Hadley Presents

Tips from a Low Vision Doctor

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, Hadley's chief program officer, Ed Haines, interviews Dr. Mark Wilkinson, as we discussed visiting with a low vision optometrist. Welcome to the show, both of you.

Mark Wilkinson: Thank you.

Ed Haines: Thanks, Ricky.

Ricky Enger: Dr. Wilkinson, thank you so much for being here, and Ed, of course it's always a pleasure to have you on the program. I know that you've been on a couple of them before, so again, great to have you here. Dr. Wilkinson, if you don't mind, before we jump into Ed's fantastic list of questions, can you just give a brief intro about who you are and what you do?

Mark Wilkinson: So, I'm an optometrist and I'm a clinical professor of ophthalmology at the University of Iowa in the Department of Ophthalmology there. At the University of Iowa, I run the vision rehabilitation service. So, in the past, we used to call it low vision, now we call it vision rehabilitation because we take care of people with a wide variety of different types of vision problems, and we'll talk about that more as we go.

I'm also the chair of the Low Vision Subcommittee of the National EYE Health Education Program, or NEHEP, which is part of NEI. And I've been using the resources that are available through Hadley for some time now and find they have excellent resources that are available to all the people out there with vision problems.

Ricky Enger: Well, we certainly love to hear that, and we appreciate you for that. We thought we would ask you to be on the program because I think a lot of times people who are experiencing vision loss are just in this situation where they're not sure where they should turn, what they should be doing, both to protect the vision that they have, and then to be able to use that more effectively and just get an idea of what's going on. And so, there are so many different types of doctors and specialties and wanted to invite you on to just talk about what it is that you do and how you can assist people. So with that, Ed, I know you've got a great list of questions. So why don't we get started on that?

Ed Haines: Well, thanks, Ricky. Dr. Wilkinson, again, thanks so much for being with us today. And just to give you a little background on myself, although I work for Hadley in an administrative capacity, most of my life I spent in the kitchens and living rooms of people with vision losses and vision rehab therapists. So, I sort of have come at these questions from that perspective.

And I'm sure you know that for an older adult who's lost their vision, either with glaucoma or macular degeneration, et cetera, one of the hardest things to get them to do is to persuade them to see yet another doctor. They've been to a bunch already. So, what do you say to folks who say, "Why should I go see yet another eye doctor when everybody else has told me there's nothing that can be done?" What do you say to them?

Mark Wilkinson: Yeah, so I think that's one of the great frustrations that we have is that people will say there's nothing that can be done, and it would be sort of like saying to somebody who'd lost a limb or something like that, "Well, there's nothing you can do," instead of going for rehabilitation, for prosthetics, for those different things.

So, I tell people if you're able to see all that you want to see at this point, great, there's no reason to add another doctor, but if you're having trouble seeing to do the things that you want to do, like reading, driving, activities of daily living, then you should see a vision rehabilitation eye care provider so that they can see what can be done to maximize your vision.

Ed Haines: And that makes perfect sense. Folks see so many doctors, it's really hard to get them to make that jump. One thing I'm pretty sure a visit with you would be different from a visit to another kind of doctor is because you're going to spend a lot of time with them. So, people aren't necessarily prepared for that. I wonder if you could go over just a little bit about what a typical appointment with a vision rehabilitation optometrist looks like.

Mark Wilkinson: Well, we always start with the functional history. So, we want to know what the person's visual history is, what they've been told about their vision, their diagnosis, prognosis, what types of tools they've tried or have used in the past and what difficulties they're having at this point accomplishing the visual tasks that they need to do on a daily basis.

From there, we're going to assess their vision, both their distance and their reading vision, oftentimes a little bit different than might be done by their medical eyecare provider. We're going to double check their glasses prescription, which many times has not been done for a number of years, see if an alternate glasses prescription will help distance and/or reading vision.

We're going to review their contrast needs because contrast is very, very important for being able to function better. The real world is not perfectly black and white. And so that's one of the things I always tell people, is the eye exam room is the most unnatural place you can be because it's perfect lighting, perfect contrast, and the real world is not like that. From there, we'll review devices and strategies that can enhance the remaining visual abilities and allow them to do the things they're currently finding difficult or impossible to do.

Ed Haines: So, it sounds to me like you spend a lot more time with your patients than what they'd experience in a normal exam. That's something I really try to impress upon folks when I talk to them. Is this the kind of exam where someone should bring an advocate or a companion with them? Is it helpful for them to have someone else to sort of go through the experience and see what's being done?

Mark Wilkinson: They certainly don't have to do that, but it definitely can be helpful to have someone with them as a second set of ears. Also, that person can be helpful to be their coach, to help them implement the strategies and the use of tools that will enhance their visual functioning that we review. So, I think having somebody with them can be very, very helpful.

Ed Haines: When I visit folks in people's homes, initially the first time I see them, they pull out of the drawer a whole range of magnifiers they've bought at Walmart or CVS or things that someone has given them. Do you recommend that they bring any devices that they're currently using, to bring them with them to the exam?

Mark Wilkinson: Absolutely. I think that it's very important that they bring the devices they've been using so we can see what they've worked with, see what has worked for them, maybe worked well in the past, and then from there, determine what's going to be the best options for them.

Oftentimes people are buying things online, are mislabeled, and so they'll say, "Well, I'm using a 6X," and actually it's a six diopter, which is 1.5X. And so, seeing the devices that they've been using, what they've been successful with and what has not worked for them is very important.

I always remember my grandmother who had diabetic retinopathy, somebody would send her a new magnifier for Mother's Day and Easter and stuff, and she just looked at it and put it in a drawer and never used them. So, there's a lot of things that sound good by the advertising, but don't work because they're not really prescription devices.

Ed Haines: Yeah, that's exactly right. And they usually all end up in one drawer. Do you see a patient more than once or is this an ongoing process yearly, every other year, or is it based on the individual need?

Mark Wilkinson: I think that care is always ongoing, but that said, not everybody needs to be seen every few months or even every year. And I tell my patients if you don't have to see me, that's a good thing because it means your vision is stable and you're doing well with the devices you have. But with that in mind, I have a plan that I set up with each patient so that we know when we're going to see them again based on their individual needs and situations. And we always tell them you can come back and see me sooner if needed.

So, I don't necessarily have to see somebody on a regular basis, but certainly we're available. For instance, if they're having issues with driving or something, we'll have to see them on a more regular basis for that, or if they have some progressive condition. It also depends on their age. So, lots of variables, but definitely it's not a one-shot deal.

Ed Haines: If you could tell us about some of the most common things that people express frustration with, when they first come to you, what are the things they're struggling with and how do you help them?

Mark Wilkinson: Well, I would say that the primary thing people struggle with is being able to read. And so, if they're not able to be independent, to be able to read the things that they want to read on their own, if they have to wait for somebody to read a birthday card or something like that, that's very frustrating for them. That would be sort of the general population. Of course, people are struggling with being able to see to work on a computer, music, being able to continue to play music. A big concern for many is driving and whether they can continue to drive or not.

So, it really varies a lot. And that's why we do a careful history to know what functional problems the person is having, and then from there, review of the tools and strategies that will help enhance their abilities so that they can accomplish those activities they've been struggling with.

Ed Haines: And that leads me to my next question. Folks, I have found generally they want to see just like they did before they lost their vision. They want the similar experience. So how do you describe to them how this new experience with these low vision devices is going to be and what they're going to be able to accomplish?

Mark Wilkinson: Well, I oftentimes have to tell people your vision has been compromised, and because of that compromise, we're going to have to do things in a little bit different way. And so, there isn't a sort of a magic pair of glasses that's going to restore your vision back to the level that it was in the past. We're going to have to do things differently, which might mean holding things closer with a stronger pair of reading glasses. It might be holding a device. It might be using reverse contrast, the dark mode on your smartphone, or using some sort of video magnification device or increasing the magnification on your Kindle or your iPad. So, we're going to have to do things in a little bit different way, but when we do that, most often we can accomplish the goals and the tasks that you're still wanting to do.

Ed Haines: Do you find there's an emotional leap that people have to make between wanting to do things the way they used to and learning how to do things in a new way? And just as a physician, how do you handle that conversation?

Mark Wilkinson: Well, we know that when somebody experiences a loss, they go through a lot of different emotions, and one of the things is denial and frustration. And so, we have to get them to that acceptance stage where they realize that they didn't necessarily cause this to happen or anything. This is the situation that they're in and get that acceptance so that they can move forward.

And we know that depression is common among the elderly, and much more so for people with vision loss. We may have to refer for some therapy to get people to be able to understand the situation, accept where they're at, and then move forward with using the devices that will help them to function better.

Ed Haines: It's more than just a functional process it seems to me. It's an emotional process as well. I'm going to hit you with two questions that generally are the ones I hear really commonly, and I just was interested to hear your response to them. The first one is that folks always ask me, "Why can't I just get a big magnifier that fits over the whole page of my book or my newspaper that lets me see the whole thing at once?" How do you handle that question? What's your response?

Mark Wilkinson: Well, it's pure optics. So, we know that lenses that magnify are thicker in the middle and thinner on the edges. And so, the problem with a really big magnifier, it should have a very, very thick lens, and it would have a lot of distortion off to the side. So, you'd have to only look through the center of the lens. It would be very heavy and very hard to hold. And so, we're limited just by the optics of lenses to have a magnifier that would fit over a whole page. And anybody who's tried the thin page magnifiers know that they make things slightly bigger, but they also make it much more distorted. So, they decrease the contrast. So, the only way to get a big field of view is to use an electronic magnifier, a video magnifier also known as a closed circuit TV. And there's just no way around that.

Ed Haines: That makes sense. But it's a common frustration people have. They ask me that all the time. The second one is, "I want to keep driving. How do I drive with vision loss?" And it's a complicated, it's a big topic in of itself, but I wonder if you could talk a little bit about your role in helping people to keep driving if they can?

Mark Wilkinson: So, one of my great frustrations is that we have 50 states with 50 different rules for driving. I have people who have had to move across state lines to be able to drive in my state, for instance, in Iowa, where they couldn't drive in Illinois or in Nebraska. And that that's quite frustrating because those people are exactly the same. So I'd love if we had a national standard for driving like they do in Europe for all the different European countries, but we don't have that now.

In many states in the US, they require the use of a bioptic telescope, which has been around for about 50 years. It's a little telescope mounted to the top of glasses that people can use for spotting signs in the distance. The reality is that research has only shown that bioptic drivers only use that about 1% of the time. And we know from human factors research that eyes on the road is the most important factor for safe driving.

So, using a talking GPS for wayfinding is a far better solution. And I have a number of people who have bioptic telescopes because of the states that they live in, but they're all using their talking GPS now for wayfinding and they're keeping their eyes on the road. And that really makes things safer.

So, it comes down to does your state allow for what I call individual review? So, we have certain standards for driving. If they don't meet that standard, does the state allow them to demonstrate that they could still drive safely despite having slightly reduced vision or slightly reduced visual fields? And that's the case in my state of Iowa. And people are able to show that they can drive safely at levels of vision that you might not normally think would be safe, but they are safe because they keep their eyes on the road. They use the talking GPS for wayfinding.

And I point out to parents and people with vision questions all the time about driving, it's like look at the eye chart, look at the letter that they can read on the eye chart and tell me what's smaller than that that you have to worry about when driving, and the only thing smaller than that is going to be street signs, which you don't have to read in 2021 because of the talking GPS.

Ed Haines: Very interesting. I hadn't thought about the GPS really changing that process for folks. Well, those were the two, of course the common questions people generally ask me, but one other thing they sometimes wonder about is do they need one device? Is one device going to solve everything or are they going to be using several devices? And what are just some of those common tools? If you would like to talk about them briefly.

Mark Wilkinson: Many people can do well with one device. If they have mild vision loss, they may just need some stronger reading glasses. Other people who need electronic magnification may have a full-size video magnifier. They may have a portable one that they take with them when they're away from home. Now we have different apps that you can use and make your smartphone work like a video magnifier. You can have your smartphone read materials with text to speech.

And so, you have lots of options that are available, and it just really depends on what the person's having difficulty with. They might want to read, do hand work, but they also might want to play the piano. And so, they would need different devices for those different things. So, it really comes down to what the person wants to do, and then the different tools that will help them to do that. So many times, it can be one device, but oftentimes it's two or three.

Ed Haines: And with most of these devices, particularly with magnifiers, for instance, are they easy to use or do people really need to practice using them?

Mark Wilkinson: I think the vast majority of people can learn pretty quickly how to use a device, but certainly we have rehabilitation therapists, we have occupational therapy that can help people learn to use the device if they're having difficulty with it. We try and instruct our patients before they leave and have a pretty good feel that they're going to be able to do well with that, but that's also the advantage of having a coach or a friend who comes in with them to make sure that they're using the devices properly. So, it's just a mix of things for people, but I think many times people understand how to use a magnifier, how to hold things a little bit closer to be able to read well, and some of the electronic things are pretty intuitive as well.

Ed Haines: Just to wrap things up I guess, I'd like to talk about a question of finances, and it's I know that low vision, it doesn't fall necessarily in the same insurance structure that other services do. So, are visits with a low vision doctor, are those covered by insurance or Medicare typically?

Mark Wilkinson: The medical side of the exam is definitely covered. So, if people come in, they have a diagnosis, so that qualifies them for Medicare coverage or their insurance coverage. But Medicare and other insurances don't pay for refractions typically, and they don't pay for devices. So that portion of the exam that's looking at devices, looking at glasses prescriptions is typically not covered, and also devices are typically not covered.

So, if the person's a veteran, oftentimes the VA will pay. If they're working, then you have the employer, or the state VOC rehab service many times will pay for devices that keep them working in the workplace and everything. Unfortunately, devices for senior citizens or people that aren't working are oftentimes out of pocket.

Ed Haines: So just as a follow up to that question, do you see that changing at all? I know some rules about hearing aids have started to change, that'll make them more accessible and available. Do you see that for low vision devices?

Mark Wilkinson: Well, I've done this for 41 years and I've thought that it should change all that time, and it hasn't. Medicare typically doesn't think about things above the next, so I'm happy to hear that hearing aids might, but dentures, hearing aids and vision enhancing devices, glasses, et cetera, are not covered so far. And so, if they're moving towards that, we certainly know that it will help the person to be able to be independent and that their cost in life is going to be last if they're able to be more independent. But despite lots of discussions and lots of legislative activities and things, nothing has happened to date. And so, I'm not holding my breath unfortunately.

Ed Haines: Ricky, that was all I had. Dr. Wilkinson, thank you very much. This was very informative. I appreciate it.

Mark Wilkinson: You bet.

Ricky Enger: This has all been just such fantastic practical information that's really going to be of good use to people. I just have one last question, Dr. Wilkinson, as we close. Do you have any resources that you would point people to, maybe even specifically if they're looking to find somebody who does what you do in their local area? Where can people go to do that?

Mark Wilkinson: So, I think that the first thing that somebody should do if they're looking for a referral is to ask their current eyecare provider for a referral for vision rehabilitation services. There is also resources that are available through the Academy of Ophthalmology, the American Optometric Association, the National Eye Institute, including the National Eye Health Education Program, NEHEP, and also there's a lot of great resources that are available at hadley.edu, where you go and register, it doesn't cost anything, and you have access to a variety of different videos and different instructional materials that can be very helpful for people with enhancing their function on a day-to-day basis.

Ricky Enger: Awesome. Thank you so much for that. We'll have links to all of those things in our show notes. And just want to say thanks to both of you, to Ed and to Dr. Wilkinson for joining us, and again, providing such practical and useful information.

Mark Wilkinson: Well, thank you, Ricky.

Ed Haines: Yeah. Thank you. This is such an important topic.

Mark Wilkinson: Yeah. For sure.

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 podcast@hadley.edu, or leave us a message at 847-784-2870. Thanks for listening.