

How to Manage Visual Issues

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GG deFiebre: [00:00:00] Hello everyone and welcome to the SRNA Ask the Expert podcast series. Today's podcast is entitled "How to Manage Visual Issues." My name is GG deFiebre, and I will be moderating this podcast. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders.

[00:00:21] You can learn more about us on our website at wearesrna.org. This podcast is being recorded and will be made available on the SRNA website and for download via iTunes. During the call, if you have any additional questions, you can send a message through the chat option available with Zoom.

[00:00:41] Our 2020 ask the expert podcast series is sponsored in part by Alexion, Genentech, and Viela Bio.

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[00:01:57] For today's podcast, we are pleased to be joined by Amanda Aaron and Deb Nikkila. Amanda graduated from the University of Southern California with her clinical doctorate in occupational therapy in 2012. In the years following graduation, she held positions working across the continuum of adult rehabilitation care from inpatient services to home health. Amanda always knew she loved community-based services and was delighted to find the position of home living specialist at the Maryland School for the Blind when moving to Maryland in 2018. In this role, she works after school with families of students who are blind or visually impaired to demonstrate teaching techniques and adaptive activity and environmental strategies to enhance student participation in activities of daily living. Amanda loves her job and is enrolled in the University of Alabama at Birmingham's Low Vision Rehabilitation certification program for occupational therapists to further her knowledge of assessment and intervention for low vision.

[00:02:52] Deb Nikkila completed a Master of Occupational Therapy at Loma Linda University in 2004. Deb advanced her clinical skills and pediatric therapy over eight years servicing children in early intervention, public school-based OT, and outpatient rehabilitation delivery models. In 2012, Deb sees the opportunity to branch into the blind and visually impaired therapy niche when she began working at the Maryland School for the Blind. Deb's role at MSB is to provide instructional strategies or accommodation ideas that support the student in common daily activities and train staff or caregivers to integrate these supports into the child's learning program.

[00:03:29] You can find Deb in a classroom, cafeteria, learning kitchen, residential dorms, and at vocational activities or student leisure events to meet the demand of providing visually impaired learners the experiences they need to help them function as independently as possible in the world. The resiliency blinds youth often display motivates Deb to continuously search for more innovative ways to support their development and reduce the social and environmental barriers they encounter. Deb's objective is to help these learners be the best version of themselves they can be. Deb's nine-year journey at MSB has inspired her to pursue an occupational therapy specialty certification in low vision from the University of Alabama, Birmingham, which she will complete in summer 2021.

[00:04:11] Welcome and thank you both so much for joining us today.

Deb Nikkila, MOT, OTR/L: [00:04:15] Thank you very much for having us. We appreciate it. Great.

Amanda Aaron, OTD: [00:04:19] This is Amanda. Thanks so much.

GG deFiebre: [00:04:21] Thank you. So to start, at what point should someone get help for their vision loss when their vision is poor from, for example, optic neuritis? Deb, do you want to start?

Deb Nikkila, MOT, OTR/L: [00:04:34] Certainly. If you're having any difficulty functioning in common activities through your day, or if you find that you're starting to avoid or eliminate activities from your daily routine specifically because of your vision and how difficult it is or, or the barriers, then it would be a good idea to seek some help.

[00:04:54] You also should probably consider, what was the length of a duration of a, of a past episode of inflammation and how long did that episode impact your functioning? Possibly, you know, getting help to have some, some coping strategies or some skills or other ways of doing things in preparation for a potential future episode would be advantageous.

GG deFiebre: [00:05:23] Great. Thank you. Then Amanda, do you have anything to add?

Amanda Aaron, OTD: [00:05:26] Yeah, I just want to reemphasize the last point Deb made, which was the importance of being proactive and not putting on the back burner. If you are experiencing any difficulties with vision during any relapses or any resulting damage to the optic nerve, it will... If you start early to learn those adaptive strategies, it'll really help you in the long run with managing your condition.

GG deFiebre: [00:05:52] Got it. Thank you. And then, can you just talk a little bit about what low vision rehabilitation is? And then also, how does one find a therapist who specializes in this? Amanda, if you want to start.

Amanda Aaron, OTD: [00:06:05] Sure. The goal of low vision rehabilitation is really to learn, to use your remaining vision as effectively and efficiently as possible. And part of this is also maybe learning adaptive

strategies or learning to use your other senses within your daily routine. And there may be devices to also improve either your use of vision or the use of your other senses when performing your important daily tasks.

[00:06:33] A low vision therapist will assess your functional visual abilities in various lighting and contrast conditions, in indoor versus outdoor settings, or within different activities in your daily routine that are important to you. There are different professionals that can specialize in low vision rehabilitation. For example, in optometrists and OD, could be a low vision specialist who really may focus on measuring your different visual skills, maybe prescribing an optical device. And occupational therapists can take additional training and low vision rehabilitation, and we'll really focus on teaching you how to do your daily living activities, how to integrate the use of optical devices within your routine activities.

[00:07:22] There's also a vision rehabilitation therapist who could also become what's called a certified low vision therapist. And that certification also allows you to look at training and use of optical devices and adaptive strategies to help you manage your visual conditions. You usually can find these therapists through an ophthalmologist or another vision provider, will know of who is in your region.

[00:07:51] AOTA - the American Occupational Therapy Association - usually has a searchable database for OTs who have this specialty training. But when I most recently checked, I think they're revamping their website, so it's not available. So that's something to keep an eye out for.

GG deFiebre: [00:08:07] Okay, great. Thank you. And Deb, do you have anything to add?

Deb Nikkila, MOT, OTR/L: [00:08:11] Well, actually, I do want to add... You know, going back to the very first statements that Amanda was saying, using your vision effectively. What I want to emphasize on that is that, a lot of times, individuals with, whether it's a progressive disorder or a relapse where they feel like, well, been through this before I know what to expect, they really feel discouraged to go back to the doctor and have the doctor tell them again, "Well, yeah, your vision is worse." And so they just might elect not to go. But what I want to emphasize is that low vision rehabilitation tries to be more encouraging than that. Yes, there is a vision assessment associated with it, and your diagnosis is considered, but really the focus is not on treating the eye disease. The focus is on treating function. It's on treating, 'How can we use your vision to the best of its ability? How can you learn to still engage in your world?' So, to not feel discouraged to go look for a low vision assessment, because it's actually an avenue of resource, not simply a verification that your vision has declined.

GG deFiebre: [00:09:31] Got it. I think that's a, a great overview. And we'll talk a little bit more in the future kind of, you know, in this podcast about different strategies for how to, how to adapt and, and function in the world. So, and then, you know, what resources are available for someone who may have visual problems but are not legally blind, or for those who are newly blind? Deb, do you want to start?

Deb Nikkila, MOT, OTR/L: [00:09:57] Well, it's going to be different state by state. A lot of states will have a Department of Vocational Rehabilitation or a Department of Health and Human Resources that is kind of the housing agency for some of the services. Then, of course there's also the, the medical system. The vocational rehab and health and human services, they're more within what would be considered the blindness system versus your insurance and going through your neuro-ophthalmologist and just your regular ophthalmologist to receive services.

[00:10:36] As Amanda said, those are the best places to kind of learn who is available. You don't have to be legally blind to receive services. Legally blind is having vision of 20/200 or a field vision restriction that's down to 20 degrees. But a visual impairment of significance more than simply acuity can greatly impact your function.

And so you do not need to be considered legally blind to receive some amount of support and assistance.

GG deFiebre: [00:11:13] Got it. And Amanda?

Amanda Aaron, OTD: [00:11:15] Yeah. Yeah, sure. Like Deb was saying, you may not necessarily need that designation of legally blind to take part in programming, especially offered through non-profits such as the Lighthouse, through the, the Lighthouse for the Blind. If you're looking for just general information, we really recommend you check out any websites that end in '.org'.

[00:11:36] It can be a good place to start. Some examples are the National Federation for the Blind, the American Federation for the Blind, or the Lighthouse for the Blind. And these websites may give you different non-profits or other agencies within your region that can provide services and supports.

GG deFiebre: [00:11:57] Great. Thank you. And then, how long does it take on average for regeneration of the optic nerve after an acute optic neuritis relapse? And is it guaranteed that vision will be fully restored? Amanda, if you want to start.

Amanda Aaron, OTD: [00:12:14] Sure. So in a relapse, which impacts the optic nerve, you won't fully know until the relapse is over whether or not there's been damage to the optic nerve, and that's something your physician should be able to tell you. If there's any permanent damage to the optic nerve, unfortunately, the optic nerve is not something that can regenerate. So any damage from a relapse will be permanent, and you wouldn't expect your vision to be fully restored.

GG deFiebre: [00:12:53] All right. And then, Deb, do you have anything to add?

Deb Nikkila, MOT, OTR/L: [00:12:56] No.

GG deFiebre: [00:12:57] Okay. And then if the majority of your vision is lost, could you be at risk of, at higher risk of losing, you know, further vision? Deb?

Deb Nikkila, MOT, OTR/L: [00:13:07] Well, visual impairment acquired by an episode of inflammation could be further aggravated or be progressively diminished with additional episodes.

[00:13:17] Each episode you have potentially can cause a greater loss of vision. Then again, it might not, it just depends on the significance of the inflammation and how long it persists. It's also important, however, to consider what is your age and your medical conditions that are not related to your neuroimmune disorder.

[00:13:40] There's many visual impairments that occur just by aging, or via chronic medical conditions. For example, diabetes is an example that has a lot of visual-related, potentially has a lot of visual-related side effects. Or age-related macular degeneration is an aging condition. So it's important when you think about your vision loss with a neuroimmune disorder that you have not only that that you're dealing with, but where are you in your stage of life?

[00:14:12] And are there other things that might be contributing beyond just your neuroimmune disorder?

GG deFiebre: [00:14:18] Got it. Thank you. And then, you know, when does nerve damage become permanent? And is there anything that can be done to increase the chance of recovery from nerve damage? Are there any sort of like exercises you can do for your eyes? Amanda?

Amanda Aaron, OTD: [00:14:35] So as I stated before, if there's any damage to the optic nerve, that is essentially permanent. And you wouldn't expect, you wouldn't expect the optic nerve to recover from damage. And there are not any necessarily exercises you can do for your eyes. Of course, there's always different lifestyle considerations to maintain your eye health, such as eating a healthy diet, exercise.

[00:15:04] And of course, if you have any medication prescribed from any of your doctors that can help manage any other medical conditions. But once there's any damage to the optic nerve, you wouldn't expect recovery.

GG deFiebre: [00:15:21] Okay. Thank you. And Deb, you have anything to add?

Deb Nikkila, MOT, OTR/L: [00:15:26] No. Okay. We're good.

GG deFiebre: [00:15:28] All right. And then, someone asked, they said that they have, they've had optic neuritis several times and experience a hot poker to the eye sensation periodically, which they find super painful. What causes this, and can anything be done about it? Deb, if you want to start.

Deb Nikkila, MOT, OTR/L: [00:15:45] Sure. Let me back up just to reiterate that it's important to take flare-ups seriously and communicate the experiences that you're having with your neuro-ophthalmologist, and do so, do that in a very timely manner. I think that it's important... you know, you're already given the education of what kinds of things could you expect, but when you develop a new or unusual symptom, those are things that you need to share right away.

[00:16:14] And I think that we've been told that the peri-ocular pain - pain around the eye area - is, is a typically documented symptom. But the poker, the burning pain sensation, you know, I'd need to refer you back to speak with your neuro-ophthalmologist on that and really kind of figure out what that is.

[00:16:38] You might want to try to take note of when it occurs, just to give your, your physician as much information as possible. Circumstances like, you know, is there a time of day? Is it when you maybe are more fatigued, or when you have demanded more of yourself? Are you stressed? Has there been any changes in your medication management routine?

[00:17:03] Just, you know, anything that could help contribute to figuring out what that is?

GG deFiebre: [00:17:09] Got it. And then, is there any medication or supplement that can increase visual healing? Amanda?

Amanda Aaron, OTD: [00:17:18] Sure. This is another question where I'll refer back to the doctor that you're working with. They'd be able to tell you better if there's any sort of medication or any supplement that's been shown to be effective at promoting eye health and healing.

GG deFiebre: [00:17:37] Thank you. And then, this question, this person has darkened vision from their optic neuritis attack. But when it's sunny, they feel like they should be wearing sunglasses, but they just make everything darker when, you know, they enjoy the bright lights that they don't get to, that they don't get to see indoors.

[00:17:54] Are they hurting their eyes by not wearing sunglasses? And if so, what types of sunglasses can they wear that doesn't then over darken they're already kind of darkened vision? Deb, if you want to take this one.

Deb Nikkila, MOT, OTR/L: [00:18:06] Sure. Bright or direct lighting is actually a very commonly used accommodation to help individuals with a visual impairment use their vision most effectively.

[00:18:16] So it's okay to take advantage of bright lighting if it feels it helps you see, and particularly if it improves your safety in using your vision. But refrain from looking toward the light or into a light source. When you're outdoors, you know, UV protection lenses are always a healthy choice for anybody, visual impairment or not.

[00:18:38] But the lenses don't necessarily need to be darkened to have UV filter qualities. There are lenses of, of different varieties that have UV filters that come in many different colors and different intensities. The best place to get some, some guidance on that is to consult with your eyecare professionals specifically.

[00:19:03] They will probably carry a range of them or at least be able to refer you to a distributor for, for some of those types of lenses. So, still would be a good idea to, to protect your eyes, but you don't necessarily need to darken to do that.

GG deFiebre: [00:19:19] Great. Thank you for that. And then what about for... we talked about darkened vision. What about for someone who's having color issues? Are there any special glasses or anything that can kind of enhance the colors that they have trouble seeing? Amanda?

Amanda Aaron, OTD: [00:19:37] Sure. So our color vision comes from the function of the cone cells in our eyes. And a lot of times when we think of colorblindness, we think of the genetic condition that some people are born with where they may have difficulty seeing some colors compared with others. And then there's people who may acquire colorblindness from many different visual conditions. Just in some reading I've done online, there are glasses for people who have very mild red-green colorblindness. I'm not too familiar with how effective these glasses are or how much they cost, so it'd be something to talk with your ophthalmologist or optometrist about. That being said, if there's any damage done to those cone cells, you can't repair that damage.

[00:20:27] So the color vision is, that's usually a permanent loss. So there may not be a device that can just automatically correct whatever your particular color loss is. That being said, functionally, you can learn to adapt to what your, what the color loss is that you're experiencing. Thinking about how you organize your home - if you know that you have trouble with certain shades of color, you may want to think about, for example, how you organize your clothing, trying to keep those colors that you have trouble with, keeping them far apart in your closet so you don't mix them up. So there's strategies like this that you can really take advantage of once you have a good knowledge and understanding of where your difficulties lie.

Deb Nikkila, MOT, OTR/L: [00:21:14] Yeah. And I, I want to just add to that, that it really is about looking at how is it impacting what you're doing? And is it something that is a priority for your independence? You know, the strategies that Amanda referred to are, are part of what that low vision rehabilitation may look at to, to teach you these adaptive or problem-solving ways about going about things.

[00:21:44] There're also, you know, there are some lenses that can help to sharpen contrast, but that doesn't necessarily improve the discrimination of color.

GG deFiebre: [00:22:00] Great, thank you for that. And then I have just a few more questions, then we'll jump into questions more about function, you know, mobility and, and stuff.

[00:22:08] So we did get a question that if your dominant eye is damaged from optic neuritis, will your brain ever adapt to dominance for the other eye if it has better vision? And so they're saying that this question comes from the inability to use monovision technique for contact lenses after an optic neuritis attack blurred vision in the dominant eye. Amanda, if you want to answer this one first.

Amanda Aaron, OTD: [00:22:32] Sure. So eye dominance generally doesn't change. It's hard-wired into our brain, much like if you're left or right-handed. That being said, that's a little bit of a blanket answer. Some people, just like being left or right-handed, may be able to use both for different tasks.

[00:22:49] Some people may have an eye dominance in one task and a different eye dominance for another. But generally, if you have lost your vision in your dominant eye, you would have to work through training and practice to improve your skills with the non-dominant eye. But your eye dominance wouldn't necessarily change.

Deb Nikkila, MOT, OTR/L: [00:23:12] Yeah. And I've seen online - greatest place for all medical advice, right? - that some people try to change their eye dominance by different methods of patching, or occluding, the dominant eye, but this isn't proven to be a permanent result. So just kind of keep that in mind. The other, the, the question... You said something about monovision in the question, didn't you?

GG deFiebre: [00:23:45] Yes. So, they wrote that, 'this question stems from the inability to use monovision technique for contact lenses, as opposed to wearing reading glasses.' So I guess wearing a, a reading lens in one eye, you know, a lens for distance in one eye and a lens for closeup in the other.

Deb Nikkila, MOT, OTR/L: [00:24:01] Right, just what I was going to refer to is, what, what is the monovision? And that's the, just as you said, one eye is corrected for viewing in a distance. One eye is corrected for viewing closeup. And when you have both eyes open, if the approach works for you, you can see indiscriminately of those two things. But if you need more detail further away or more detail close up, then you can use a single eye to do that.

GG deFiebre: [00:24:32] Got it. And then, you know, similarly kind of in the, in the same sort of topic area, if you've lost vision in one eye and understand that you might lose it in the second eye, are there ways to kind of train your visual, your vision to make any future loss less difficult? And then also similarly, like if, if you only have vision in one eye, are there exercises you can do to train your brain to process that single stream of information more quickly? Amanda?

Amanda Aaron, OTD: [00:25:01] Sure. It really... Yes, you can train the, you know, whichever eye to do whichever task you need it to do visually. And the beginning of the question about... Can you restate about if you have vision loss? What was the question?

GG deFiebre: [00:25:20] Sure. Yep. If you have vision, if you've lost vision in one eye and understand that you might in the future lose vision in the second eye, are there any ways to kind of train how you use your vision to make any future loss less difficult potentially?

Amanda Aaron, OTD: [00:25:36] Right. And that's absolutely what low vision rehabilitation is. It's working with you to understand and use your available vision. And in thinking of future, if there is expected to be progression of your visual loss, the low vision therapists would help you to learn about what other adaptive strategies there are that can help you do tasks if your vision is either like fluctuating or if you anticipate there being any more vision loss. There's definitely a lot of sensory substitution strategies we teach and instruct in and practice to help you cope with moving through your routine with, you know, changing level of vision.

Deb Nikkila, MOT, OTR/L: [00:26:26] Yeah. And I think what the question is alluding to is the idea of, of what we consider a non-visual approach or vision-free skills. And that is something that can definitely be taught and adapted to, you know, with the motivation to do it. The low vision rehabilitation therapist, or any part of that low vision team, is going to guide you through what needs to be done. Ultimately, it's about practicing it.

GG deFiebre: [00:27:00] Got it. Thank you. And then just one last question before we move into kind of the functional aspects of, of things: can vision loss in one eye, fully - so full vision loss of one eye - and then peripheral loss in the other cause someone to have something like dizziness or confusion or difficulty focusing?

[00:27:19] Deb, if you want to answer that one?

Deb Nikkila, MOT, OTR/L: [00:27:22] Absolutely. So for example, with the example given, complete loss in one eye and periphery loss in the other eye. So one of the accommodations that person's likely going to need to make is body positioning to scan and assess their environment. And that takes more time, and it takes more concentration. Let's say that you were at a street crossing or you were in a busy grocery store, and you're having to not just look and go, but you're having to look, shift your body, turn your head, shift in the other direction, and look more than once before you go to avoid collision, to avoid, you know, safety issues. So, so it, it, it does, it takes a lot more concentration, a lot more deliberate use of vision. Let's see, did I answer the question?

GG deFiebre: [00:28:19] Yeah, I think so. Amanda, do you have anything to add?

Amanda Aaron, OTD: [00:28:22] Yeah, I have something to add. Our vision is closely wired into our vestibular system, which is basically the balance center in our brain. So if anyone is experiencing vision loss and they're still, their brain is still adapting to that vision loss, it's not surprising if you're experiencing some difficulties with balance. And it's something definitely, you know, to talk with your doctor about and get appropriate referrals.

[00:28:50] It may be worthwhile also to look at physical therapy if you're experiencing a lot of balance issues, alongside with, what I think we'll talk about a little bit soon, is your functional mobility and travel skills. There're specialists to help you with that too, that may help resolve some of your balance issues during traveling and moving.

GG deFiebre: [00:29:15] Got it. Thank you. And, so now we're going to kind of move on to the more kind of functional aspects and how to adapt and what kind of devices or technology exists. So to start, you know, what types of canes or other assistive devices are available for people with visual issues? And is there training available for people to learn how to use these devices?

Deb, if you want to start and then Amanda, you can add on as well.

Deb Nikkila, MOT, OTR/L: [00:29:43] Certainly. Thank you. So there are a variety of different kinds of canes. The individuals who vend those canes to you and provide training in the use and decide what kind of cane is best for you is called a Certified Orientation and Mobility Specialist.

[00:30:00] These individuals provide training to the visually impaired, looking at improving their independence and functional mobility. They provide instruction in route planning, utilizing their remaining senses to determine their position in, in the environment, how to navigate safely from one place to another, and then of course the use of a cane, as well as even the use of the environment. There are a lot of things that are just naturally there that the sighted person doesn't necessarily even realize is there that can, you know, you need some training to discover that. So for example, we all know that at a street crossing, you can push the button, so that the light signals allow for the pedestrian to cross. But many don't know that at some of those intersections, not all, if you push the button and hold it in, I think it's for like a second and a half, it will actually say to you, what streets are you at? So some of these things are out there in the community and the sighted individual doesn't even know it.

[00:31:15] And you need some training to become aware of it. An orientation mobility specialist might be referred as part of your low vision rehabilitation. It might be referred by your ophthalmologist. But it doesn't necessarily require a referral. You do have the ability to seek out assistance on your own. And that again is where some of those state agencies might be able to be a resource. A lot of times they have connections or even contract agreements with orientation and mobility specialists to connect you with someone.

GG deFiebre: [00:31:57] Great. And then Amanda, do you have anything to add?

Amanda Aaron, OTD: [00:31:59] Yeah, I was just going to re-emphasize that orientation mobility training is just such an important component to learning to cope with vision loss, and not having to lose your sense of confidence and, you know, navigating and moving through the world. So it's something definitely to look into, to start finding information. If you're, again, experiencing any fear when it comes to traveling and, whether it's in your home or your community environment, to see what supports are out there for you.

GG deFiebre: [00:32:34] Great. Thank you. And then, how does someone qualify for a guide dog if that's the, you know, the route they want to go down? How can you start the process, and do you need to go through an organization? Or can you train a guide dog yourself? Amanda, if you want to start with this one.

Amanda Aaron, OTD: [00:32:51] Sure. So you definitely need to go through an organization to have like a certified guide dog. Because the process isn't just about giving people who are blind or visually impaired a dog that's been really well trained to support someone who has a visual impairment. It's also about having extensive training for that individual. And this is because a guide dog is not a replacement for good travel skills.

[00:33:18] So going back to that orientation mobility training, the guide dog won't just know where it is you need to go. You need to have the navigation skills in order to direct the dog, and then the dog is there to support you and, you know, guiding you around obstacles or through crowds. And an example of requirements of an organization to, to have a guide dog, for the Guiding Eyes for the Blind, the requirements to apply for a guide dog are you must be legally blind, over the age of 16, live in the US, Canada, or Puerto Rico. You must walk outdoors regularly unaccompanied and independently using a white cane, and you must be responsible for the care of the dog. And you've had orientation mobility training. So this is just one organization, but it wouldn't surprise me if for others they have similar requirements. Because, again, the dog is just a different support for travel, much like the white cane, the individual still needs to have the travel skills.

Deb Nikkila, MOT, OTR/L: [00:34:31] And I'll just add that there, as Amanda said, there are many organizations that do the training and the matching of a guide dog to a user. The National Association of Guide Dog Users and the National Federation of the Blind both have lists on their website of different agencies across the US. I can't say that those lists are completely comprehensive, but they are kind of possibly a place to get started with connecting with an agency.

GG deFiebre: [00:35:05] Great. Thank you. And so then now we have a few questions about driving. So at what point is it unsafe for someone to drive who has low vision? Are there any resources to adapt a car if you do have low vision? And then are there any resources for people who can just no longer drive because of some sort of visual impairment? Amanda, if you want to start.

Amanda Aaron, OTD: [00:35:29] Sure. So I guess my first response to this question is if you yourself are questioning your safety, if you've had any near misses when driving, and you think it's because of your vision, or if you find yourself making rules for yourself about driving, like any self-imposed restrictions, like I can only drive if it's going a place where, you know, I've traveled the route many times, or I can only drive during the daytime or only drive in good weather, I think you should start considering if there are other alternatives for

community mobility. When it comes to, 'at what point is it unsafe to drive?' - each state has different vision requirements for you to maintain your driver's license.

[00:36:19] So you really need to reference your department of motor vehicles to know for sure. But Deb and I are in the state of Maryland. Our minimum vision requirements are having binocular vision of visual acuity of 20/40 in each eye and a continuous visual field of at least 140 degrees. And these requirements are very reductionist.

[00:36:42] If we think about driving, it's a very complex task, and it's much more than just your acuity and visual field. And a big part of driving is the integration of your vision and movement. You know, if you see something knowing, you know, how to time turning the wheel or, you know, pushing the brakes.

[00:37:02] And so if you're really maybe starting to question your safety, there are driving rehabilitation programs that would assess in greater depth what your driving skills are and, you know, your vision being a part of that.

[00:37:18] And they do on road training too. You can find a certified driving rehabilitation specialist, either through a searchable database on the Association for Driver Rehabilitation Specialists or through the American Occupational Therapy Association. And for people who, you know, have decided or it's been determined, or they've had their license revoked because of a visual impairment, whether that's due to MOGAD or NMOSD, it's really based on your locality, what the resources are for community mobility and what the different transportation supports are.

[00:37:57] And that's something, if you are in touch with any of your state agencies, like your Department of Rehabilitation or Vocational Services, they'd be able to point you in a better direction of what's available in your community for support getting where you need to go.

GG deFiebre: [00:38:16] Great. Thanks. And then Deb, anything to happen?

Deb Nikkila, MOT, OTR/L: [00:38:19] Well, just that the decision to reduce or cease your driving is a very difficult thing for someone to accept if they're simply being told, 'this is what you need to do.' And when Amanda was talking about those self-imposed driving adaptations, that, you know, you only drive and familiar routes, or I don't drive at night, or I only drive if it's only me and I'm not transporting anyone or, you know, all of those things, really taking control of your own safety and deciding, 'Hey, I need help with this' or 'I need professional guidance with this' will make the process of adjusting to reduce driving or no driving much more easier to cope with than if you're just told you need to do it. So I encourage anyone who is experiencing these self-imposed adaptations to really seek out some of the help from the driving rehabilitation specialists. Or even just talking it out with your eyecare professional, asking for some low vision, a referral for low vision rehab so that, you know, you can get in connection with the right people.

GG deFiebre: [00:39:44] Great. Thank you so much. And then moving on, are there any technologies to assist visually impaired and blind people to use a computer?

[00:39:54] Deb, if you want to start.

Deb Nikkila, MOT, OTR/L: [00:39:56] Sure there's many assistive technology resources, but I would say that the first thing that you need to look at is what are you using a computer for, so that the technology is matched to what you need to perform. Sometimes just changing the settings in your computer itself is enough.

[00:40:17] So making icons larger or changing the contrast, changing the brightness, adjusting the color templates. Those are some things that might be enough, and you wouldn't necessarily need to go to true

assistive technology. However, if you do, there are different screen magnifiers, there's devices, CCTV - a closed circuit unit - that can help you.

[00:40:47] It's not your computer, but it can help you in, in reading text material. On your computer, there's screen readers so that the material that is on your device that you are trying to read, it reads it for you. There's also other technologies available just, like, on your television. Netflix has audio describe for some of its programs.

[00:41:12] That's a setting that you can set in your Netflix profile. So there are a lot of assistive technologies, but again, this is one of the roles of low vision rehabilitation to properly match you and what your visual disturbances to what your functional performance needs are, and bring those two together so that it's, it's a good resource for you to use.

GG deFiebre: [00:41:41] Great. Thanks so much. And then Amanda, do you have anything to add?

Amanda Aaron, OTD: [00:41:46] No, Deb's answer was great.

GG deFiebre: [00:41:48] Awesome. Okay, great. Thank you. And then is there a visual device that aids in significantly enlarging words or reading something for you? Amanda, you want to start.

Amanda Aaron, OTD: [00:42:01] Yeah, there's plenty of different powered magnifying glasses that can enlarge words. So this is where being evaluated by either a low vision ophthalmologist or optometrist really is important because they'll look at what your, what's impacting your visual acuity and to determine what power magnification is best for you to see the words on the page. And then the low vision therapists can help you learn to use whatever powered optical device, to use it within your daily living tasks or whatever reading tasks you'd like to do.

[00:42:45] So, there's magnifying glasses that are either handheld or come in a stand form, some with lights to help illuminate the words you're reading. There's also electronic magnification, and there's many different devices out there where you're, you're using basically a computer. Or it's a camera looking at the print, and it's being projected on some sort of screen. It can be within the device itself or on a separate screen to aid in enlarging prints for vision tasks, for reading tasks.

Deb Nikkila, MOT, OTR/L: [00:43:25] And I'll add that, you know, your smartphones these days have a lot of accessibility features and apps that can be helpful. There's the accessibility option of voiceover that you can set your phone to so it basically tells you what icon is selected at that moment. And then you learn a different series of tap sequences to select what it has said you're on right now. There's apps like 'Seeing AI' or Be My Eyes. Those are apps that you can scan things in the environment, and it will tell you what it is you're looking at.

[00:44:10] So those are, you know, some other things that, I think the question was specifically about things being read to you or said for you. There's a lot of talking devices, like talking watches or clocks, food scales that talk, food thermometers that talk, money readers that talk. So there's a lot of those types of devices as well.

[00:44:34] And again, I, you know, just can't say it enough, this goes back to the same idea of looking at your daily routine management strategies and where are the barriers that are impairing your function and matching that to what device or strategy do you need to use to overcome it.

GG deFiebre: [00:44:54] Great. Thank you. And then, you know, if someone's working, how can they adapt their job after experiencing vision impairment or vision loss, and what are the requirements of an employer

to accommodate someone who's experiencing, you know, new vision loss? Amanda, if you want to start.

Amanda Aaron, OTD: [00:45:13] Sure. So the Americans with Disabilities Act, or the ADA, states that employers cannot prevent an individual from maintaining his or her job if the individual can perform the essential functions of that job. So that goes back to when you, you know, took a job, usually the employer will have you sign something saying you can perform these such-and-such essential functions.

[00:45:38] So the employer is required to provide reasonable accommodations to allow the employee to continue to perform his or her job effectively. And your state agency that has either vocational or rehabilitation services is usually the place to go to find a specialist who will actually come out to your job site to help evaluate how any vision loss is impacting your performance of those essential functions and to determine what appropriate accommodations are. So again, it's just so important to look into what is available in your region or your state and to get in touch, because likely there's a lot of resources out there to help you support continuing the life you want to live.

Deb Nikkila, MOT, OTR/L: [00:46:36] And I want to add on here. So, you know, I am not a specialist in accommodations for the workplace necessarily, but there are people or organizations who are. I found a particular website I've referenced myself in the past, called the Job Accommodation Network. It's askjan.org. And they do have actually a lot of reference material on accommodations for low vision in the workplace. I think it's just a good place to maybe check out if you're really having challenges. Because, you know, sometimes your employer, they want to help, but they don't know how. They aren't necessarily a specialist in low vision or understanding what you're trying to manage either.

[00:47:24] And so I think it's important to realize that while these accommodations are things that do need to be made, you might have to be an active participant in identifying what would help you. Perkins School for the Blind also has some, some recommendations on their website that are very basic, things like that, you know, if your employer is requiring certain websites or portals to be used with your job, well then that website ideally has some kind of accessibility to it. Or if it doesn't, is there a way to adapt your computer to make it more accessible? You know, maybe you need additional training in the use of different softwares that are required for your work.

[00:48:09] Maybe a flexible schedule to enhance your ability to be productive with your work. You know what if you have more of a visual, what we call fluctuating vision and your vision is worse in the morning, or maybe just you have random days. So, I guess the point is, you know, working with your provider for a solution is going to be a lot more productive for you than expecting a solution to just kind of happen.

GG deFiebre: [00:48:46] I think that's a great point. Amanda, do you have anything to add?

Amanda Aaron, OTD: [00:48:51] Yeah. And one thing to understand, and what I think Deb was also referring to is, you know, your employer really may have no idea how your vision is impacting your function at work. And so, like she said, it's about coming up with strategies that work for you, because usually it's not like one strategy works for everyone. It's very individualized and being open to the process and learning modifications or adaptations to help support you.

GG deFiebre: [00:49:26] All right. So do you have any final thoughts or anything you want to talk about that we didn't talk about during this podcast? Deb, do you want to start?

Deb Nikkila, MOT, OTR/L: [00:49:36] Sure. Basically just, you know, losing your vision is, is a traumatic and possibly anxiety-provoking experience that people don't know what to do with, which is understandable that

so much of our world and our relationships are interpreted through the use of our vision.

[00:49:54] And that's what we know. And suddenly having to cope with losing that is, is really hard. That coping process is very individualized. But a common thread that many people might experience is a sense of isolation. The reason for that is not only because you lose some of your own skills or abilities, or you feel that you do, but also low vision is not perceived by the sighted world.

[00:50:21] Things that seem simple and automatic to others might suddenly be a big barrier for you, and others don't understand that. But what's important is to remember that you are not your diagnosis. You are still you, but you might need to try to do things a little differently. That's hard to accept, because there's a fear that if you accept your vision loss and doing these differently, it could equate to limitations in your independence.

[00:50:51] But the big message with some of the things that Amanda and I have been talking about is that that does not need to be your story. Trying to get yourself to a place of accepting and that you are able to do things differently and accepting the help to do so is actually a sign of strength and resilience that could improve your connection with the world and lessen the isolation you might feel.

GG deFiebre: [00:51:18] Great. Thank you. And then Amanda, do you have anything else to add?

Amanda Aaron, OTD: [00:51:22] Sure. In brief, low vision is a term we use for vision conditions that can't be corrected by glasses, contacts, or other medical interventions. And then what we've been talking about today is low vision rehabilitation is a service to teach you how to best use your remaining vision, manage any visual disturbances you're having, and learn alternative ways to do your daily activities.

[00:51:51] And I really hope through our discussion, you gained an awareness of the possibilities of living with changes in your vision and that there are many different services and resources that exist to support you. And really thank you so much for having us here today.

Deb Nikkila, MOT, OTR/L: [00:52:08] Yes. Thank you.

GG deFiebre: [00:52:09] Thank you so much.