Hadley

Vision Loss and Family Dynamics

Presented by Ricky Enger

**Ricky Enger:** Welcome to Hadley Presents. I'm your host, Ricky Enger, inviting you to sit back, relax, and enjoy a conversation with the experts. In this episode, we discuss vision loss and family dynamics. Our guest is licensed marriage and family therapist, Sarah Clark. Welcome to the show, Sarah.

**Sarah Clark:** Thank you for having me, Ricky.

**Ricky Enger:** It is really good to have you here. And no pressure or anything, but I think that this topic of family and vision loss, and how do we deal with things that tend to crop up in most situations, those common scenarios, people really want to know about that. So, lots of expectations, but no pressure.

**Sarah Clark:** Perfect. Okay. We'll do our best.

**Ricky Enger:** Indeed. Before we get into talking about the topic, why don't you just give us a bit of info about yourself, who you are and what you do?

**Sarah Clark:** Sure, absolutely. I am a licensed counselor. I work with individuals and couples to help them with disability adjustment, and I also provide training through an organization I started recently called Disability Counseling Institute, to help therapists and other rehabilitation professionals learn what they need to learn about working with people with disabilities. And I've started a series of workshops for helping people who aren't able to get access to counseling services, when it comes to needing some extra support with disability adjustments.

**Ricky Enger:** Fantastic. Well, it sounds like you are certainly the ideal person to talk about what we're here to discuss today, which is families and how the adjustment period look for families. In addition to the person who has received that diagnosis of vision loss, how does that family dynamic play out and get to a healthy place? I think it's fair to say that there are probably some common things. Everybody's journey is going to be different, but there are things that certainly will pop up in a lot of situations. When that diagnosis happens, you've got the person who's adjusting to the vision loss, the person who's received that diagnosis, and then there's the family. What do you tend to see as far as common initial reactions to that diagnosis from the family?

**Sarah Clark:** Yeah, there's a few common responses that happen. Oftentimes what will happen is different family members within the same family unit will react differently. And unfortunately, because a lot of people don't have experience with vision loss and they don't know what to expect, don't know how to be a healthy support system, they react in negative ways unintentionally. One of the most common reactions that a family member has is to become overprotective. Just all of a sudden, the view of the person who has just become visually impaired, or just received that diagnosis, changes.

I can definitely say that happened with one of my family members. The very next week after my diagnosis of retinitis pigmentosa, I was just doing my normal thing about to run up the stairs to do something, and I hear this panicked, "Watch out for the stairs." I was just floored. I stopped, I was like, oh my goodness. I had been running up and down those stairs my whole life, it was not an issue. But all of a sudden because that diagnosis happened, they were worried. And so, that's a pretty extreme reaction, but it's not uncommon. There's a lot of other types of overprotectiveness or ways that show up.

The other extreme, which also happened to me with other family members, is for people to be in denial, so they just act like nothing's changed. They think they're doing this to benefit the person who was newly diagnosed, to keep things normal, not have a lot of things change for them, act like it's no big deal. Unfortunately, by acting as if nothing has changed, they're minimizing the impact of the diagnosis and the vision loss of that person. They will often push the person to do things in ways that are no longer safe for them to do, or to do things or make choices that push them in a direction that's not beneficial based on their vision loss.

The third most common is to express embarrassment. And that is very, very common. It's usually well-intentioned, not always, unfortunately, but usually well-intentioned, and they are trying to protect their loved one. They not only are experiencing that embarrassment for themselves, but they're experiencing that embarrassment for the person that they care about, the person that's experiencing the vision loss. So, they will ask them to basically hide it. If the person's using a cane, they'll ask them to not use it in public. If they pull out a magnifier or a light when they're shopping or at a restaurant, they'll encourage them to not do that in the future. Sometimes that even goes as far as not wanting the person to really leave the house or interact with others.

**Ricky Enger:** Yeah, that's tough. And while those do sound like extreme reactions, they are as you say, very, very common. I think people are listening and probably nodding their heads, like at least one of those things has happened. It can be difficult if you are at the beginning of this journey, and so much is happening, you may not even know what healthy support from family members is supposed to look like. What is the ideal that we are hoping comes about? What sort of support do we hope for that isn't detrimental to the person's journey or to the family dynamic?

**Sarah Clark:** Yeah. It looks different for every person, based on their own disability, their ability to function, what level of support and training and all of that that they have. But ideally, the way that family members should support, the healthiest way to support, is to simply be there for the things that the visually impaired person asks for assistance with. And this is a really common thing that I discuss with family members on a regular basis, simply don't offer support. Don't step in and take over a task if a person is struggling. Just be there and support if the person asks.

Because it's important for the person who is visually impaired to struggle, and learn, and practice their skills without using their vision. It's important for them to learn when to ask for help and that's a hard thing for a lot of people to learn. So, if they never have to, because somebody always just steps in and says, "Here, let me do that for you," or "Do you need help with that?" they won't progress with their rehabilitation as quickly. And then the family member has evidence that reinforces that they should be overprotective, that they should take over tasks that the person is struggling with. It really does hinder the process for everyone involved.

Healthy levels of support look like letting the person be as independent as they can possibly be, and provide support when requested, and try to provide that support in the way that it is asked for. But like you said, in the very beginning when somebody's newly diagnosed or going through this, they might not know what to ask for or how to be supported. And that's when training and rehabilitation professionals, online tools, and videos and things can provide guidance on how to make that transition.

**Ricky Enger:** Yeah, that makes perfect sense. And I think that underlying all of that is just learning to maintain your own agency as the person with vision loss. Because I know that sometimes that is lost. You feel like, well, it is easier to let somebody else do this. But even if I want to learn, I'm making people uncomfortable, so maybe I should just fade into the background. And that's a horrible feeling, right? To no longer feel like you should make your own decisions.

**Sarah Clark:** Absolutely, yeah. And the unintentional harm that is done by offering help repeatedly is that it does draw attention to the fact that the person is struggling. And without saying it out loud, the undertone of what they're saying is, you're having a harder time doing that and I can do it easier, so let me just take that over. And that is crushing to self-esteem and self-image.

**Ricky Enger:** Exactly. Let's circle back then, to this overprotectiveness, this need to keep your loved one from experiencing something that is difficult or experiencing that struggle. How can people work together to minimize that, to work their way through the well-intentioned overprotectiveness from the family member? And for the person experiencing the vision loss, how do they get that independence back in a healthy way?

**Sarah Clark:** The person who's new to vision loss, usually I will recommend that they rely on other tools, resources, other professionals to help them facilitate that. Because they don't really know what to ask for yet. That was my experience. I knew that I didn't like the way people were treating me, but I didn't know how I wanted to be treated, or what I would or wouldn't need help with, because it was all so new. And a lot of forms of vision loss changes from moment to moment, day to day, based on lighting and other situations. So, one day you might need help with something, and the next day you wouldn't.

Oftentimes I will suggest, if there's a particular thing that somebody is being overprotective about, we'll find a resource, a YouTube video, a podcast. Something that describes that particular thing and how the person can do it, and how a family member might be able to assist. If a person is being pulled around by a family member because they're so afraid they're going to bump into something, I will say, "Okay, here are three different YouTube videos on how to do a sighted guide. You share this with your family members, ask them to do it." And that way it's coming from another source, and you know exactly what's the right technique, and it doesn't have to be a complicated discussion.

But for people who do know what they want and they just need to get that across, it's really helpful to come at it from a perspective of, "This is what I need, and I know what you've been doing has been intended to be helpful, but this would be most helpful if you would shift to this other approach." For example, to go back to that idea of only helping when I ask for help. That's a really, really big one to start with. It makes a huge difference in a lot of different areas, whether that's with things like a sided guide, or just tasks around the house. If the person says, "I need you to help me in this way," and that lets the family member know that they are being helpful without being overprotective. They're being helpful by not helping, and it shifts that perspective for them.

**Ricky Enger:** Excellent. What about the embarrassment factor? I think we've touched on some of this earlier, but I know it's tricky, because as the person experiencing the vision loss, you might be feeling some of this yourself. I don't want to look unusual because I have a white cane now, or because my head is closer to something as I'm trying to read it, or whatever. And then you have the family members who are whispering to you, "Somebody's staring at you, stop doing that," kind of thing. And so, it's a big issue. How do people navigate this when everyone is feeling that embarrassment to one degree or another? How do you get through all that?

**Sarah Clark:** A lot of transparency usually helps. Because unless it's the edge cases where the person is more concerned about their own embarrassment than the visually impaired person's, they will make adjustments if they know what they're doing is harming rather than helping. And so, if the person is experiencing that from a particular family member, or multiple family members, if they can just sit down and have a conversation and say, "When you say this, when you that, when you do this, this is how that makes me feel." And acknowledging it, voicing it, that there is embarrassment, there is shame that has to get worked through by the person experiencing blindness, and the person is making that worse by their actions.

If you give somebody guidance on what to do, they usually respond very well. Like the example you gave, which is something that happens very often, "Somebody's looking at you, somebody's staring at you." You just very kindly say, "I know that you're intending to be helpful in pointing out what I can't see, but that makes everything worse. It's better if I don't hear those things."

Because absolutely, as a person who is visually impaired, I've been dealing with blindness now for more than 20 years, and I can say people still look. People don't really mean anything by it, and I don't take it personally anymore. But in the beginning of my vision loss experience, I was embarrassed. I was ashamed. I felt like there was something wrong with me, and that's why people were looking. But that's not it at all. They just don't understand, and it's something that they don't see every day, and they're curious. But usually, they don't have negative perceptions or intentions. And by drawing attention to that and saying, "Somebody's looking at you," it automatically makes it something that's bad and wrong, and it makes the person feel worse.

**Ricky Enger:** What an excellent point. Yeah, I think that's going to be so helpful for people to hear. Because we do internalize that if someone is looking, then it's because you're unusual in some way. And sometimes unusual can feel that that means bad, but not so much. It's just, it's curiosity. So ideally, there is a situation that can be talked out among the family members. Something happens, and you and the family talk things out and come to some sort of resolution, and you can move forward. But a lot of times that may not happen initially, and you as the person experiencing the vision loss, you have to set boundaries. And that can be really hard with people who are close to you. We all have these dynamics, that one person may push a little, "I know you said I shouldn't," blah, blah, blah, "But I'm going to anyway because I feel like it's the right thing to do." How can people set boundaries in a healthy way with people that are close to them?

**Sarah Clark:** Typically, I recommend people start by setting boundaries that are nonverbal and just personal to them. By that I mean it's not a conversation, it's not that you go to that person, and you say, "I'm setting a boundary here." You just make a change in how you're doing things, in order to create that boundary to protect yourself.

Just a random example might be if you have a family member that despite showing them the correct technique to do sighted guide and support you when you're doing shopping, they still do things the way that they want to do them. They still just drag you around and say things that are embarrassing to you. Instead of just getting frustrated with them, despite the fact that you've told them, and they've been shown the right way to do it, just change the fact that you go shopping with them. That's a boundary that you can set with that one individual person and say, okay, well, this is not working well. This is not good for my mental health or my adjustment, so I'm going to either choose to shop in a different way, maybe have things delivered, use one of those other resources that's out there, so that you don't just acquiesce to whatever the unhealthy situation is. And if you can make that change personally, then it's a lot easier to navigate.

The other way of setting boundaries in a healthy way is to discuss it with the individual. But you have to pick and choose which type of boundary is appropriate, based on your relationship with that person and what the behavior is. And it's okay to verbalize a boundary to somebody if that's what's necessary. It doesn't mean that you're excluding them from your life, or you're eliminating part of your support system. You're just setting boundaries that change how you interact with a particular person in your support system.

**Ricky Enger:** Right. I know that as much as people hope to navigate these tricky waters on their own, and they may progress significantly, there might still be some things where a person is saying, no matter what I've tried, no matter how hard I've worked to address this particular thing, we're just not at a healthy place yet, and I need some help. How can a person seek that outside assistance? And maybe equally importantly, how do they even know who to approach for assistance in this? Because it's not like in the Yellow Pages or whatever, there is somebody with the title that says, help me navigate my vision loss journey with my family, or whatever. What can people do?

**Sarah Clark:** Yeah. There's a lot of options, and there are more and more all the time. In the situations where the typical approaches don't work, for whatever reason, because there's all kinds of reasons why just things are not clicking, somebody's struggling more with their adjustment, a family member's resistant to change, where you can get other people or other resources involved to support that. Like I said earlier on, there's all kinds of tools in terms of videos, websites, podcasts, things that provide information to the family. Vision Aware, Hadley, of course has all kinds of resources. There's plenty of blind YouTubers that talk about all of these different things. And sometimes it helps to get unstuck, if the family member that's struggling with this can hear it from another person.

Sometimes just for whatever reason, the dynamic with their visually impaired family member is not allowing them to really take it seriously, or really hear it the way that it needs to be heard. And if other resources, and oftentimes the more resources, the better, if they're hearing the same thing over and over again from multiple sources, it's going to get through a lot more. Oftentimes that'll work for the boundary setting as well, because when we're trying to set a healthy boundary, if somebody's not respecting that boundary, that doesn't mean that we don't keep trying to set that boundary. The goal of boundary setting is not to get somebody else to respect it, but to put a boundary in place that we maintain for ourselves. And so, the more often, the more reinforcement with any of this stuff, the better result you're going to get.

And then there are additional types of supports. There are adjustment to vision loss support groups, both live interactive ones that you can do in person or virtually. There are online ones through forums like Facebook, and people can get support through those. Either individual support in how to navigate a particular family dynamic or get the particular family members who are struggling to get the support on their own. And those can be really beneficial. That's one of the reasons I started doing some workshops for people experiencing vision loss and their families, because it is hard to find something that is unique to the different dynamics of vision loss. And with counseling, which is something I recommend for everybody, that you have to work with a counselor who knows about vision loss, or at least is willing to learn about vision loss from other resources, so that they're not learning from the client, and the counselor has to be licensed in the state where the client resides. That makes it very, very challenging for people to find individual or family counseling that's specific to the adjustment to vision loss.

And there are unfortunately, not an abundance of resources that will address these particular issues, but they are out there. There are online courses that talk about family support. As I mentioned, there's the support groups. There are organizations, usually vision loss rehabilitation programs in every state. There may not be one close to where everybody lives, but if it's not close, they might provide remote services. And between all of those different programs and services, usually you can find something that will support what it is that you need assistance with.

**Ricky Enger:** Fantastic, thank you so much for that. I know this is going to be incredibly helpful for people who are either new to this, or perhaps they've made some progress and might be stuck at some point in this journey. I so appreciate just all the advice and the resources that people can look at.

As we mentioned earlier, Hadley has some resources on family dynamics as well and we actually have a series on “Adjusting to Vision Loss” and we’ll have that link along with links to other resources in the show notes. But there are two workshops that I think really do speak to this in that series. And one of them is on how to ask for help when you need it and how to turn it down when you don’t. And there’s another one in this series that is on partnering to build skills. And that one is great for actually showing to family members and then talking about how you can work together to build those skills and be supportive of one another.

Any final thoughts that you would leave the listeners with before we wrap up?

**Sarah Clark:** I would say the most important thing if a person is struggling with not having healthy support from their family members, is to recognize that the family dynamic is extremely complicated. And as much as you, as the visually impaired person might be struggling with your vision loss, the family's struggling too. I mentioned a few times that typically the family members are well-intentioned when they're making these mistakes that can cause problems, and they really, truly want to help, and they do care. And that's part of why they struggle with their adjustment with all of this, is they want to be supportive, but they don't know how.

And being on the other side of that, I can absolutely get that. Because before I lost my vision, I did not know how to deal with it, so I can't expect that other people who haven't experienced it would get it too. And so, as hard as it is at times, try to be patient. Try to understand that it's coming from a good place. That doesn't mean that it shouldn't change, there's always room for change. That's why they call it an adjustment process. It should transition over time. But try not to take it personally, because people just oftentimes internalize these things as negatives. They think the person that they're dealing with is intentionally causing them more stress, more problems than they already have. And vision loss is hard enough without other people adding to it.

The more you can understand that it's not a personal thing, that it's not meant to be malicious. Again, most of the time, I don't want to minimize the fact that there are people out there who are not well-intentioned, and definitely there's different directions to take in those situations. But the majority of us have people who will accommodate and adjust based on what it is that we are giving them, in terms of positive reinforcements, and suggestions and feedback about what they're doing.

**Ricky Enger:** Fantastic, that's such great advice. Thank you so much, Sarah, for stopping by and sharing both a bit of your personal story and your expertise in this. It's much appreciated, and I know that people listening will get so much out of this as well. Thank you.

**Sarah Clark:** My pleasure. I hope it's helpful.

**Ricky Enger:** Got something to say? Share your thoughts about this episode of Hadley Presents or make suggestions for future episodes. We'd love to hear from you. Send us an email at podcast@hadley.edu. That's P-O-D-C-A-S-T, @hadley.edu. Or leave us a message at 847-784-2870. Thanks for listening.