Hadley

Navigating Health Care with Vision Loss

Presented by Ricky Enger

**Ricky Enger:** Navigating health care with vision loss can present some unique challenges. In this episode, Christian Zapata, director of program services at the Friedman Place, joins us as we share some common situations and tips on how to manage them. I'm Ricky Enger and this is Hadley Presents. Welcome to the show, Christian.

**Christian Zapata:** Thanks, Ricky. Thank you for having me.

**Ricky Enger:** It is really so good to have you here. And no pressure, but today's topic is one that we've been trying to get a guest on for a very long time, so a lot of people are expecting perfection. So again, no pressure.

**Christian Zapata:** We'll do our best.

**Ricky Enger:** Exactly. So we do have a lot of great informative stuff to talk about today. But before we jump into that, I'd like to just get a little bit about you. Give us a bit about your background and what you do at the Friedman Place, and what even is Friedman place?

**Christian Zapata:** Great. Thanks for asking, Ricky. So my name is Christian Zapata. I am the director of programs and services at the Friedman Place. I'm a licensed clinical social worker in the state of Illinois.

And Friedman Place, we are a residential program for people who are blind or visually impaired. There's about 85 people who live here who have varying degrees of vision, and my job is primarily to manage our social services department and our activities department, as well as our case management programs that we provide for offsite services as well.

The reason why this job I felt was so appropriate for me at the time was not only did I have clinical experience in working with people who are at all stages in life, but I too have a visual impairment myself. I have retinitis pigmentosa. I've known that I've had it since I was a young kid, and over the course of my life my vision has slowly been deteriorating over time.

But I've been able to make adaptations and accommodations to allow me to continue to do my work while at the same time just being extra sensitive and having empathy into the experience of what people go through because many of the things, not only what we're speaking about today, but so many other facets of vision loss, I'm challenged with them myself. And so just kind of having that layer of sensitivity too and insight definitely helps in the work that I do here.

**Ricky Enger:** Absolutely. And truly, you are the perfect person to speak about today's topic because, as you said, you have that empathy, that complete understanding of what it's like to experience some of these things yourself, and the professional background to talk about it too. Let's jump right into it because, my goodness, there is a lot when we think about healthcare. There's so much to manage. And we, at least speaking for myself, dread going to the doctor just because it's never fun. And then you add some of these challenges that vision loss brings on top of that and it's like, oh, wow, how do we manage this?

So the first one is when you get to the appointment, and sometimes even before the appointment, there is the dreaded paperwork. There's always going to be paperwork. And maybe you can't read it at all or maybe you have a magnifier and you're able to read the paperwork, but then how are you going to look to see that you're writing in that tiny little space and make sure your writing is readable? So there's a lot to think about. Are there some ways that people can manage to get this paperwork done and still have their medical privacy intact and to get everything done in an efficient way?

**Christian Zapata:** That's a really great question. And like you mentioned earlier, it can be a little complicated. But I think the best way to begin this conversation is that, for someone who is sighted, some of these things may not come into play because you can just show up to an appointment, you can drive yourself, you can find the suite, you can find the address, you can fill out paperwork, and things kind of get done just very naturally and just very, there's a flow to it. When you're experiencing vision loss, there's a lot of planning that has to go into it, not just with medical appointments, but just life in general. So I think the biggest thing to keep in mind is the preparation and the planning that goes into, and we're going to keep it focused to medical appointments.

So I think that whenever you go to the doctor, there's always the HIPAA form that you have to sign with every medical professional. There's the insurance information, there's the application that sometimes you have to fill out. So again, part of is knowing, one, where the appointment is going to be. A good rule of thumb is to contact the provider before your appointment, hopefully with plenty of time in advance, and ask, "Is there any pre-paperwork that I can fill out beforehand?"

And if it's a blank form, they can email it to you, and so then you can download it or you can pre-fill it out on your computer if you have adaptive software built into your computer. Or sometimes you can just print it out. If you have a magnifier or a CCTV, you can try to use that to fill out the paperwork. But I think especially now where we are with technology, as you mentioned earlier, so many providers, whether it's a small doctor's office, like a family practice, or even larger hospitals that are connected to larger healthcare networks, they all usually have portals. Again, just having access to creating a portal for your personal health information is so important because there's so many things that you can do to, again, prepare for this appointment. You can check in online, you can complete... In my case, I went to the doctor actually just last week and I had to do the COVID checklist. Do I have any symptoms?

**Ricky Enger:** Right, right.

**Christian Zapata:** I would check off no, I don't. And then it's all self-guided. And for reference, I use ZoomText. So it reads to me some of the options on there and I can also use the magnification aspect of it. But it'll verify your insurance, it'll verify the primary reason for why you're seeking to make an appointment. You can select your provider. And a lot of these things, what's good about it is that if you can do it in advance, it kind of minimizes some of the stress or the pressure for when you show up and some of the anxiety of is there someone going to be there who's going to help me? Will I be able to give the right credit card? Will I be able to find my insurance card? So when you can do it on your own time without feeling that pressure, doing some of these things in advance really helps in freeing up some of that mental space for you to be able to focus more on the actual care that you're hoping to get.

**Ricky Enger:** Yeah, that's a really good point because even if you're not super technologically minded, having the ability to get it done beforehand with the help of someone that you definitely trust or with the help of a magnifier. Now you don't have to be concerned that your medical conditions, you're going to have to be talking about them in the waiting room with everyone else listening. That can definitely be a challenge as well. So we alluded a little bit earlier to getting to the appointment. And that actually can be a challenge in and of itself. Whether you have an appointment planned well in advance or sometimes things come up unexpectedly and you need to get to urgent care. So figuring out that transportation is kind of a key piece of this. Are there things that people can look at or resources that people may not be aware of? Just how do we think about getting to the appointment?

**Christian Zapata:** That's another really great point. And I think that so much of what we're talking about is what happened when you need to get to the appointment. But what I'm trying to hopefully make the point today is we have to kind of pull ourselves back a little bit and do a lot, again, more of this planning and preparation. If we wait until the moment when we need to go to the appointment, the stress level causes us to not kind of fire on all eight cylinders like we normally would because we're concerned, we get nervous. Am I using the right technology? It's not working how it should. So a lot of things come into play. So one is programming important phone numbers. That's a huge first step, making sure your doctor's office phone number is in there. You have alternate emergency contacts, so if you need to contact a supportive person, a spouse, a family member that you can reach out to in case you are going on your own that you have some of these phone numbers that are readily accessible.

When you're creating a contact on your phone, if you're putting the phone number you probably want to add the address as well too, so that way it's easily accessible, you know where it is. So it doesn't always have to be on your phone. So if you do have low vision, you can write with a Sharpie pen on a sheet of paper and just making sure that you've written down in a manner in which that you can see it, the address, the phone number, the name of the doctor. So that way you have this information and it's accessible to you when you need it. That way you're not feeling, "Oh, I wish I would've done this before my appointment." You have it easily accessible. And I think another part of that as well is having phone numbers for transportation.

So depending on where you are in the country, I can speak specifically here in Illinois, there's a lot of different transportation options, so for folks that use a service similar to the ADA paratransit program. So having phone numbers like that already in your phone contact or written down somewhere where you could see it, having a few taxi numbers already pre-programmed in your phone or written somewhere where you can easily see them as well too. So that way, in the event that you need to call someone and it's not a loved one or family member, you have other plan A, B, and C just in case.

The third option that I feel is just synonymous with independence as well for people with low vision is just having access to ride-share programs as well too. Again, this isn't something that you want to do the day of, but set up an Uber account, set up a Lyft account. Use it a few times because if you're using it for the very first time on the day of your appointment, that's just yet another obstacle or stressor that may not go as planned because you've never used it before.

But if it's something that you're comfortable with, you've set up your payment method, and you need to go to the doctor, you can already schedule the address into your Uber app if that's what you're using to get to the appointment. So all this to say is that to have a successful appointment where some of these details don't cause stress, it's pre-planning, is setting up phone numbers, having access to these things. And it will make the experience of getting to the front door much more seamless and will reduce the amount of stress that you may feel or some of the anxiety, because this whole point is not everyone likes going to the doctor. So just minimizing some of these minor stressors would help make the actual visit more enjoyable or more productive.

**Ricky Enger:** Yeah, exactly. And I think pre-planning is sort of the theme for this episode. And you may not always be able to plan ahead, but when you can, it helps so much. It's one thing to pre-plan, but sometimes you're not even sure because you've never done it before. How do I go about doing this? So I'm thinking, for example, you’re taking an Uber, you feel really good about it because you've done that a time or two before, you've got the address and the phone number for your doctor in your phone. And now you get there, and your Uber drops you off somewhere, but it might not be clear where exactly you are because there's these huge medical complexes and they all have these different buildings, and then there's getting to the suite of the place. It's a lot. So what are some things people can do to pre-plan for that to make sure, if I'm dropped off somewhere weird, rather than panicking, what's my next step?

**Christian Zapata:** So I don't want to keep harping on the pre-planning, but it's so important, especially if you're doing these things on your own. Again, you can contact the hospital if it's going to a large hospital building or a medical complex. And you can request that someone from the office meet you in the lobby. Again, this is something you would have to pre-arrange in advance, but you can definitely request it. Definitely in hospitals you can always request assistance because when you enter the doors at a hospital, there's always the main lobby. The person behind the desk may not be the one to assist you, but they can request assistance from the many staff who are available who can then take you the next leg of the journey to whatever floor or whatever suite that you're going. But again, it's always best if you pre-arrange in advance so that way you kind of just don't catch them off guard.

So those are always really, really good things. If you're a super high achiever, one of the better ways to do it is going on a dry run. Especially if it's a really important appointment and you don't have anyone else to go with you, try going on your own first without an appointment. So just to get familiar with the location where, if you're using a ride-share, you can verbally tell them where you'd like to get dropped off. You can navigate without the risk of being late for anything. Just kind of orienting yourself to the building, knowing at least where the elevators are, knowing that when you exit the elevator on the second floor, you're going to hang a right and it's the fourth door on the left. You already have a mental map as to how to get to it. And eliminating some of these minor details reduces that stress and anxiety the day of. And so kind of doing a dry run sometimes is really helpful, especially in hospitals because hospitals are huge and there's so many different wings, connections. It can be a lot. I have found even through personal experience and even for the people that work here, when you ask for help, nine times out of 10 there's going to be someone there who will provide the assistance. It may not be immediate because, again, people are doing their jobs and there's things to do. But rarely have I experienced where someone will flat out refuse to provide assistance. Again, it's just approaching someone and saying, "Hi, I have a visual impairment. Could you assist me?", or, "I have a disability, could you assist me in locating suite 101?" Nine times out of 10, a person who you're communicating your need to may not be the one to assist, but they will definitely connect you with someone who can make sure you get to where you have to go.

**Ricky Enger:** Yeah, that's a really good point. And goodness knows I have a story or two to tell. And thankfully, it was all the people that were very kind. I might've been dropped off at a building in one of these large complexes and it turns out it's the entirely wrong building and where I need to be is across the street. And yet, the people were always so kind in assisting me to get to where I needed to go. No one was put out. And getting there a bit early is kind of a good idea too because then there's more time if something happens where you get lost or whatever, there's still time to recover before you have to be where you're going. So yay, we made it to the appointment. Everything is good finally, except sometimes it's not always perfect.

There are instances where you get to where you're going and the healthcare provider is looking at your Uber driver and trying to ask them questions about your medical situation, or you get into the exam room and you're talking about, "I've been falling a bit more lately." And some things that may need to be looked into a bit further could be attributed to your vision loss if that's what the healthcare worker is really thinking about. So I think this one is kind of tricky, but maybe you have some advice on how to make sure that the vision loss is in its proper context, it's important when it needs to be, but it's also not the exclusive focus and the person who is treating you is recognizing that you are a whole person, not just vision loss in front of them?

**Christian Zapata:** Again, that's a great question. I think that putting it all within context is that sometimes we may feel a little intimidated when we're meeting with our physician or a doctor because they know it all. We're going to them for help. Sometimes in a hospital or a clinic there's tons of patients and stuff just moves really fast, and the doctors are expected to diagnose, to treat, prescribe within 15 minutes and then the next patient is up to bat. And I think, again, it creates a little pressure on the patient. But I think the biggest thing to keep in mind is to always go into any appointment with having clear goals in mind and being able to advocate and express what those goals are. I'm here because my leg hurts. I'm here because I need a prescription refill. I'm here because I need an annual physical.

And being able to express those needs directly to your physician, to the nurse, or whoever's attending at the time and letting them know, "Hey, I really need assistance with this specific thing." And if the doctor asks or if you feel that it's pertinent to why you're there, you can mention your vision loss. But I think the biggest thing is just keeping in mind what you're there to be treated for. If your visual impairment is the reason why you're there, then obviously you want to mention it. But if it's not, then it's really up to you. I think the biggest thing is just keeping in mind to articulate that I am here for this reason. And I think that helps in making a connection with your provider and letting them know, "Hey, this is what I need from you and this is what I'm hoping to get."

**Ricky Enger:** Yeah, that's a really good point, being able to speak up for yourself, I suppose, because sometimes it's hard for people to do that. We feel intimidated, as you say. Or maybe you're a little shy and you are waiting to be directed in a specific way. But if you go in knowing, "I may have to speak up for myself. I may have to redirect the physician to focus on why I'm here," again, it's that pre-planning. If you go in knowing that this could happen, you have a couple of scenarios in mind that could happen and ways to talk about that and move forward.

**Christian Zapata:** Also, remembering you can ask your physician. As much as you may feel like they're trying to rush you, you can ask them, "You know what? You're using terms that I don't understand. Can you speak to them in a way that I can understand what you're trying to explain?" Because sometimes there could be a lot of doctor speak and using really complex terminology. And it's hard to wrap your mind around a diagnosis or a treatment approach and it can feel overwhelming and rushed. So like you mentioned, you can advocate and say, "Hey, you know what? I'm really trying to wrap my mind around this and it's a lot to digest, but can you repeat it in a way that I can better understand what you're trying to say?" So just kind of making sure you can slow it down so that way you feel you're getting what you need out of the appointment as well.

**Ricky Enger:** Absolutely. We've talked so far about doing this all on your own, so independently getting there, figuring out ways to fill out the paperwork, and being the only person in the room with your care professional. I think there are times when people may choose not to do it alone. And I think there are some very valid reasons for why you might want to bring someone with you. Can we talk about what advantage that might bring for someone? Why would you take someone with you? What can they help with?

**Christian Zapata:** I think that's such an individual choice to make, and there's no right or wrong. There're some people who are more private and just want to handle things on their own. And just because someone may feel more comfortable by having a supportive person, a spouse, family member, or friend, that's okay too. Again, you may be consumed with getting to the appointment, figuring out how to get there, and I think sometimes your focus may not be fully on what's being said or what needs to be done. So just having a second set of eyes, a second set of ears can really help in getting through the appointment, especially if there are decisions to be made, treatments to discuss, or procedures to contemplate. So it's always good to have a trusted person with you.

I've been to the doctor and when I leave my wife says, "What did they say?" "I don't remember. I'm not sure, but I know we did stuff." But having someone who's there who may be there to take notes for you, who may be there at least to write down dates or who can help you with saying, "Well, two weeks ago we were in the emergency room and then we followed up with immediate care on this date," who can easily reference back, especially if you're dealing with a complicated medical situation. So just having someone who can provide facts, who can take notes and be able to discuss it with you post-appointment. And again, just having someone there that you trust. And even if they don't say a word, or even if you're not even sure if they're taking notes at all, but if you feel comforted by having a trusted person there, especially if you're going through something difficult, I think that's always really helpful to have. And it's something that you have the right to do if you feel it's going to help you through it as well.

**Ricky Enger:** Yeah, definitely some really great points there. Taking notes, someone who's, I don't want to say objective because they're there for you, but they may be a little more easily able to process what's happening because you're sort of in the moment, like this is happening to me and it's hard to take all of these things in. And just someone in your corner, it gets stressful. So whether that person is there to help you from a vision loss perspective or whether they're just there as support makes sense in the moment, it can be a good idea. So we've covered quite a bit, but there's never really an end to the things that we can talk about when it comes to figuring out healthcare. It's a pretty complex topic, so I'm wondering if there's any major category or point that we've not covered yet that you want to leave listeners with to think about or just a tip or trick that people may not know when it comes to navigating this stuff.

**Christian Zapata:** I don't know if it's necessarily anything new but just want to reiterate the importance of planning ahead. Making sure that when you have all of your ducks in a row, you have your dates, you can access the information that you need. You've done your homework in preparing for this appointment, so that way when you go to the appointment, you're there to attend to what you need to do, and your visual impairment is not going to be an obstacle in getting what you need to get done. Knowing and preparing for the transportation, knowing what paperwork needs to get done, knowing that you're getting your prescription refill or your procedure scheduled, so that way you're focusing on more what you're there to do as opposed to being distracted by all the little details that go into it.

A big part of it too is again choosing and knowing who to take with you. Who do you think would be a supportive person who can help you through the appointment itself, or even that person who can help you fill out paperwork when you're there? Not everyone feels comfortable asking for help, and not everyone feels they need to give their entire medical history or diagnosis to the front desk person if they can't fill out a form. So everyone's at different stages in their vision loss. And depending upon where you are, only you know that. And knowing where you are can better inform the type of assistance you're going to need and the type of people and things that are going to help make this appointment successful.

**Ricky Enger:** Absolutely. And it sounds like what you're really saying is control as much as you can. You're the one who can make the decision about how to approach this, and so whether you choose to bring someone in, whether you choose to do everything ahead of time or get there or what have you, it is within your control. You have the right to make those decisions. Thank you so much, Christian. This has been really, really informative and helpful. And if you're listening and you're thinking, "I'm kind of interested in figuring out that portal stuff, but I'm not really sure about technology. I need to brush up on that," we do have info here at Hadley about that, as well as once you get your prescriptions and how to manage those in terms of labeling them in a way that works for you. So if you do have questions, do contact us, 800-323-4238. And Christian, I just want to thank you again for bringing your experience, both personal and professional, to this discussion.

**Christian Zapata:** Thank you for having me. It was my pleasure.

**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@hadleyhelps.org, that's P-O-D-C-A-S-T at hadleyhelps dot O-R-G. Or leave us a message at 847-784-2870. Thanks for listening.