Hadley

Coping with Vision Loss Triggers

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 coping with triggers. Our guests are Hadley's director of community, Marc Arneson, and psychologist, Ed McDaniels. Welcome to the show, both of you.

**Ed McDaniels:** Thank you.

**Marc Arneson:** Thanks, Ricky.

**Ricky Enger:** So happy to have you both. And in fact, we were in a virtual room together not so long ago. We did an episode along with Jeff Flodin and we talked about vision loss and shame. So, if you haven't listened to that one, it is well worth checking out. But today, we're going to talk about something that comes up just about as often as that previous subject. We're going to be talking about triggers with vision loss and what are they? How do you navigate your way through them? What are some strategies to deal with them in a healthy way? And so, really excited to talk about all of that. Before we do that, let's just get a few quick words from both of you and introduce yourselves. So, we'll start with you, Marc.

**Marc Arneson:** Sure. Thanks, Ricky. My name's Marc Arneson. As Director of Community, one of the things I do here is I get to just meet interesting and fascinating people and hear their stories. And then, I also get to visit different conferences, and groups, and share all about what we're doing here at Hadley.

**Ricky Enger:** Very cool. I love it. If I didn't have my job, I would want yours.

**Marc Arneson:** Can't have it.

**Ricky Enger:** Well, that's all right. I'm happy with technology. So, we're both doing what we love. And Ed, how about you? Tell us a bit about yourself and what you do.

**Ed McDaniels:** I was a psychologist for the state of North Carolina for 30 years before I retired. Since then, I've been doing a variety of things. But, more recently, I have focused on some volunteer experiences with people with vision loss. I have recently started a vision loss support group in my area.

**Ricky Enger:** Wow, that's fantastic. It sounds like for a variety of reasons, you are the perfect person to come and share with us about triggers. I know that you, both as a professional and as a person with vision loss yourself certainly have some experience with this. So, why don't we then jump right into talking about these triggers? What they are? How can we deal with them? And just getting some of those strategies. So, Marc, I know you've got great questions. Let's get into it.

**Marc Arneson:** Great. Yeah, I'm really excited for this. Ed, thank you, again, for joining us. This is going to be a great conversation. I was thinking we just start right at the beginning and maybe Ed can help us better understand, what is a trigger?

**Ed McDaniels:** Well, with vision loss, of course there's stress, and sometimes pain, and even trauma associated with vision loss, particularly if you have had better sight earlier in your life and you're experiencing a change. That painful event, even though maybe you're getting to a better place, something along the way may come up that will lead to those feelings that you've had early on to re-emerge. Sometimes, to others, it may appear that what we're experiencing may be an overreaction to the event. But really, maybe they're not seeing that we have an underlying pain that we're experiencing as well.

**Marc Arneson:** That makes a lot of sense. So yeah, in relation to vision loss, are there common triggers for folks with vision loss? And I don't know, maybe even you personally, do you see common triggers in your own life?

**Ed McDaniels:** Yes. I’ve met a lot of people with vision loss, and I hear some common things that people will say that trigger them. Sometimes it's when other people around them don't understand what they're experiencing. Sometimes it may be something as simple as frustration with technology, trying to access things that are difficult to access due to vision loss if you're in a crowded place. For me, one of the common things that I've had over the years, and I think I've gotten better at dealing with it, but of course it still happens as a person was vision loss. I have retinitis pigmentosa, so I still have some central vision. But I do from time-to-time trip on things, or bump into things, or hit my head on things. So that's something that is a reminder to me about my vision loss and some of those feelings I had when I was first diagnosed with RP re-emerge. And I think more about them. And have those feelings to re-emerge.

**Marc Arneson:** Thanks for sharing that, Ed. I appreciate, even from a personal perspective, some of the things that can set off a trigger. One of the things I've heard from different folks, I don't know if you can speak to this or if this is your experience, but I've heard how sometimes it can be frustrating when you feel like you finally figured that thing out that's been so difficult for you. You've got it down now. And then, for whatever reason, when you try to do it the next time, it's just difficult. Is that something that you've experienced? Or have you heard that from other folks as well?

**Ed McDaniels:** Yeah, and I think the feeling associated with that is maybe disappointment, where you thought that you had figured things out or gotten past something, and then when it does happen, you have that sense of disappointment, because you thought you had it handled and you didn't. So, yeah, it's very frustrating when that happens.

**Marc Arneson:** Yeah, makes sense. The other thing, I don't know if you can speak to this too, is I understand that sometimes events related to vision loss can be a trigger for some folks. Are you able to talk a little bit more about that?

**Ed McDaniels:** Yeah. As I was saying earlier, some of the types of events that happened are just environmental things. I can give maybe another example of one that happened to me recently. The town where I live, they don't have audio description with our cable service. I followed up with their customer service, excited that I might be able to have some impact on that and see if that might be a service that they could provide since it's not currently being provided.

After several calls, and nothing happening, I noticed when I was calling, one time I was feeling more impatient, more agitated, and trying to advocate for myself and the need for services. That was an event that I hadn't really experienced much. But the customer service person didn't really seem to understand how important that was to me. After the phone call, I recognized those feelings I was having. So, the next time I called, I was better prepared to deal with that, because it's important to me, even if I'm feeling agitated or upset, I want to make sure that some of the things that are important to me, like being kind and calm around people, that I can still do those things. So, when you're triggered by an event, you want to make sure that you are still doing what's important to you in a way that you're able to interact with other people in a productive way.

**Marc Arneson:** I imagine that's not always easy to do, interact with people in the way that you want to.

**Ed McDaniels:** No, it's not. No.

**Marc Arneson:** And, you have these feelings. That actually leads me to my next question, Ed. I've heard you mention a couple of different feelings that can come with being triggered. You mentioned disappointment, agitation, or frustration. I wondered are there other common feelings you would imagine people are experiencing. And then, how do you stay true to yourself in those moments, being kind and respectful in the things that you want to be with people?

**Ed McDaniels:** Yeah, I think some of the common feelings are your sadness, anger, disappointment, sometimes shame, a whole variety of things. And, to prepare yourself, everyone needs to make sure that they know what's important to them in their lives, the things that you value. For myself, I have a list of things that are important to me, and I use that as a compass for my life. Things I'm trying to move towards. For example, fitness is one of the things that's important to me. For example, if I have a trigger related to my vision loss, if I'm out walking or running and I bump into something, I might have a feeling, "Well, this is not worth it." But I remind myself, fitness is important to me, and I need to figure out a way to address that trigger. And there are a number of things I've done over the years to make sure that I can continue to be fit, even when I'm faced with obstacles or triggers related to that.

A simple example, something that happened to me because of my narrow vision field, as I mentioned earlier, is hitting my head on things, or bumping into things. So, over the years, I've done some things to help with that. Mobility training. One of the simple things I do with the regular routes that I use, a lot of times there's branches, and branches are more difficult for people with vision loss, because if you're using a cane, you're only sensing what's on the sidewalk, even with a guide dog. For the most part, my guide dog does move me around branches. But I had a recent situation, where there was someone on the sidewalk approaching at the same time where there was a branch.

My guide dog was trying to help me navigate the branch and the person. I did hit the branch. So, one of the things I do, particularly in the springtime, with my regular rounds, is I take some clippers with me and if there are branches hanging over the sidewalk, I will go along and clip them. So that's something that I can do. That's a practical thing. There's a lot of things that we can do to address triggers in a practical way, and that's something that has helped me to not get triggered.

**Marc Arneson:** Yeah, that's good advice. Now that you mentioned it, I wish fitness was more important to me in my life too. So maybe that's something I need to figure out. Okay. So, we know triggers are out there, they're not pleasant always, I imagine. And there's things that you've given some practical advice on that we can manage those. But, what about preventing them? Is that possible?

**Ed McDaniels:** Yeah, I think so. As I mentioned, there's some practical things that you can do. If you think about triggers, it is an emotional reaction and it's real important to take care of yourself. If you're not eating well, or sleeping well, or staying active, you're more likely to be triggered by things. I know when I'm tired, I'm more likely to respond to something in an emotional way, than if I'm feeling well rested. So, definitely taking care of yourself is, I think, the number one thing. And then, as I mentioned before, recognizing what's important to you and making sure you are going in that direction, rather than letting an emotional trigger lead you in another direction.

**Marc Arneson:** That makes sense. For me, I think, it's hunger.

**Ed McDaniels:** Yeah.

**Marc Arneson:** I have to be careful with decisions I'm making and things that I'm doing when I'm hungry.

**Ed McDaniels:** Or it can be a combination where you're tired and hungry at the same time.

**Marc Arneson:** That's not a good combination for me. So, there are things that you can do, you can feed yourself and take care of yourself and all those things. But what if it's somebody else that's causing that trigger? Something that somebody else is doing that you don't have a lot of control over. What can you do in moments like that, Ed?

**Ed McDaniels:** Well, as you said, the first thing is to recognize that you don't have a lot of control over what other people do, that's important. Although, you may have some influence. And I think, depending on what the situation is and who the person is, you have to make that choice as to whether that's something you want to address with that person. If it's somebody that you don't really know and you're not around them much, it’s probably best just to let it go. But if it's someone that you live with, or you work with, then I think it's important to open up and talk to that person.

The thing you have to be careful about is sometimes when you have talked to someone about it and it happens again, that trigger might even be more pronounced the next time. So, you have to be patient, because unless someone is experiencing vision loss, it is hard for them to really understand what you're going through. Sometimes people just forget. So, I think just being patient and just recognizing sometimes it's easier to change your own behavior than other people's behaviors. But it depends on the situation, I think it's worth a try.

**Marc Arneson:** I imagine it comes up quite a bit with social media these days. People post what they want and that can oftentimes be a trigger for some folks.

**Ed McDaniels:** Yeah. And I think that one of the reasons you see that on social media is because if they're in a group of other people who, for example, have retinitis pigmentosa, those people understand. So, sometimes it’s helpful to vent to people who understand and get what you're going through. And also, support groups, I think that's another place to give you an opportunity to express what you're experiencing with people who understand.

**Ricky Enger:** Is there ever a point where you've done what you can and you have tried to change your behavior, or you've tried to back away from people or situations who might be triggering you, and it's still happening. You're still really struggling with this and you're just encountering these things over, and over, and over that are putting you in an unhealthy place. How do you know when it's time to look outside yourself and your own support network and get some professional help? What things can a professional do to help you address those triggers in a healthy way when you just can't manage it yourself?

**Ed McDaniels:** I would just again remind everyone that experiencing triggers is something that happens to everyone. It's a normal thing to happen. And it happens because we're trying to figure out ways to address the situation. So, our mind is trying to help us come up with a solution. But, as you were saying, it's something that is continuing and you're really feeling like you're stuck, that you're continuing to have these painful thoughts and feelings, that is a grieving process. And that can take time. For some people that takes longer than others and I really would encourage anyone who is experiencing vision loss and struggling to seek help. After I was first diagnosed, I went to see a counselor, and that was very helpful to me to have someone that you can open up to that's objective, someone that can help you process things.

As I was talking about before, they could help you identify what your values are and what's important to you. It's helpful to have a professional to talk you through all of those things, so that you can hopefully over time respond better. And as I said, it's a process. I know for myself, I got help early on, and that was great, particularly with the progressive vision loss for me. It's been progressing for more than 30 years. Things happen and your life changes. So, even though maybe you felt like you dealt with it a long time ago, things may happen in your life that you might feel like you need help again. And that's okay. It's helpful to recognize that things aren't always going to be the way you want them to be. When you're really struggling, it is okay to ask for help.

**Ricky Enger:** Yeah. That's a really good point. It can be hard for people to ask for help, right? Because like you said in the beginning of the episode, a trigger might be something where the people in your life watching you become upset about this thing. They think you're overreacting. And sometimes you can internalize that too. Like, "Well, I'm overreacting to these things and therefore I really don't need help. I just need to get over myself." But there is a point where it helps to just get those strategies and have someone talk you through it, right?

**Ed McDaniels:** Yeah. Definitely. And I think we just have to do our best to have some self-compassion and realize that sometimes we are hard on ourselves and think we should just get over it. But that's not something that we would tell a good friend just to get over it. So, I think we have to be kind to ourselves as well. And it's okay to ask for help and recognize that you need help. And, not just with people with vision loss, but anyone who is struggling, there is sometimes stigma associated with seeing a mental health professional. And that's unfortunate, because I think sometimes people aren't accessing the help that could help them really get through some difficult times.

**Ricky Enger:** Absolutely. Well, this has been really informative and so helpful. I think people just want those practical strategies for how to deal with things. And then, there's that very basic approach of being kind and compassionate with yourself that can go a long way. Ed and Marc, I want to thank you both for spending a little time with us and chatting about this.

**Marc Arneson:** This is great. Thanks Ricky, I really enjoyed this.

**Ed McDaniels:** I did too. Thank you.

**Ricky Enger:** Me as well. And thank you, Ed, for sharing some personal things along with the professional. And, again, always great to have you both stop by. Thank you.

**Marc Arneson:** Thanks, Ricky. Thanks, Ed.

**Ed McDaniels:** 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@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.