Hadley

How Community Insights Connect and Inspire

Presented by Ricky Enger

**Ricky Enger:** When you are the only person you know with vision loss, it's easy to feel like you're going through it alone. In this episode, Hadley's Marc Arneson joins us as we talk about our sister podcast, Insights and Sound Bites, where people share what has helped them to cope and adjust. I'm Ricky Enger, and this is Hadley Presents. Welcome to the show, Marc.

**Marc Arneson:** Thanks, Ricky. So good to be back.

**Ricky Enger:** Yes. It has been a while, and in fact, you've had a title change since the last time you were here and so have I for that matter.

**Marc Arneson:** That's right.

**Ricky Enger:** You are now, what's your title?

**Marc Arneson:** My title is Director of Emotional and Social Support here at Hadley. Some of the new things that we're doing to try and help with some of the emotional challenges that come with vision loss, I'm getting involved in some of that.

**Ricky Enger:** Yes. Awesome. I am the Director of Practical Help. The reason I bring this up is, we will be hearing a few stories today that encapsulate both those things. And I don't know why I find that surprising, because when you're going through an adjustment like this, or maybe your vision loss has always been at the level it is now, but you're living in a world that isn't necessarily designed for you, there's both of those challenges. The practical help, what do I do? How do I figure out how to find my way around or cook or clean? And then, of course, there's your side, Marc. What are the things that people tend to deal with from the social emotional side?

**Marc Arneson:** Some of the things that I often hear from folks who are reaching out to us is, sometimes they're the only person they know that is dealing with vision loss. There can be a lot of isolation with that and some loneliness. As the vision continues to decline, relationships change. Both dynamics within perhaps a marriage or parent-child relationships or even friendships. And so, oftentimes, we're trying to help folks find a space where they can talk about that and explore some of that stuff.

**Ricky Enger:** I think one thing that really helps people is to know you are not alone. It's not just you who's going through whatever this is. While every person's story is different, there do seem to be just some common threads, I feel like, that come up over and over again. That's one of the reasons that we have created the sister podcast, Insights and Sound Bites. It's where people call us or send us recordings through our website, and we'll talk about how to do that at the end of this, but people who are willing to share their stories. I think it's been tremendous just hearing from people.

**Marc Arneson:** It's interesting, Ricky, in preparation for this and just been thinking ahead about this time today. I spent some time listening to some of the different episodes, and you're right, there are just some common themes that we hear from folks, but they're just so powerful, these personal stories of challenges that some of our members are facing, but then how they've overcome. But I know that it is really cool to hear the ways that folks are managing some of these difficult situations and coming out with more hope.

**Ricky Enger:** Absolutely. In this episode, we're just going to play a few of these, and we'll comment on them. We'll keep it short, because it's really about sharing these stories more than what we have to say about them. They're all so, so good. I think the ones we've chosen are just some of the top things that we hear from people, and one of those things is, "Hey, this was such a surprise to me, it came out of nowhere." And then, "How do I deal with that?" To represent that, up first, we're going to hear from Emma.

**Emma D:** My name is Emma D. I am 77 years old. I live in Illinois. My blindness occurred four years ago. It took me totally surprised. I went to the doctor like in November, found out, I went blind in March. I had no time for preparation, and that's what bothered me the most. I had to get past psychologically because I didn't have time to prepare myself. I'm an avid reader. I was a teacher, and I love to travel. Travel was my thing. Seeing things, writing down things, sending memos out to people, sending cards out to people, that was my love, and it kept me going for years. All of a sudden, I went blind. I had been around maybe just a couple of blind people in my life. I didn't know this drug that they had. I didn't know the challenges they had. But then, when it hit me smack in the face, it was totally different.

It was something that it was hard for me to accept. I never really said, "Why me?" But I did say, "Why?" Right now, I'm going to be honest with you, I want to see right now. I miss the sun. I haven't seen the sun in four years. I miss my reading. I couldn't even write my own name. It's hard enough being blind and you feel insecure, and your self-esteem has plummeted.

Blindness is not only blindness. Blindness is psychologically, it's physically, it's mentally, it's spiritually, it's anything you want to say, because when you are blind, you have to start all over. The frustrating times that I run into is when I turn around sometimes and I get lost. You can get lost in your own home. And then, I have to feel something to bring my sight back, and I just sometimes have to just stop and scream. And then, I settle down and I pray and I touch something and I remember, "This is where I am. Emma, this is where you are. Settle down. This is where you are. This is something you're going through. This isn't the end of the road for you. You're going through it. So just deal with it with as much grace as you can." And that's how I make it on a day-to-day basis, knowing this, as far as I'm concerned, and that's how I make it.

I feel like I am alone a lot of times. Even though there's people sitting next to me, I don't know whether there's a chair here, a stool here or whatever. This vast darkness is just here, and you do feel like you're alone. Even though a lot of times you are in a room of people, you feel like you're alone. Then, sometimes you have people. I have a good peer group, and I got people all around me like all my ladies. We can laugh together. We come pray together. They give me their experiences and it feels like I am not alone. People have been my foundation. When I didn't even know they were here for me, they were here. Just a telephone call helps you through the day. Just a kind word helps you through the day. Just knowing someone thinking about you helps you through the day. That's how I deal with my blindness.

**Ricky Enger:** Wow. She really said a lot, right? Just that no holds barred, "It's bad sometimes." And yet, I do feel like there was that hope, right?

**Marc Arneson:** Just listening to Emma, I'm like, "Gosh! It's so powerful." I actually was on the phone with her when we recorded this, and I just remember just sitting there just being amazed at her story. She's such a good storyteller and the way that she just shares her life, she's so open and vulnerable. I remember just sitting at her feet as she shared her story, and it was just so cool to hear.

**Ricky Enger:** Absolutely. I love how she takes us through the darkest parts of it, but also, the joy that she has and who is helping her and how, so very powerful.

So next up, we are going to hear from Albert. He found his own bit of salvation and something that helps him cope.

**Albert Papazoni:** My name is Albert Papazoni. I live in Houston, Texas, and I am 63 years old. When I got into my early 50s, I started noticing my vision decreasing very rapidly. What I found is that I had a genetic issue that skipped a generation. Today, I would say, I have maybe 10% vision depending on the lighting and then the stress level, of course. You wouldn't believe it, but that does have a huge impact. I can't read hard copy paper any longer. Probably, the biggest one is I have to plan my day a little more than the average person.

In the past, I jumped in the car, run to the store, and got a quart of milk. I can't do that as easily. I went to the Humane Society; I ended up getting two cats. They want to lay in my lap. The minute I come in the door, they follow me to my chair. Animals are so smart, but I sit in my chair and they both want to pop up there and sit in my lap, and that's very comforting. I found a lot of comfort in my cats, and maybe they know I saved them. Maybe there's a little bit of that too, I don't know, but they certainly helped me.

**Ricky Enger:** That just makes me smile. Any stories about animals make me smile. We recently lost our cat, unfortunately, but she definitely knew, and he's so right, animals are smart. They can figure out, "Oh, you can't see me, so maybe I shouldn't be under your feet quite as much."

**Marc Arneson:** You're so right, Ricky. I was just smiling, listening to Albert that whole time talking about his comfort cats. It's just so nice.

**Ricky Enger:** Yes, absolutely. If you're listening and you're thinking, "I'm not sure if I can care for my pets. Are there different things that I need to think about?" It's important to know there are ways to do that. In fact, Hadley has a couple of workshops on those things to keep in mind, like measuring the medication and different things that you might need to know to care for your pets effectively. It's certainly possible, and so very rewarding, right?

**Marc Arneson:** Yeah, yeah.

**Ricky Enger:** Next up, we are going to hear from Jayne.

**Jayne Surrena:** My name is Jayne Surrena, and I'm from Philadelphia. I went to school for painting and got my master’s in art education. I have been painting and showing my art since I was 20 and working nonprofits and teaching. I have retinal dystrophy. I didn't realize I had an issue until, I guess, the beginning of the pandemic. I honestly thought everyone saw the same way I did my entire life. I went to a different eye doctor. They're like, "There's nothing we can do. That's just normal. It usually happens when you're older. We can't do anything about it." I felt so in the dark about everything and just very isolated. I would go online and just try to look up the terms that they were using, because I still feel, I guess, very vulnerable about it. With vision loss, so often I spend so much of my day trying to force myself to see things I can't see, like trying to focus on something that's blurry or not there anymore.

I get anxiety and I stress out about it, and I just shut down, because it's never going to come back. It's never going to come into focus. But the one positive of everything is with my artwork. The fact that I can't see every imperfection and mistake in my artwork anymore, I have so much more freedom. Instead of spending hours trying to make everything meticulous, I am going through pages and using colors for the first time and creating images that are just actually from inside of me and from emotion instead of trying to remember technical skills that I was taught in school years ago. I am enjoying myself for the first time. I feel like myself smiling as I work and I step back, I'm like, "Yes!" It's there because I'm not focused on any details. It's just the overall piece that is, I just feel like it's a part of me now.

**Ricky Enger:** It's a part of me now. That was actually the title of the episode, and I think that sums it up so well. Just going from, "Wait, what is this,” to figuring out a way to incorporate that in her life. Her story actually reminds me of another artist with vision loss, Chloe Duplessis, who was on Hadley Presents, and she said something very similar, where she's talking about instead of saying, "I have to give up my art," she finds a new way to do it, and her art is actually better and different.

**Marc Arneson:** I appreciated her, just her honesty. I think she talked about how she is forcing herself to see the things that she can't, and I was thinking that I'd probably be doing the same kind of thing. Having the anxiety and to find that outlet in her art. I think she said she's creating from emotion instead of technical skills now and smiling as she worked. That's so cool.

**Ricky Enger:** I love it. Next up, we're going to hear from Bruce. Bruce is sharing something that, it's one of the top things that I think about that people who reach a certain point face this struggle and everyone overcomes it in a slightly different way. Let's hear Bruce's story.

**Bruce Wyland:** Hello, my name is Bruce Wyland, and I live on Bainbridge Island, which is an island off of downtown Seattle. I have retinitis pigmentosa, and I've watched my vision get narrower and narrower from the outside coming in. I've adjusted to it along the way, giving up various things, sports, driving, etc. But it wasn't until I hit my 60s that my vision deterioration finally reached the center of my vision. My tunnel vision became so narrow that I was literally tripping over things, bumping into dogs and children, open doorways. And as I walked around my hometown, I found myself more and more embarrassed, apologetic to people. People just didn't understand about my problem because I was keeping it a secret.

The one thing I want to recommend to people is, when you're ready, get cane training and embrace the use of a cane. I have to say, I hesitated and resisted for a long, long time until my wife finally convinced me that I had to use the cane when I walked about, both for safety and for maximizing social interactions. When I started using the cane, first of all, I stopped tripping over things and running into things. Second of all, it was a way to gently announce to people that I had a visual problem. Suddenly, people who were confused or angry were helpful. Rather than feeling embarrassed, as I was afraid I might, I felt like I had suddenly been given a ticket to travel around without embarrassment, without mishaps, both safer and happier.

The final thing I will say is, I was a little afraid of the cane as a negative symbol, and I was worried that people might ridicule me or be less than supportive. I will tell you, in the two years I've been using the cane, I have not had a single negative interaction with another person. People are kind, understanding, they are welcoming, and it's been a real plus for me. That's my suggestion. When the time is right, embrace the cane. Thanks for listening. Bye-bye.

**Ricky Enger:** That's so awesome. He quickly encapsulated this whole journey. Does this come up a lot, Marc, in people that you talk with?

**Marc Arneson:**

Oh, yes, absolutely, Ricky. You can imagine, and I love what he says, "When the time is right, embrace the cane." I think what you shared earlier, it's a different journey for everybody, right?

**Ricky Enger:** Exactly.

**Marc Arneson:** And I imagine it's different for everybody. It's sometimes not an easy decision to come to when it's the right time to explore using the cane, but I love, "A ticket to travel around without embarrassment." What a cool quote.

**Ricky Enger:** Yes, that was the best. Just that moment of going, "I thought it was going to be really negative, and it turns out that people were actually nice about it."

**Marc Arneson:** There's another episode, you probably remember it. Angela, where she talks about her little secret.

**Ricky Enger:** Yeah. Angela Delgado, yes.

**Marc Arneson:** Yeah. It reminded me quite a bit of Bruce's story as well. I think she had a similar experience. I think she thought she would get different reactions from her family and from others, and it was a real positive experience for her too.

**Ricky Enger:** Yeah. That's amazing. I just love sharing these different stories and that's exactly what Insights and Sound Bites is, just these little clips of people figuring out what it was that finally helped them to turn a corner. We have one last clip here, and I feel like it encapsulates one thing that we've been saying all along, and in fact, it is the title of the episode. We're going to hear from Ashia.

**Ashia James:** I'm Ashia James, Georgia. I was diagnosed with a rare neurological disorder called benign essential blepharospasm, and it's where I have uncontrollable eye spasms, and I have eye closures. I don't know how long they'll close. Sometimes they close for a few seconds, a few minutes, or hours at a time, like maybe about 10 hours at a time. I found out about this, I think it was in September 2022, I started panicking, because I saw that there was no cure for this, and I was hoping and praying that this was not true. I was afraid to go outside. Even walking around my house would be a challenge because you think you really know your house until you lose your vision completely. You struggle to figure out where you are.

I came across American Print House and I reached out to them. She recommended Hadley, and really Hadley changed my life, because I got to hear sound bites of people dealing with issues just like me. Even though our conditions are different, we seem to be going through the same thing with dealing with it, dealing with grief, the stages of grief and acceptance and finding our way out of it.

What gets me through the difficult moments is knowing that there's a community out there that is experiencing similar things. The first feeling for me was feeling that I'm in it by myself. There's no one around to help me. They don't know what I'm going through. But with Hadley, that community, we all share similar experiences. Even though they may not be exactly the same, we're similar. That gives me hope, faith and confidence. It's said so many times, and I hate it to be a cliché, but it's true. Finding out that you're not alone makes the biggest difference in the world.

**Marc Arneson:** As I was listening to this, I'm just so grateful that she found us here at Hadley, and then, she's getting connected with others who understand her story and her challenges.

**Ricky Enger:** Absolutely, because it is so powerful going through something by yourself, you think, this is all on me, I have to figure it out by myself, my friends don't understand, my family.

**Marc Arneson:** She said, "I feel like I'm in it by myself."

**Ricky Enger:** Yeah, and then, to find a group of people that are going through the same thing you are.

**Ricky Enger:** And that actually brings up the question then, if people are listening and Insights and Sound Bites is new to you, Hadley's peer-to-peer program is new to you, this is the first time you're hearing about this sort of stuff, we'll have this information in our show notes. But Marc, I'm wondering if you could just give us a quick rundown for, number one, how does it work? How do you submit a sound bite? Do you have to get it perfect the first time around? Take us through that.

**Marc Arneson:** Yeah. Ricky, there's lots of ways that you can share your story with others through our Insights and Sound Bites. One of the easiest ways is to call our 800 number at 1-800-323-4238, and the folks at our support center can get your story and get it out there for folks to listen to. You can also record directly from our website. There's a record button right on our site that you can select and just start recording, and that'll be saved, and we'll have that available, and we can get it that way. You can also call. There's an Insights and Sound Bites podcast voicemail line, and that number is (847) 512-4867. If you call that number, you can just leave a message on our voicemail, and we can get your story that way too.

**Ricky Enger:** Awesome. I know you all make it so friendly; it's not a nerve-wracking process. If you have a story and you're not quite sure how to tell it, Marc and his team are really good at teasing that out of you and getting you to open up a bit and share what you need to in the way that you want, as opposed to when I leave a voicemail, I'm kind of stuttering and wishing I could do it all over again. If that's a concern, don't worry about that.

And if you’re wondering how to listen to Insights & Sound Bites, you can of course, find it on our website. But it’s also available on places like Apple Podcasts and Spotify. Really wherever you’re getting Hadley Presents, you’re also going to find Insights & Sound Bites as well. We do have a phone number if you would like to listen by phone, if that’s just a bit easier. That’s 847-558-1317. So there are lots of ways to listen.

**Marc Arneson:** Honestly, Ricky, it's one of my favorite parts of my job, is hearing people's stories. Sometimes I'll spend half an hour, 45 minutes on the phone with somebody and just to be able to talk and we'll pull out some of our little clips from our conversations. I really enjoy being able just to sit and chat with people and hear their stories.

**Ricky Enger:** That's great. How about for that one-on-one connection? How do people get involved with the peer-to-peer program?

**Marc Arneson:** Yeah, it's a program. It's so encouraging to hear about some of the connections that folks are making with one another and the support that they’re able to offer each other. If you ever feel like you would benefit from connecting with somebody else who is going through something similar, we're happy to see if we can figure that out with you. Again, the easiest thing to do is just call our 800 number. Again, it's 1-800-323-4238. The folks at our support center, they'll want to get to know you a little bit, and so they'll just ask you a few questions, maybe about your eye condition, maybe hobbies, interests, things like that, and then, we'll do our best to try and connect you with somebody who has some similarities, and then, we'll introduce you to one another.

**Ricky Enger:** Awesome. Well, thanks, Marc. It's been a lot of fun just listening to a few stories together. I always feel, at the end of each one, just how powerful it is. It's like a roller coaster, where it goes down, oh, it's going back up.

**Marc Arneson:** Yes, that's exactly right. No, thanks for inviting me, Ricky. I do appreciate it. I really enjoy listening to these as well. It reminds me that there is a lot of hope out there and there are others who understand and are willing to be there to help.

**Ricky Enger:** Thanks so much, Marc, for stopping by, and of course, thank you all for listening. We’re just about done but I couldn’t resist. We put together one last clip of clips, if you will. And it’s just a couple of people expressing how they felt when they discovered Insights & Sound Bites or decided to share their own story.

So, if you’re still on the fence, I think this last set of clips is going to really encourage you to check out the podcast and hopefully share your own story.

**Marilyn B:** One of the things was I was listening to Insights and Sound Bites where the lady, she just turned everything around. And that's what I am doing. I think it's the path. I believe it's a path we go on but it's in a different direction, depending on what you're looking for, for everyone with vision loss, I have reached out and got help and, but I love the Insights and Sound Bites, and I listen to as many of them as I can.

**Charles C**: Hadley has really, really helped me kind of feel like I have a community of some sort where I just listen to everybody's stories, and this is absolutely wonderful. And I want to thank you all from the bottom of my heart for even deciding to do this, because this is something that I thoroughly enjoy.

**Dia K:** This year I have given up so much. Driving the car, sold the car. Gave up my business, my work of 50 years and everything changed. If I could help one person with my story, I’ve achieved a great deal moving on to the next phase of my life with low vision. It just made me happy because I knew that I could help somebody, and if I helped one person through Hadley, I achieved a great deal.

**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.