind?” And then I read the article and there you learn that someone you would never expect to be having the same experience is, right? So you got the interview for your podcast with Frank Bruni, and I thought it was really an incredibly, really beautifully done.

I also really appreciated what he had to say, because he spoke about the experience of losing sight, going through the whole healthcare and medical and physicians experience, and how that felt for him and how he was dealing with it and the fears and also the revelations, I guess, and how he sort of came through that.

Ricky Enger: Right. His story was so powerful because what he experienced sadly is pretty common. Having not just people who are prominent like Frank Bruni, New York Times columnist, share what he's going through, but other people that maybe feel like that could be my next-door neighbor and they're going through this as well. I think it helps people so much to read about those things or to hear about those things on a podcast.

Dorrie Rush: Yeah, and the most important thing to me was it's very rare that we hear from someone prominent who is willing to talk about this so openly.

Anyway, and to move on to another star in his own right, one of the podcasts in our podcast section is “A Conversation with Hadley's Douglas Walker,” who is one of my favorites. And really the way I came to had like honestly was through Douglas Walker's video tutorials, which I discovered way back at the beginning of the iPhone tutorials when I was still at the Lighthouse, and I started to share those with our clients way back when and I still follow all of them. That was a great podcast, and it is also one of the favorites.

Ricky Enger: Absolutely. That is so awesome. What I love about OE Patients is that there is so much information there and more is being added every day. If I'm a person who is curious about, hey, I wonder what's going on that website, what's being added? What's the best way that I can find out what's going on other than just checking in on the site every day? Are there other ways that people can stay in touch and stay up to date?

Dorrie Rush: For sure. It's interesting because people don't really check in on the site every day. They basically check in once a month, so we make it easy. I think that the favorite way to follow us, of course, you can follow us on social media, on Facebook or on Twitter. But the favorite way is to sign up for our monthly roundup email, which brings together all of the content that we've published newly and that we've updated and some that we just think is timely for the month or whatever's happening.

Once a month, we send out a very easy to navigate email with everything on it that you can link back and read at your convenience. You can sign up for that on our website. It's at the bottom of every single page. There is a place that says stay posted and you could just put in your name and your email address, or you can go to oepatients.org/signup and sign up there, or you can always send us an email to info@oepatients.org, and we'll sign you up or answer your questions or love to hear your feedback.

Ricky Enger: Thank you so much for that. We're going to have all of those links plus links to every article that we've mentioned here. There have been quite a few. They're definitely going to be of interest to the audience, so we'll have all of that information in the show notes. I want to thank you, Dorrie, for taking a little time to come and join and just chat about what you're doing. I think it's so important, and I love hearing your passion. It's clear that you love your job, that you really thrive on sharing information with people. So, love it.

Dorrie Rush: Thank you so much, Ricky. I do.

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.