Hadley

Peer to Peer at Hadley

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 Hadley's peer-to-peer program, and we are joined by Hadley's Director of Community, Marc Arneson, and Hadley learners, Greg Peterson and Bill Massey. Welcome to the show everybody.

**Marc Arneson:** Hey Ricky.

**Bill Massey:** Hey Ricky.

**Greg Peterson:** Hello, Ricky. Hello, Marc.

**Ricky Enger:** Delighted to have a full house here today, and I'm really excited about the topic, too. I say that about every episode, and the good thing is, I mean it. So, before we get into talking about the peer-to-peer program, I want to know just a little bit about each of you so that we can get familiar with who you are, what you sound like, and a bit about you. So, Marc we'll start with you because you just get a sentence or two. You've been here before.

**Marc Arneson:** I have been here before. No, thanks, Ricky. My name is Marc. That is true. So, what I do here at Hadley is really, what I get to do is just meet some amazing, interesting, fascinating people, hear their stories, and share as much as I can about Hadley.

**Ricky Enger:** Perfect. Thank you. Bill, let's hear from you next.

**Bill Massey:** Okay. I'm very pleased to be taking part in this today. My name is Bill Massey. I live in Raleigh, North Carolina. I am a retired public middle school teacher. It was the best job I ever had, actually. I was diagnosed with glaucoma when I was 65-years-old. It took me until I was 75-years-old to reach legal blindness, that's how slow and insidious it is. And now at 80 I only see contrast and dark and shadows and shapes, et cetera, and have what my doctor calls minimal vision, but minimal vision, when that's all you have, is maximum vision in my mind. So that's me and that's where I am.

**Ricky Enger:** Excellent. Thanks so much for sharing. And Greg, that leaves you.

**Greg Peterson:** Oh, thank you, Ricky. I'm really glad to be part of this. It's been a pleasure doing this. Well I'm Greg from right outside of Chicago, Illinois. I was diagnosed when I was young with cone rod dystrophy and never really affected me. I just thought I had bad eyes. As I got older, I'm 60 now, I had cataract surgery done because I noticed my central vision was declining and I thought getting the cataract surgery was going to bring me back at least five years. And unfortunately, as my doctor says, "Well, cataracts are like a geriatric for your eyes. It's as good as it's going to get." So, I was legally blind. I still have central vision and peripheral vision is good, so I'm still able to move around. And, yeah, that's it in a nutshell. And so now I'm just going to the, like I said, next chapter of my life.

**Ricky Enger:** Great. Thank you for sharing your story as well. So I am, again, delighted to be talking about this today. I think one of the most common things that we hear, whether it's in discussion groups or whether it's people talking about Hadley's Insights & Sound Bites, or just as we have the opportunity to chat with people each day by phone and email, the most common thing is, "I wish that I could talk with someone who understands what I'm going through. I wish that I could share this really cool tip that I was struggling with something, and I figured out how to do it. I know others would benefit."

And so just that desire to connect with other people is really, really strong. So, I'm happy that Hadley is developing a program to address that. And so, Marc, I think you're probably the best person to talk about what this is. So, what is the peer-to-peer program?

**Marc Arneson:** Well, Ricky, it's exactly what you just shared. As I mentioned, part of what I get to do here at Hadley is meet people. I get to know them, I hear their stories, and then just like you shared with our discussion groups, our Insights & Sound Bites, so often people would share with me that they really wish they had someone they could talk to who just understood what they were going through. Actually, I was chatting with somebody a couple of weeks ago, she was sharing with me that she has lots of friends that she gets together with often. She has a husband that lives in the same house with her and kids that come and visit every now and then with grandkids that run around the house and things like that.

But she said, even with all of that, she's never felt so alone, which I thought was super powerful. And she said she loves her family, she loves her friends, but they just don't get it. It's hard for them to relate to and understand what she's going through with her vision loss. And she was just super honest, and she just shared that she wished she could have someone to talk to that just understood. And that's one end of the spectrum. I also hear from quite a few folks who don't have a lot of people in their lives and they're trying to manage this new life with vision loss all by themselves. And our hope is, with this program, they don't have to keep doing that.

**Ricky Enger:** Yeah, that makes perfect sense. And I think for a lot of people, they are the only blind or low vision person they know. They're the only person going through this, and so that really contributes to this loneliness.

**Marc Arneson:** No, I was just going to share, Ricky, I think you're right. A lot of people, this may be they don't know anybody that's going through something similar. And I think that as people, as human beings, when we hear someone talk about going through something difficult, like a difficult moment in life, when we hear them talk about what they did or how they handled it, when we just hear their story, I think that can give us hope, too. And that's another piece of this that I think is a huge piece that I didn't want to forget to mention as well.

**Ricky Enger:** Yeah. Again, that makes perfect sense. And so, is that how you came up with the name for this program? So, we're calling it Peer-to-Peer, and I think that really nicely encapsulates what people are looking for in any case. So, is that how this came about and why you decided to call it that as opposed to something that sounds a little more intimidating perhaps? Or...

**Marc Arneson:** No, that's exactly right. When we were trying to figure out a name, what we wanted to do was really capture something that reflected that this is all relational. It's about a relationship. I know Bill and Greg, you guys are going to be able to share what that means for you two, but our hope was we could connect someone who's going through something similar, maybe who has been where you are and understands a little bit about what you're going through. Two people who are trying to figure out what to do with all the emotional and practical challenges that can come with vision loss so they don't have to do it alone so they can do this now together.

And that's the idea of what we came up with peer-to-peer. And the other piece of that too is, is we wanted something that was going to, again, speak to what this relationship was. This is not a relationship where one person is kind of over another person. It's not a professional relationship, it's not therapy, it's not a therapist and a client. It's, again, simply two people, peers, who are in a similar situation trying to help each other out and to be there to listen to each other.

**Ricky Enger:** Well, this sounds amazing and I can't wait to hear a bit more about Bill and Greg and just how all this has happened from beginning to where they are now, which as we were sitting and talking together before the meeting, it just seemed like this wonderful friendship. So, Marc, I know you have some questions. Let's get to it.

**Marc Arneson:** Yeah, thanks Ricky, and again, thanks Bill and Greg for jumping on this episode and doing this with us. But I would actually love to hear how you guys would describe your relationship. Bill, maybe we can start with you and then Greg, you can jump in when you get a chance.

**Bill Massey:** Actually, when I got the call asking if I wanted to be a part of the Peer-to-Peer program, I had never thought of myself as some going blind, being blind guru. I just knew that I had to learn a lot of things on my own over the years that I knew other people like me didn't know at this point in time, but I didn't know how the relationship with Greg was going to go. I didn't even know what we might talk about. But as it turns out, we spent very little time talking about rod and cone disease or glaucoma, because the cause is not important as the consequence is, because that's the same. And so, we spent some time talking about our experiences and going through the denial, then going through the acceptance, and going through the adjustment, that was all essentially a mental process.

And then I call that the road to blindness. And then the road through blindness, you start talking about what you're going to do about it and what resources are available. And I had some things to suggest, and Greg had some things to suggest that I didn't know about. And I mean, pretty quickly we were on par with what we were bringing to the conversation, and it didn't take long before the conversations and the phone calls evolved into just friendship. I mean, we would talk about things that we do when we can't see that are funny, and we would talk about things that we do that are not funny to us, but are funny to everybody else, and just those types of things. And Greg always ends a phone call with a joke. So, anyway, it was always good. I said, "Well, if there's nothing else, I'll get a joke out of this."

**Greg Peterson:** Bill, he has his jokes.

**Bill Massey:** Yeah. And there wasn't one that he could tell now, but anyhow. And so, it has just evolved into... It's not like a formal thing. We went from talking very structurally once a week to very structurally every other week to, "I'll call you when I need to and want to, and you call me when you need to and want to." And so maybe every three weeks or so one of us will call and we'll chat and we'll talk about Greg being up on the ladder in Wisconsin, putting up gutters and stuff like that. And so, it has nothing to do with blindness anymore. And that's great because we can talk to each other knowing what the other situation is without having to explain it to everybody. And so, that's how it is for me right now.

**Marc Arneson:** That's great. Thanks, Bill. So, Greg, how would you describe this relationship that you have with Bill?

**Greg Peterson:** It's one of the best things that I think that's happened since my vision loss where I really had to come to grips with it. When I first contacted Hadley, my mother-in-law told me, says, "Oh, you should contact Hadley." So I did and I had to give up driving and working. I was in the hospitality industry for 25 years and always being around people and customer service, and I didn't know where else to go. You have family that are there, but they don't understand. They try to, and I love them for it, but when I got in contact with Bill, it was immediate. I mean, it was almost the first time you talked, you're like, "Oh, this is going to go really well." He listened to me, I listened to him, and like he said, it's been a tremendous help.

My wife, she says, "Without him," she goes, "I noticed a change in the depression," and that I look forward to our calls and our friendship just grew from there. We were talking about snakes, because there was a snake on the ground and I thought I was picking up something, and next thing I know, here's this big three-foot garden snake slithering along. And he's like, "Well, in North Carolina, let me tell you, what the copperhead..." So, I mean, that's the kind of relationship. He understands what I'm going through, or he tells me, when he used to blow the leaves and he don't know if he's blowing a leaf or a dollar bill, so he sort of cut that out.

**Marc Arneson:** No, it sounds like you guys have just developed this wonderful friendship as Ricky had mentioned. It's just obvious. I'm curious though, Bill, I think you talked a little bit about this, but do you mind sharing more specifically what helped you decide to be part of this program? And was there something that you were hoping to get from it?

**Bill Massey:** I just wanted it to have a relationship with someone that would understand not only the destination but the journey, and where we are now in this process without having to talk about it incessantly. And so, I wanted someone that was a friend that had a visual impairment. I have friends they don't have a visual impairment, and they want to give me advice that they really don't have a foundation for. They want to help me do things I can do on my own. And so that's the kind of relationship I wanted. Just somebody that you could talk to, and you could make casual reference to our visual impairedness without having to make it the sole topic of conversation every time. And anytime I'm around people who don't understand this, they either don't know what to say to me and say nothing, or this is all they want to talk about.

And so, I would like for us to, and Greg and I do this, reference this and the problems, but the opportunities too, that it presents us with. But I don't want it to be the only thing we talk about. But I have found that that just comes very natural, that you just don't feel the need to do that. There is innate sense of understanding, and I've gotten everything I expected to get out of this, and I frankly don't know what I would do at this point. And I've been at it for a long time, and I'm surprised at the difference just having the relationship like this makes to me.

**Marc Arneson:** Got you. How about you, Greg? Was there something, expectations that you had going into this?

**Greg Peterson:** I was just looking for somebody to talk to that understands the same that I'm going through. It's like I listened to the Insights & Sound Bites to navigate through the vision loss because it's devastating. People can't say, "Well, you can't imagine." We used to be able to, you walk outside and you can't see the crosswalk. Somebody to talk to. He's not my therapist, by no means, but it was therapy for me because I like talking to people and being around people, and it was a stepping stone for me to go onto the journey. And then now it's blossomed into something that is really good for me. I get a lot out of it and it's fulfilling. It's like, "Hey, I accomplished something today. I got to talk to somebody, and it makes me feel better."

**Marc Arneson:** That's awesome. So, it sounds like for both of you guys, you were going into this looking for someone to connect with that understood what you were going through. I'm curious, Bill, is there anything that you've gotten out of this relationship that you didn't expect you would? Were there things that you, I guess, didn't consider or expect that you would receive from this relationship that ended up happening?

**Bill Massey:** Well, I think the most unexpected thing to me and the most pleasing thing to me was that it became informal and relational very quickly. I was afraid to get into something that would be more similar to counseling, and I'm not qualified for that. And so that was the most surprising and pleasing thing to me was, we got away from the formality and the structure and all very quickly, which allowed us to be much more effective talking to each other than trying to provide counseling.

**Marc Arneson:** Gotcha. No, I think that's an important piece too, because you don't want to be put in a position where you don't feel like you're able to do that, able to provide that help that somebody might need in that particular way. So, I think both of you guys have a couple of different relationships, your people that you're connected with in this program. Greg, a similar question. Are there things that you are getting out of the relationship that you didn't expect? Maybe it's this one or maybe another one that you have as well.

**Greg Peterson:** Just talking to Bill you know just what kind of person he is. He's an author. A lot of people don't know that. He wrote a book, and soon as I'm able, it comes on audio, I'm going to listen to it. But, yeah, it's just a friendship, and the other person that I speak with, it's the same way. It's like you call and it's a friendship that you have. Thank god for technology that we can stay connected and talk, and it's very fulfilling for me. I don't know what else really to say about it. It just makes me feel better.

**Ricky Enger:** And you actually made a really good point, Greg, about technology is such a wonderful thing because it means that people can be connected with each other even though geographically it would be difficult to see each other as often as you can pick up the phone or jump on Zoom or whatever. And so, it means that if your perfect friendship is across the country or in a different country across the world from you, you can still have that connection.

So, Marc, we know that people are going to want to be a part of this because the description of how well it came together and what Bill and Greg both get out of it sounds amazing. So, can you talk about how these connections get made? How do people say, "Okay, I want to be involved." And then once somebody does do that, what are those next steps to helping them to find somebody they're going to connect with?

**Marc Arneson:** Yeah, it's actually pretty simple, Ricky. We just would ask that you give us a call at our 800 number. You'll reach the folks at our help desk and you can just mention that you're calling about our Peer-to-Peer program. They'll want to get to know you a little bit, so they'll have some questions that they'll ask and talk to you about. And it's really, the whole purpose of getting to know you is to try and connect you with someone who hopefully has some things in common with you. That's the idea of getting to know each other. From there, we'll send you an email and there's a couple of links. We have this online introduction to the program. There's a video that we put together.

It talks a little bit about what the Peer-to-Peer program is, what it is and what you can expect and things like that. The other link that we'll send to you is a waiver form that we ask you agree to before being connected with someone. And if you're not online, it's totally fine. We can just walk you through the content that's on that video and walk you through the waiver as well so you can agree to it just over the phone. But that's basically it. Once we get the waiver form, we'll do our best to connect you with someone as quick as we can, but it really just all starts with just giving us a call and we'll walk you through everything from there.

**Ricky Enger:** Well, this is wonderful. Thank you. I know that the phones, I'm imagining that the sound of... You remember the telethons and you would hear the phones ringing in the background. I'm just imagining that happening as people are playing the episode, suddenly the help desk phone is ringing, ringing, ringing.

**Greg Peterson:** Well, it's a good help desk.

**Ricky Enger:** Oh, for sure. Yes.

**Greg Peterson:** It really is. And they get back to you, right? You just leave a message.

**Marc Arneson:** No, and again, I so appreciate Bill and Greg, you guys just sharing about this relationship and how it's formed and what it's become, and it's just really encouraging to hear that. Our hope is that many other folks can, like you said, Ricky, can benefit from something like you guys have.

**Ricky Enger:** Yeah. It's clear just from listening to the two of you that this really has gone from something that may have started out that formal relationship, but just very quickly became a very valued connection for both of you. Are there any final things that any of you would say to someone who's thinking about becoming a part of this program? I know that for some people reaching out and making that connection can feel difficult because if you are at a point where you're feeling like, "I don't know if I have anything to provide for another person," I think everyone has something to give. So, again, what would any of you say to somebody who's thinking about this but might be a little hesitant to reach out?

**Bill Massey:** Well, I would say that if you have any inclination at all about being a part of this program, that you please follow through with it. And not everything you have to say to your peer needs to be profound. It doesn't need to be earth-shattering information, because frankly a lot of times one of the most welcome responses you get from someone is, "Oh, me, too."

**Ricky Enger:** Yeah, that's beautifully said. It's so true.

**Greg Peterson:** Yeah. If you're thinking about it, just do it. It doesn't hurt. It's just a phone call and nobody's judgmental. We're all going through the same thing, vision loss. It's devastating, but it's not life-threatening, so we can get through it. If you're thinking about it, just make the call.

**Ricky Enger:** Fantastic. Wow. This has really been a wonderful episode just to get to know both of you, and again, see how your friendship has blossomed and just to hear in your own words how much this has meant. So, thank you everyone for stopping by and for sharing. And again, if you're listening, pick up the phone and call. Get involved.

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