Hadley

Shame and Vision Loss

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 address the topic of shame as it relates to vision loss. Joining us are Hadley's, Director of Community, Marc Arneson, along with psychologist Ed McDaniel and social worker Jeff Flodin. Welcome to the show, everybody.

**Marc Arneson:** Hey Ricky. Thank you.

**Ricky Enger:** Wow, we got a full house today. That's exactly what I like to see. It's an incredible topic, something that people ask about from time to time, so I'm delighted that we're having the chance to really dive into it. But before we do that, why don't we just get an idea of who everyone is. Marc, we'll start with you. You're no stranger to the program, but just a few sentences about who you are and what you do.

**Marc Arneson:** Of course, Ricky. I'm Mark Arneson, as you mentioned. My title is Director of Community. I actually spend a lot of my days just meeting interesting and fascinating people and talking about all the things that we do here at Hadley. I get to join a lot of low vision support groups and just share about all the ways that we can help.

**Ricky Enger:** Nice. Ed, how about a little bit from you? Tell us about who you are and what you do.

**Ed McDaniel:** Sure. I'm Ed McDaniel, and I've been a psychologist for quite a while. I retired from the state of North Carolina after 30 years and worked for a nonprofit for a while. More recently, I've been transitioning to doing more work with people with vision loss. My previous 30 years was a whole variety of people with disabilities.

**Ricky Enger:** Excellent. Thank you. Can't wait to hear your perspective on things. And Jeff Flodin, you too are no stranger to the Hadley Presents podcast. We've had you on once before, but for those who may not have heard that episode, give us a bit about who you are and what you do.

**Jeff Flodin:** Thanks, Ricky, and it's nice to be back. My name is Jeff Flodin. I'm a social worker. I got my MSW when Gerald Ford was president if anybody remembers him. I'm also a writer. I'm the author of the Jalapenos in the Oatmeal: Digesting Vision Loss blog, which deals with how to cope with vision loss. I try to be humorous, serious and practical in alternating blog postings. I live in Fort Collins, Colorado, but spent most of my time, including the last 12 years or so in Chicago where I've worked for Friedman Place.

**Ricky Enger:** Excellent, thank you. I’m looking forward to your perspective. So, it's interesting, Hadley Presents is kind of a grab bag of things, and we talk about a lot of practical things, and we also talk about technology, cooking. The sky's the limit, I suppose, but maybe someone is listening and thinking, why exactly are we going to talk about shame? What's the importance of discussing that and vision loss?

I guess it would help to frame the conversation a little bit and talk about what the definition of shame is and see if everybody even agrees on that. Once we're on the same page, we can get to Marc's questions. So, I guess the formal definition of shame is a painful feeling of humiliation or distress caused by the consciousness of wrong or foolish behavior. I don't know if that's exactly what I think of when I think of shame. So why don't we just see where everybody is on that. What do you think about this definition?

**Marc Arneson:** Yeah Ricky, after hearing that definition, it’s actually really interesting to me, and it makes me think. Jeff, I don't know if you want to jump in here, but I'm curious about your thoughts of where you think shame comes from or what might be the source of shame.

**Jeff Flodin:** Thanks, Marc. With regard to the definition, my understanding of the difference between guilt and shame is that guilt is a feeling that arises when you do something wrong, it's an action. And shame comes more from a feeling that who you are yourself, your core, is deficient or even worthless. The difference, I think, is partially that guilt can be assuaged, let's say, by asking forgiveness or going to confession or whatever you do in your culture. Whereas shame hits a lot deeper into the core of the personality.

It's almost like a rejection of self. I think there's a lot of different applications of shame in psychology, which I'm sure Ed will look at. But in the vision loss realm, I think if a person feels shamed by what they perceive as the deficiency of vision loss, then hopefully it won't go any further than that. It'll just be a part of their persona that they feel deficient or less than.

**Marc Arneson:** Thank you for that, Jeff. Yeah, that's really helpful. Ed, do you have anything that you want to add to Jeff's comment?

**Ed McDaniel:** I think Jeff described it very well in regards to vision loss. First of all, just to state that shame is a very common, normal emotion that we have for a whole variety of reasons. But as it relates to vision loss, I think the source I would say would be that we may feel different, maybe feel that we don't fit in, that we're not good enough or as capable as others, afraid others will not accept us or may treat us differently. So it is, as Jeff described, how we feel about ourselves, but also our perception of how others may feel about us.

**Marc Arneson:** Gotcha. Yeah.

**Jeff Flodin:** I think too, that it's important to point out that shame is a necessary part of growing up. It's important for a child when they reach the terrible twos or when their ego is just boundless, that the fact that they are not omnipotent is reinforced. Some of the ways that shame is helpful, or at least ordinary in growing up is the feeling of bashfulness, which does have maybe a benefit of keeping people a bit cautious as to their relationships and so on. And then embarrassment, which is also kind of a check on somebody's behavior that says, oh, no, I think I went too far with that. When it gets toxic, like some people refer to it as a difference between ordinary shame and toxic shame is when it really starts being self-destructive and hurtful to your perception of yourself.

**Marc Arneson:** I'd never heard those differentiations before, between toxic and ordinary shame. That's so interesting. I'm curious, I know both Ed and Jeff, you're living with vision loss yourselves. I'm wondering if you could just share how feelings of shame may have affected you in your own lives? Jeff, I don't know if you want to go ahead and share first.

**Jeff Flodin:** Sure. Well, a bit more background. I was diagnosed with retinitis pigmentosa, also known as RP, when I was 35 years old. I had no background in vision loss. Even though RP is hereditary, nobody else in my family had it. So, I was really thunderstruck by that definition, which came totally out of the blue. My initial reaction to the diagnosis and the prognosis that I was exposed to for RP was to feel that maybe even beyond shame, the world was coming to an end. I started listing the roles that I had as a 35 year old man, who would love me in this deficient state. And there were practical things. How am I going to drive? How am I going to learn if I can't read print? How will I keep myself going and energized when I can't play golf or take photographs? So there were a lot of roles about what I am, but the shame kind of hit deeper than what I am. It hit, who am I going to be? What's going to be left?

**Marc Arneson:** Thank you for the honesty, Jeff. I appreciate that. And Ed, I don't know if you want to share as well, maybe the same question, how feelings of shame may have affected you in your own life?

**Ed McDaniel:** Sure. Like Jeff, I also have RP, but in addition to that, I have hearing loss. And so what I have is called Usher syndrome Type 2A. So that means I've been hard of hearing since birth. As I got older, the RP started to reveal itself and I've been slowly losing my vision most of my life now. When I was five years old, I started wearing hearing aids. Around the time I became a teenager, I could see that I was feeling shame about my hearing loss because I started to make sure that my hair covered my hearing aids. Developmentally, when you enter your teen years, you are more concerned about what your peers think about you. And so that was something that I wanted to hide.

I think that's common with feeling shame is that we want to hide what we may see as a deficit in ourselves. As a young adult, I began to come to terms with my hearing loss, but then at that point I was diagnosed with vision loss. And so then I started feeling shame about that, having some of those similar emotions that Jeff talked about. It was kind of going through that same kind of thing, but for two different reasons.

**Jeff Flodin:** And I think that in my case, with progressive vision loss, as both Ed and I experienced, you can feel that you've adjusted well to a certain level of eyesight and then all of a sudden it diminishes and you're almost back at square one if you're talking about the grief reaction and so on, then denial and all that kicks in. But in general, I think it's like the shame starts to kick in at times when you don't feel adequately equipped. It's like too soon to go public with this. It's too soon to be out there under the scrutiny of the public. And those are the really the most self-conscious times. Like the first time that you go out in public after you've had training with a white cane, for example.

**Marc Arneson:** No, that's interesting. Ed and Jeff, when you talk about that, and you talked about the roles that you've played in life as a photographer, a golfer, things like that, these moments when you don't feel adequately equipped, I think is what you said too soon to go out in public with this. I'm curious, just your reaction to that, and maybe in addition to that, are there times where maybe you felt this idea of shame, this concept of shame more strongly throughout your life? And maybe what do you think has led to some of those moments?

**Ed McDaniel:** I think for me, particularly, as Jeff mentioned, starting to use the cane was probably the time that I felt it the most in my life. Certainly before that I stopped driving when I was 29 and I felt it to some degree at that point. But with the cane, it was probably the most. When I got a guide dog last year, I didn't feel that at all. It was at that point, I think I had come more to terms with my vision loss, and I was really excited about having a guide dog where I wasn't so excited in the beginning about getting a cane.

Fortunately, that feeling of shame when I started using a cane, worried about what people would think of me, was replaced over time with a feeling of confidence about being able to get around safely. And the shame started to go away. And it was really replaced with a feeling of independence and confidence.

**Jeff Flodin:** Thanks, Ed. I had the same experience in switching from cane to guide dogs. And I think there were two factors. One, I felt more equipped and I was ready to be in public. I had come to terms a little bit more with my vision loss by the time I trained with my first guide dog. I'm on my third now. And the other factor, it's kind of selfish, it may be silly, but I think it does relate to the sensitivity to the perception of the public of you, which is kind of like where in certain respects shame comes from is that dogs are cool.

I was living in Philadelphia at the time I switched from the cane to the dog. I was commuting by the regional rail. And the difference in the reception that I got every morning when I would step onto the train was drastic between the cane and the dog. With the cane, people just kind of buried their noses a little bit deeper into their newspapers. But with the dog, it was, “Hey, come on over here, this is really cool.” So I don't like to admit that other people's perception of me does matter, but it's a rare person that doesn't.

**Marc Arneson:** This is a rare person indeed. And just so you know, I actually never thought dogs were cool until I got a dog. Now they are super cool. Jeff or Ed, whoever wants to kind of chime in on this as we're talking about these moments that can possibly lead to shame, I've often heard folks talk about the idea of having to ask for help can be really difficult, especially when you're kind of new to vision loss and trying to figure all this stuff out. I've heard people even share that sometimes they feel like they're a burden. I'm wondering, have you ever experienced something like this or has asking for help ever led to feelings of shame for you?

**Ed McDaniel:** As you said, in the beginning it was more difficult for me to ask for help because it wasn't something I did a lot. So it was a new thing for me to ask for help. And that took some getting used to, how I felt about myself and how I was concerned about how others felt about me if I was to ask for help. Even before my vision loss, I was not someone who really liked to ask for help. Even now, I will do everything I can for myself. And the main thing that I ask for help for nowadays is rides to go places. But I think I’m still reluctant to ask for help, particularly from people who I don't know, it's a lot easier for family and friends who I know and trust and they know me and what my abilities are.

**Jeff Flodin:** Yeah, and I think that's a really good question, a really good topic because I think that over the 36 years or so that I've lived with RP, I've struggled at different times to accept the level of dependence to which I am able to submit myself. There's a pejorative word right there, submit myself. And just to go back a bit in terms of what Ed had said, we are in a culture that values self-reliance and independence and pull yourself up by your bootstraps and just snap out of it, and all the phrases that go by that. So, it was a leap to ask for help. And although this may not be fair or totally accurate, I think in this culture, especially with men, that big boys don't cry and so on, it makes it rather difficult. And so I think it may be beyond culture, it may be deeper into our makeup.

But yeah, asking for help depends on how you interpret it, putting yourself in a one down position. One thing that I learned recently is there's a term called mitzvah, M-I-T-Z-V-A-H, I believe. And it's defined as when you grant the opportunity to another person to be helpful without feeling inferior or dependent. And that kind of put a new slant on things for me in terms of asking for things. It's like giving somebody else the opportunity.

**Marc Arneson:** That's a really cool way to put it, Jeff, giving somebody else the opportunity. But I think you're right. I agree with you. I think that there are these cultural norms that we're meant to live up to, and that can be challenging sometimes. I also think our society is really kind of built for those without disabilities. I think maybe what perhaps you're talking about a little bit is this idea of being viewed as different in our society that can lead to these negative self-views or even oftentimes feelings ashamed. Do you think that this has changed over time as a society and maybe even for you personally in your own life? Has this changed over time? Ed, I don't know if you want to go ahead and share first.

**Ed McDaniel:** Sure. I do think to some extent society's views have changed. I think in my lifetime, I think there's probably more awareness, and I think some of that comes through media and maybe things that we see on TV and movies where people maybe have a little more of an awareness about vision loss. But on the other hand, I think you can only get a limited view from that. I think it's really from repeated exposure to someone with vision loss or other disability over time where your views really change. So I think that there have been improvements, but I think there's more that we can all learn about differences.

**Marc Arneson:** I agree. Yeah. Jeff, how about you? Has this changed over time and maybe even for you personally, have you seen it change in your own life?

**Jeff Flodin:** Well, I mentioned earlier that I enjoyed photography during my sighted era, and there was a real iconic black and white photograph of a woman who's probably in a seated position propped up against a brick wall. She has obvious visual deficits in terms of cataracts or whatever. She's rather shabbily dressed, and she has a sign around her neck from a string that says blind. And this was long before I had a diagnosis and any vision loss. I was struck by what an iconic photograph that was and how much that said. And I think, yes, we live in a sighted society and there's no way to get around it.

So, I mean, it's so ingrained. I had a teenager once who had just been diagnosed with RP come and say, “I think I can put up with the eyesight thing, but right now, is it going to make me look different?” There was so much invested in him with maintaining his identity within the sighted community. And I mean, it's obvious that different perceptions or different reactions hit at different times. A teenager is mostly worried about whether they're going to fit in and whether they have the right clothes. And as Ed said, he could cover his hearing aids with the length of his hair and stuff like that. So it really takes a lot of constant vigilance and bringing attention to people that it's not a negative.

**Ricky Enger:** I imagine that having this knowledge that most people either consciously or unconsciously view any change, any disability, anything as this is a tragedy. And that gets internalized if you grow up with that. And if you haven't experienced vision loss before and suddenly you do, there's still all of these things that you've absorbed over time just because it's ingrained to think of difference as perhaps tragic or you're suffering from it or whatever.

I imagine that brings about all sorts of feelings of shame, and I just appreciate that both of you have been willing to talk about times in your lives when you've felt that. Things that made you look at yourself and feel like I'd rather hide this for a bit, and then suddenly I'm ready to make this public. So I guess as we wrap up, having talked about ways that we feel shame in situations that bring that about, are there some things that have helped each of you to get past that and not have those feelings anymore, to just come to accept whatever this thing is that made you feel shame initially? Ed let's start with you.

**Ed McDaniel:** Okay. I would say that the emotions that we have, while we would like to think that we have control over them, we really have very limited control over our emotions. But what we can control a lot of the time is our behaviors and even act with those emotions. For example, with shame and any other negative emotion, our tendency is to want to avoid that feeling and get rid of it. But maybe a better approach is to notice that feeling that we're having, acknowledge it and sit with it for a while.

Really, a lot of times what we want to do is avoid that feeling and get away from it. But a lot of times, even though that might provide immediate relief, when we ignore our pain, oftentimes it will last longer. So if we can kind of sit with our discomfort for a while, and sometimes I would even say I probably wallowed in some of my emotions as I was dealing with vision loss for a while, but that allowed me to experience those emotions without pushing them away. And that helped me to move forward.

And some of the ways that you can do that is by opening up and talking about how you feel, and if that's difficult, maybe writing about how you feel about what's going on, and just recognizing that even with those feelings, you can move into the direction that you want to. For example, with the cane, I was feeling shameful about having to start using a cane, but I knew that I wanted to maintain my independence, and that was important to me. So I moved in that direction, even though in the beginning particularly, I still felt that shame.

The other thing I would say is when you're doing this, take small steps, have compassion for yourself because it's not going to be a straight line from point A to point B. That is going to take time. This is something I've dealt with for many, many years and continue to deal with to some extent, and really focusing on what I can do today here and now, and not worrying about the way things used to be or worrying about what might happen in the future.

**Jeff Flodin:** Thank you, Ed. I really endorse and appreciate all the different facets that you covered. I only have to add that shame is internalized, and there are some internal processes that can be helpful in terms of working on acceptance and unconditional positive regard for yourself. Give yourself a break. You're doing the best you can, and it's like shame fosters and flourishes in darkness. It's important to keep up with your skills because that way when you do reach the point where you have to go out in public or go under the scrutiny of people, you feel more competent, you feel better about yourself. And the other thing that's been helpful for me is to find people who are going through the same thing and can understand and empathize. And I think the biggest thing for me was to realize that maybe the best way that I can cope with my vision loss is to try through whatever means to help others who are going through the same process.

**Ricky Enger:** Thank you. Very well said, both of you. And again, I just want to say how much I appreciate your willingness to come and talk about this stuff because it is a moment of vulnerability that can be hard to be comfortable with. It's easy to talk about things that make you happy. It's probably less so to talk about things that make you feel discomfort in whatever shape that takes. So again, thank you for agreeing to come and join us and talk about that. Any final thoughts before we wrap up?

**Marc Arneson:** Well, Ricky, I just want to say thanks again to Ed and Jeff, you guys, I really appreciate the time. I think it's a really important conversation and just appreciate a start to a really important conversation today. Thank you.

**Jeff Flodin:** Well, and I want to thank you too, and Ed and Hadley for giving us the opportunity to bring this out in the open a bit.

**Ed McDaniel:** I would just say I have enjoyed discussing this and appreciate the opportunity.

**Ricky Enger:** Thank you all so much and thank you for listening. 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.

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