Hadley

Emotions, Mental Health, and Vision Loss

Presented by Ricky Enger

**Ricky Enger:** With vision loss, we experience a wide range of emotions. In this episode, clinical psychologist, Dr. Ann Wagner and Hadley’s Marc Arneson, join us to share how learning from and connecting with our emotions can bring about healing and transformation. I’m Ricky Enger and this is Hadley Presents.

**Marc Arneson:** Welcome to Hadley Presents Dr. Ann Wagner. Thank you so much for joining us today on the show.

Ann Wagner: I'm glad to be here.

**Marc Arneson**: I've been eagerly counting down the days for this episode.

Ann Wagner: Aw.

**Marc Arneson:** I am. I'm really excited about this conversation. Even some of the questions that we came up with, I'm really excited to have this talk. Honestly, I know it's not always easy, and I'm sure in your experience you come across this. It's not always easy or even comfortable to talk about some of the difficult emotions that can come with vision loss and the importance of connecting with others. I can't imagine it's always easy or comfortable, but I think it's such an important conversation to have. So I'm grateful to have you on the show today.

**Ann Wagner:** Thank you.

**Marc Arneson:** Dr. Wagner, Ann, I have some questions for you that I was hoping we could run through, but before we get to those, do you mind just sharing a little bit about yourself?

**Ann Wagner:** Yeah. I am legally blind due to retinitis pigmentosa, an autosomal dominant form. I had genetic testing and it's PRPF3, which means if you have this particular gene type, you have the symptoms and any children you have will have a 50-50 chance of inheriting the eye disease. So my grandpa had five kids, three of them inherited RP, and one of those was my mom. My mom and dad had five children and four of us inherited RP. So I kind of grew up in a blind culture where everybody understood that retinitis pigmentosa primarily involves progressive loss of the peripheral vision and night vision. So we have worsening tunnel vision, worsening night blindness. In childhood is when the night blindness is usually quite evident and then the acuity is affected more in our later teens, early 20s. So my mom, her vision met the standards for legal blindness when she was 16 due to the severity of the tunnel vision. I was 18 when my vision loss met those requirements.

Growing up in this blind culture meant I had support, I had people who understood what I was going through, and the sighted people in our lives knew what we needed and what we didn't need. And so I know how lucky I am for that, and I have a lot of gratitude. Currently, my vision is quite impaired. I have end stage complications that would take a while to explain, but I'm pretty blind. I have some light vision left. With ideal lighting conditions and contrast, I can still make out some shapes, but that's where my vision is at now.

Professionally, I am a board-certified clinical psychologist, and I’ve worked 26 years at the Minneapolis VA Healthcare System on the PTSD clinical team. In the field I'm considered a trauma specialist, but everyone on our team was also considered a generalist.

I loved my work at the VA. I am now retired. But even though I'm retired, I'm still required to make a disclaimer that the views I express today are my own in my role as a citizen psychologist. The views do not represent any official views of the federal government or the Department of Veterans Affairs. I just felt I needed to say that. But even though I'm retired, I'm still professionally active with some consulting work and invited guest speaking, particularly on topics related to mental health and vision loss.

**Marc Arneson:** Speaking of that, I've had a chance to hear you speak a few different times, and I've listened to some of the conversations that you've had and in some of your presentations. You talk about this concept of complex grief. I was wondering, just to get started, do you mind sharing with me a little bit about what that means and maybe how it relates to vision loss?

**Ann Wagner:** Yeah. I think complex grief can resonate with a lot of people experiencing any kind of progressive medical condition where each incremental change in the condition can mean it affects different areas of functioning. So particularly with progressive vision loss, every degree of peripheral vision or loss of acuity can potentially result in additional losses of independent functioning. So with each loss of independent functioning or an activity of daily living becoming more challenging, there's going to be grief attached to each of those with different meanings attached. And so it's by no means simple. It is quite complex. And there's a nuance there that I don't think a lot of people are aware of. But whenever we have to pause and do some problem solving to do something differently, to try to figure out ways ... If we learn new blind skills, is there a way we can continue to do something independently?

Or the time it takes to utilize resources or connect to supports to still engage in activities, we value that time and our relationship to time becomes an area of grief in the sense that I know how I would most want to spend my time. And yet, to adapt and to move forward, I'm going to have to dedicate some time to the problem solving and to figuring things out. So there's a loss there, a loss of maybe what we call the freedom of how we want to use our time, and those are the things we do to adapt and we make all sorts of sacrifices in life to do things that are important that may not be our preferred, but it's part of that complex grief process.

**Marc Arneson:** It's fascinating. I think you talked about some of the different challenges that can come with vision loss, and I know the day-to-day challenges. I've heard a lot of folks talking about trying to discover new ways to do things that have now become more challenging. I've also heard a lot of people that I've talked to share that the emotional challenges that come with vision loss can be even more difficult sometimes than the physical or practical challenges that come with vision loss. Emotions, we all have them, right? Some are pleasant, some are not pleasant at all. But I'm curious, do you mind sharing a little bit about what our emotions tell us and is there something that we can learn from those emotions?

**Ann Wagner:** Yeah. In fact, they tell us a lot. They actually tell us who we are at our core and what matters to us. There's a principle that's shared by a couple of different therapy models. It's this principle or idea that emotions only show up to tell us what we value, what we hold dear, what matters to us. The problem is that the more painful emotions, we've been exposed to programming and messages and judgments that somehow we're not supposed to feel what we feel unless we're presenting as happy.

We've learned all sorts of avoidance patterns or self-protective patterns that distance us from our own core emotions when actually they are so important to connect to and to understand. And so to illustrate, I use this idea every day myself, and I used it in almost every course of therapy, this foundational principle of connecting to our core emotions to listen to what they're telling us and to process them in a naturally healing way. I’d like to share stories in my examples of how things work if that's okay.

**Marc Arneson:** Great. I'd love that. Yes.

**Ann Wagner:** Yay. Good. I have a grandson who is almost two years old, and when I connect to this truth that I'm not able to see his face, then a couple of emotions show up. Helplessness and grief. When I think about what are these emotions telling me about what I care about, to start with, the helplessness is a very important emotion. It's probably the one we struggle with the most. It's the one that shows up when we wish we could control something that we really can't. So it tells us two truths. First, it tells us the truth about the limits of our control. And actually we only have control over one thing in life, and that's what we choose to do in this one moment right now. That's it.

We don't have any control. If controllability was a scale, I'd say we have zero control over the past because we don't have a time machine, or the future because we don't have a time machine. We have zero control over what people say, what they do, what they feel or what they believe. We actually have no direct control. So really we have no control over anything except what we do in this one moment. The helplessness is telling me I can't control the fact that in this moment I can't see my grandson's face. But then helplessness always tells us a second truth. That we care about something. So it's trying to help us connect to that core deep sense of where our most important values are. Otherwise, it doesn't even show up if it's not something we care about that we can't control.

**Marc Arneson:** That makes sense. Yeah.

**Ann Wagner:** It's telling me that I care about something. So if we were to give a name to a person who always told us the truth and always also tried to tell us what matters to us, we might call that person a friend. Yet we have been taught to struggle with helplessness. It shows up hundreds of times every day because of the things we can't control. We've been taught to struggle with it and to keep trying to control things we can't. That's wasted energy and can create suffering. And that helplessness rarely shows up alone. It almost always is going to show with other emotions that will help with that second piece of what is it that I care about? So grief shows up in this example where I can't see my grandson's face. And the grief emotions show up to tell us that we are holding an attachment.

We form attachments to people, to things and to ideas. We have many attachments to ideas. Our preferred ideas are wantings. We might call hopes. We might give them different names. But I clearly have an attachment to this idea of being able to see my grandson's face. So when life gives us information on our actual experience and some truths show up that say that this idea that you're attached to is not going to happen, then we have to detach from that attachment and let that idea go and that's grief. Grief and loss. And depending on how deep or meaningful that attachment is, whether it's to a person, to a thing or to an idea, the level of pain of that grief will be higher or lower. So grief is telling us that when we're actually feeling it and allowing it to flow like waves it means we are connecting to truth. We're not in denial. And that's important.

The helplessness and grief are showing up when I connect to this idea and this truth. I can't see my grandson's face and I wish I could. So I'm going to go through the steps of connecting how these emotions are telling me what I care about. So I'll ask myself why does that matter to me? And then I'll connect to this other idea. Well, I don't want to miss a single nuance of my experience with him.

And then I'll ask, well, why is that important to me? And then I can feel when I'm connected to the deep core, core values, what I stand for is deep, enduring, loving relationships with the people I love. And for all of those, I wouldn't want to miss nuances. But when I connect to that deeper core value, openings always happen because there are going to be other ideas that I can connect to then for how I can act on that core value even if this one idea cannot be acted on. When I connect to that, often memories or ideas from other people in my life might show up that were meaningful to me. In this example, when I connect to being a loving person, I have memories of my mom, and my mom died in 2017 from pancreatic cancer, but she was an incredible role model in my life. We grew up on a farm and she worked hard on that farm just like us, even though she was blind. So my mom, by the time her grandchildren started showing up, she couldn't see their faces.

From the day they were born, whenever she'd be holding them, many times, she would say, "I'm going to braille your face." And she would feel their faces. Then as they grew up, she'd say, "It's been a while. I'm going to braille your face to see how you're changing." They just grew up knowing grandma was going to braille their faces. When my nieces were in their teens, for some reason when they had school dances or other events where they were going to dress up, they liked to bring their makeup and clothes to my parents' house to get ready there. I'd be visiting sometimes, and my nieces would hog the back bedroom and the bathroom until they were ready and then they'd come out all beautiful in their dresses and they say, "Grandma, we're ready for you to braille us." The room would just become filled with their giggles and laughter and chatter and my mom's oohs and ahs, as she brailled their faces, gently touched their hairdos, felt the bows or ruffles, whatever their dresses were. She'd ask them to describe the colors. The room would just be filled with joy and delight. And it didn't matter one bit that she couldn't see them. I connect to those memories.

**Marc Arneson**: Yeah

**Ann Wagner:** I have a grandson who is almost 2 years old. From the time of his birth till today when I hold him, I say, "I'm going to braille your face," and I touch his sweet face and his chubby cheeks and feel his hair and his little hands and feet, and I am just filled with so many emotions. And again, emotions show up to tell us what we care about. Yes, there's the grief and loss of not being able to see his face, but also missing my mom. I understand what that emotion is telling me, and I respect it, and I even have compassion for that emotion because it's affirming who I am, and I also feel such gratitude for having such a loving mom. I feel closer to her in those moments. So every emotion tells us very important information if we can open to it and learn about our emotional world better.

**Marc Arneson:** Those are wonderful stories, Ann. I so appreciate you sharing those stories and just the importance of understanding how our emotions show us what's meaningful to us. It seems like you've really developed a skill to be able to step back and recognize the importance of this emotion, and I think you said even have compassion for it at affirming who you are. I imagine for a lot of folks though, it's tough to step back from these really difficult and painful emotions like helplessness and grief or sadness or anger and look at it in the same way that you're able to do that. I imagine sometimes getting other people to help you understand what those emotions are telling you could be really important as well, whether that's a close friend or a professional. I've heard you talk about this concept or idea of village moments and connectedness and the importance of relationships. Do you mind sharing a little bit more about the idea of village moments and why they're important, particularly for folks living with vision loss?

**Ann Wagner:** Yeah. I have this idea that in the very early years of humanity, our ancestors were probably all in villages where they felt seen and known and secure with people knowing what things came easily for us or what things were more challenging. And when there was something weighing heavy on us, we had people to listen and be there. We are still born as social creatures, and we need a sense of belongingness. There's a theory from the '70s called the social buffering theory. At least I think it was the '70s. It’s when we have adequate social support, and by that, I mean emotional support, it can buffer the negative effects of stressors in our lives, even trauma level. A lot of people think the support that's needed is advice and that's not really what I'm talking about. We need to feel a sense of safety and security sharing our deeper emotional pain or even moments of joy. Sometimes we just feel like, oh, I want to share this story with someone because it gives us that sense of belongingness.

When two people show up, being able to share from this deep, real, and authentic place, I call that village moments. It's where healing can happen, and transformation can happen. If we don't have people in our lives that we can feel that level of security or even within ourselves, if we've had so much programming that we just don't feel safe to open up to that deeper pain within ourselves, then find a professional. I like to share this idea by Diana Fosha. She developed accelerated experiential dynamic psychotherapy. In some of her writings she talks about how really the core of human suffering is profound loneliness. When we do experience something really painful and we don't feel that sense of security and safety that we can share and not feel judged or have somebody still feel distant from us because they're in their head thinking of advice to give us instead of just really being with us, we are going to learn all sorts of ways to protect from the feeling of the painful emotion, we're going to feel that deep loneliness. When you feel so alone with that kind of pain, it's really painful.

I had many veterans over the years talk about when we're processing trauma memories or other healing work that they wanted to do in the therapy, I would share words from other veterans to see if they resonated with them. I'd tell them that some people say, "Yes, there's incredible pain related to the trauma memory itself, but what's even more painful is feeling alone with it." I would have veterans start to cry at that point and they're like, "Yes, I connect to what those other veterans were saying." And so this profound loneliness.

It's important to validate those experiences and it's so important to feel heard. If we don't have people in our lives that we can feel that level of safety and security to share and trust that we won't be judged or that they're going to just give us advice that we're not asking for, then trying to find a therapist is highly recommended. I like to help with stigma. It's decreasing. I think every year the stigma against seeking mental health care is getting better and better and better because so many people know it's healthy. It's like you're going to exercise for your health. You can seek therapy for your health.

I'm very open that I sought therapy. People with vision loss are at higher risk for anxiety and depression, and I had more of the anxiety side to things here. So I completed a course of therapy for anxiety, and it was incredibly helpful and I felt heard and understood, and that's so important.

**Marc Arneson**: Yeah. And I love the concept of village moments, this connectedness. So that's kind of what we were made for is what I'm hearing you say as well.

**Ann Wagner:** Yeah.

**Marc Arneson**: We were made for relationships and connection. A lot of the folks that find us here at Hadley are new to vision loss. They're kind of new to this whole way of life. Can you talk a little bit about how that might even have more of an effect on these feelings of loneliness or isolation?

Ann Wagner: Yeah. Well, 10 to 20% of retinitis pigmentosa gene types are recessive, which means there isn't going to be another person in their family probably. I had this incredible blessing of growing up in a blind culture, but most people are alone. They don't have role models. They don't know anybody else experiencing vision loss and that would feel so, so lonely and kind of scary. That's why resources and connecting to communities that support people with vision loss is just so important. I wouldn't want anybody to go through this alone. That would be so overwhelming. That's why I loved hearing about Hadley Helps and your peer-to-peer program, connecting people one-on-one so they can do their deeper sharing or all the different things you're doing. Foundation Fighting Blindness also has ... each state has its own chapter and communities of support are happening through that. There are resources out there. And state services for the blind or the vocational rehabilitation programs in most states have vision rehab, rehabilitation services that can also help with adjustment by experts who can help. So that can help people feel a little less alone and with people who understand.

**Marc Arneson:** Yeah. Part of my job is just getting to know folks and spending some time hearing their story. When I hear people say, "I don't know anybody else who's visually impaired. I'm kind of in this by myself." It just makes me want to feel like we're here and we want to connect you with somebody. I'm glad you mentioned our peer-to-peer program. One of the women that I met, she shared that she lives with her husband, and she has grown children that come and visit quite frequently and grandkids that are kind of running around the room. And she said, "With all these people in my life, everything that's going on, I've never felt so alone. Because of my vision loss, I don't feel like I have somebody to talk to about it. If I could just spend time with somebody who understands what I'm going through I think that would make all the difference." We were able to connect her in our peer-to-peer program with somebody who had a similar eye condition and similar life experiences. And she said, "This was the missing piece for me." Which is just so fulfilling to hear comments like that.

**Ann Wagner:** Yeah. And she was listening. It's a theory, but I absolutely believe it's true that we all have an adaptive energy that we can connect to or wants us to connect to it to help adjust and cope as part of resiliency. And she was listening to her core self saying, "If I just had somebody I could talk to who might understand." She knew what she needed, what feels healthy and healing and what doesn't. That's so lovely. I just hope more and more programs can find ways to help because the anticipated rates of people with vision loss are growing as people live longer and there's a lot of people experiencing vision loss or who will.

**Marc Arneson:** That's right. All this complex grief you talk about, all these emotions that can just kind of overwhelm us sometimes and with these challenges that come with vision loss. I imagine it can sometimes consume you even to the point where you feel like, okay, this is who I am now. It starts to form your identity. Have you felt that way yourself, and what would you offer to folks who might be feeling that way as well?

**Ann Wagner:** Yeah. It's such a good question. When I started wanting to date, I would lead with, by the way ... At that point, I wasn't using my white cane yet. You couldn't tell by looking at me.

I would let people know, "Hey, I'm losing my vision." And I led with that as if that was my identity, because I wanted them to have a chance to say, "Oh, I don't want that to be with somebody with blindness in my life." And yet, because of my own personal growth and work and these concepts I learned from my professional work, I absolutely no longer feel like I have that internalized self-esteem as somehow being less than. Being surrounded by such a loving partner who treats me as an equal and just lovely friends and of course my family.

But what's helped me in particular is this principle from narrative therapy about the idea of how problems are external to who we are. To recognize that the blindness, it's an experience I'm having. It's separate from me, the whole person who I am. And it may walk alongside me and it's going to have its effects and each of those effects are an experience. They're not who I am. So I will refer to blindness moments of humor and hilarity because they certainly help create moments of grief and sorrow and other emotions of frustration. But I am not the blindness. I'm Ann.

Our identities are really more about what do you stand for, what matters to you. And we can live those values in many, many different ways. The disabilities or the limitations, whatever word we choose to use to describe bodily changes or losses of vision, those are just companions that maybe we didn't want in our lives, but we can actually, potentially at least, respect and appreciate that they're external to us and we can give them our own names.

I'll be free in my transparency. I tend to fret. I'm a bit of a worrier. And that was part of ... So staying in my head with the worry thoughts of what if this or what if that. The what ifs kind of keep me in my head, and it is a form of distancing from my core emotions. So I name my patterns. I've recognized when that's showing up that there's a need for me to slow down and think about what is the core emotion really that I'm trying to avoid here and to learn to be with it. But I name all my protective patterns Melvin.

**Marc Arneson**: Melvin.

**Ann Wagner:** Melvin. Yeah. So that's one of my Melvins. No offense to anybody named Melvin. It's a fine name. It just helps me smile and it helps me relate to the patterns in a completely non-judgmental way. These patterns were programmed. None of us are to blame. We've all been taught these messages to try to avoid what we feel. So that's one of my Melvins. And overthinking. There's a lot of things, but I named mine Melvins.

What I encourage people when they're looking at the patterns of things they're doing is just ask, is this a valued activity? Is it meaningful to me? Is it feeling helpful in some way that feels healthy? Or is it potentially one of those self-protective patterns? Because I'm not feeling like I can safely or securely connect to what's going on deeper and start to consider ways to maybe connect to your emotions or take a risk to share with somebody and see how it goes. And I will tell people, and it's what I do, is I will ask Eric, for example, my husband, when I'm feeling the need to just feel heard, I'll set the frame in advance. I'll say, "There's something kind of weighing on me that's feels kind of heavy and I want to share it, and I really just need you to listen and just love me. Just care for me. I'm not asking for any kind of advice." So letting people know that upfront helps a lot.

**Marc Arneson:** That's a great idea.

**Ann Wagner:** And I'll validate when somebody does give advice. I know they're trying to be helpful because they care about me. That action is quite valued for people giving it, but they just don't understand in the moment what I really need. Or they're feeling so uncomfortable with my distress that they want to ease it, so their minds are giving them an idea, and they become very attached to that idea. Like, "Oh, if they just do this, this and this, then Ann won't feel this distress. So I'm going to give her this idea." So we get attached to our own ideas like, "Oh, if somebody just does this, they'll feel better." We're getting attached to an idea and we're putting it at the foot of somebody else without necessarily checking in. Is that what they're wanting or needing from us? And it happens so fast and so subtly that I just encourage people to check in with each other. What is it you're needing? Or, hey, I'm really going to try to work on being just a listener. And even though my mind may give me ideas to give advice, I'm going to try to just observe that chatter and still show up in a real way with the people I love.

And again, when I heard about your approach with that help desk and the peer to peer, my core just felt this warmth and respect for you and having help staff because you're ... It's like you're all psychodynamic therapists. You know the importance of belongingness and just being with it is actually healing and it's doing something so important.

**Marc Arneson:** Well, Ann, I want to thank you so much for just spending this time with me here today. I know when we put this on the calendar, I was eagerly anticipating it, and it was well worth the wait. Such a wonderful conversation. I feel like we could keep talking all day too. But maybe you'd be willing to join us on another episode down the road here in the future.

**Ann Wagner:** Absolutely.

**Marc Arneson**: Yeah. Your personal stories, I just appreciate you being so open and just sharing those and then your professional insights I think are so helpful. So again, just thank you. Thank you so much for this conversation today. I really appreciate it.

Ann Wagner: You're welcome. Thank you.

**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@hadleyhelps.org. Or leave us a message at 847-784-2870. Thanks for listening.