Hadley Presents

Peer Support for 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 discuss the importance of peer support for those with blindness or low vision. And joining us are guests Tracy Simon, peer-to-peer support partner for the Eye2Eye Program, interviewed by Hadley’s Director of Community, Marc Arneson. Welcome to the show, both of you.

Tracy Simon: Thank you. Thank you.

Marc Arneson: Thanks, Ricky.

Ricky Enger: Marc, it's great to have you back on the show. And Tracy, good to have you as a first-time guest. And I always like to, just before we jump into the day's topic, get people to tell us a little about who they are and what they do. So we'll start with you, Marc.

Marc Arneson: My name is Marc and I am the Director of Community at Hadley.. What I've been doing here at Hadley is just getting to know as many people as possible and really listening as much as possible and understanding what are some of the challenges out there with those who have a visual impairment and what are ways that Hadley can help? And then bring it back to Hadley, see what we can do and then bring it back and see how we did. And then once we have something that we think is helpful, just go tell as many people as possible about it.

Ricky Enger: Awesome. And such an important job that is. And Tracy, how about a little about you?

Tracy Simon: My name is Tracy and I actually am a peer support partner for the Eye2Eye program, which is based out of New Jersey. We are a peer-support program which is phone-based and we speak with individuals that are blind and vision impaired and we just help them to get to a mental wellness and help them with coping with everyday issues that they have in life and build a relationship with them so that they can become independent and confident in their lives and dealing with their issues.

Ricky Enger: And that's such an important thing, right? Part of being blind or low vision is doing the practical things, but that's only a part of it. You know, a bigger part is being able to go through what it is that you're going through and feel a sense of confidence on the other side, and be able to face some challenges that maybe you weren't expecting and just to get some help, whether it's in how you feel about what's happening to you, and even some of that practical help as well. So I think peer support is such an important thing. And we're going to talk about that today. With that, I want to turn this over to Marc. I know you've got some great questions. And let's just kick this off and talk about the importance of peer support and kind of how it works.

Marc Arneson: Tracy, thank you so much, again, for joining us today. You had mentioned that you have a visual impairment yourself. Can you share with me a little bit about your eye condition?

Tracy Simon: I have Stargardt's disease. And for those of you that aren't aware, Stargardt's is a disease that you usually get when you're a child and it impacts your vision in a multitude of ways. For me, I actually did not get Stargardt's when I was a child. I actually got it maybe eight years ago as an adult. And for me, the vision loss, it was gradual. It started off with loss of pigment colorization, floaters, blurriness, dark patches behind the retina, so that I would not be able to see items in front of me, a lack of light in my environment. And to this day now, it has progressed to the point where my central vision is extremely poor, and my peripheral vision gets me around just enough so that I don't need to use a cane every day. So for my vision now, I'm not able to read my mail or letters without ultra-magnification devices. And I don't recognize faces unless you are in front of me and I know you.

Marc Arneson: Tracy, can you share with me, do you have children? Are you married?

Tracy Simon: I am divorced and I have three adult children.

Marc Arneson: So how did that ... Did it have any impact on your relationship with your children and your family life?

Tracy Simon: You know what, Marc? It certainly did. And for me, I actually lost my vision and my marriage at the same time, the same year. And so that was a pretty hard hit for me. It was a struggle because I was scared. I was alone. I had to start life pretty much anew in all different dimensions, as far as being a single mom now, having to raise kids. My children at that time were middle school age, I guess, and high school age. And then I had to become the head of the household and then learn how to navigate and get around life with this vision loss. I eventually ended up having to give my license, my driving license, away because I could not drive anymore because I couldn't even see the traffic light to drive. It was not safe for me to drive around the car with myself or kids, or even for pedestrians and other drivers. So I had to give that independence up. So it was a really challenging time for me. I felt that I needed to be strong for my kids. I felt that I needed to set the example and the bar for them. You know, when life gets tough, then you get tougher. You learn to keep going and that was a heavy weight for me.

And I carried that weight for several years. I tell you now, eight years later, I've learned to put the bar down just a little bit lower, because it kind of boomerangs on me because my kids just thought that there was not really a lot different about me until it was time to go to the supermarket and I'm asking them, what's this and what does it say? And how much does it cost? Because I truly couldn't see and they didn't understand. It's like, well, you can do everything else, how come you can't see that? But my kids have been supportive. We're managing this vision loss very well now.

Ricky Enger: It's interesting that you bring up kind of how your kids responded to this, where it's a little bit confusing because you're obviously the same mom that they've had forever and yet suddenly things have changed. And especially when there isn't a complete immediate change, so you've gone from seeing everything to suddenly seeing nothing, that's a little easier to explain and understand than something that's happening gradually and possibly even something that you could do six months before is a struggle for you now. So it's interesting how that impacts family dynamics.

Tracy Simon: And like you said, it was really very true, Ricky, is that your kids see you as mom. They don't see you as this person that walks around with a cane or needs to have so many lights on in one room to be able to stay and still use the magnifier sitting at the kitchen table with the CCTV to read the mail. And my kids were pretty compassionate, I would say, about it. I'm sure they had questions about it, but they didn't really ask too much unless I asked them. And it's really important that you have that conversation with your family because they don't understand, because they have vision. They don't understand when you have partial vision and the magnitude of what that vision can be different. And it varies from day to day.

It was important for me and it helped my anxiety levels so that I would express to them, "I know that it looks like there's nothing wrong with me, but what I need for you to understand is that I need your help in certain areas." I'm a pretty independent person. And I like things done a certain way. So my kids just take the safe way and they just stay out of my way. You know, they're just like, "You know what? I'll be there if she needs me." And that was the way we functioned and operated, but I wouldn't advise it everyone do it the way I do it. You have to find what works for your family. But as long as you're communicating to them what your specific needs are and where you need the help, is a conversation that needs to be had.

Marc Arneson: So I'm curious. Can you tell me about maybe some of the relationships that you have with others who have a visual impairment?

Tracy Simon: I absolutely love my new community. They are the most optimistic and resilient people that I have ever met. I have two actually of my coworkers in the program that are amazing. One is Aretha and she has RP. She is so strong and I look up to her because she's withstood her vision impairments since she was a teenager. And so she's had to jump through a whole bunch of hurdles and she's gone to college and she's a licensed counselor. So she has gone to school and she's gone through all that studying. And for me, I'm just like, "Oh my gosh, I can barely read my mail." You know? So she's been a really role model for me.

Then we have another one, his name is James, and he is totally blind, and he lost his vision through a car accident and he had to raise his children being blind. And I admire him because he again is strong and has raised his kids and has done dynamic things within the blind community and for his own community as well. So I really look up to those two major people in my life because they helped me to grow up. Because I'm the baby of the group. I've only been in this for eight years. So I'm still learning.

Ricky Enger: And it is helpful, right? To see people who are in a place that you want to be, or they've done things that you admire and maybe you aspire to. It fills a need in us just to look up to somebody and have something to strive for. It isn't one-sided, I think. I think that you have probably talked with people and you've been the person that they look up to. You're on the other side of some things and perhaps they're just starting out. Can you talk about that if that's happened? Like how does it feel when you're giving someone some insight that they may not have had before, just based on your own experiences?

Tracy Simon: I absolutely am so humbled to have this experience to use my own life as a help for others. I have people that I speak with that have just become blind or vision impaired, and they have no idea what to do, where to turn to. They feel like life is over. There's no meaning and purpose. And just to have those conversations with them, to let them know, "I know exactly how you feel. I've been there. And if I could just share with you that there is a way out of it. It's not always going to be easy, but together we can get through it." And I've been able to speak to so many people that they absolutely admire me and the work that I've done for them.

And I say this so humbly, so appreciatively. Because I'm just having a conversation with them and sharing with them my experiences and what has worked for me. In my listening to them and what they're going through, I can only offer suggestions through what they're saying to me. But the most gratifying experience that I have, Ricky, is when they call me back and say, "Tracy, guess what? I did what you said, and oh my gosh, I can't believe I did that. It was wonderful." Like I have one friend, she was very scared to walk by herself and I encouraged her and gave him some tips. And one day she went out and it made her feel so good. She went shopping by herself. And that's something that we take for granted when we have vision that you can just jump in the car and go shopping. But she did this one little test by herself and it's just brightened her world. And those are the stories that really warm my heart and let me know that I'm doing a good thing.

Marc Arneson: Over and over again, I do hear the importance of connecting with others who just understand what you're going through and how important that is, that relatability. And I love that you want to use your life to help others. And it sounds like what you're doing with this program, Eye2Eye. Do you mind sharing a little bit about the program that you're working at?

Tracy Simon: Eye2Eye is a phone-based program and what we do is we offer peer support for people that are vision impaired and blind. And we too, as peer partners, are also vision impaired and blind. We're a small team at this time. However, we do plan to grow. But what we do at the Eye2Eye program is we offer support to people to help them to be able to function in everyday life with their vision impairment. And so we may also offer support in ways of resources, if we're giving suggestions for home care or even self-care, mental wellness, physical, emotional, spiritual, financial, environmental. Because it all counts. Because everything works together. Because if you don't feel good, then you're probably not going to really want to have the enthusiasm to do other things.

So what we do at the Eye2Eye program is we help people get to a place where we can cope with our situations by using the resources for people and social environments or helping with the family so that the family can be a part of our journey, and devices in regards to technology that we can use to help us to be able to function and to be independent, because that is one of the goals that we want our callers to become, to have a sense of good self so that ... And that's really important. While help is really important, and sometimes it's difficult asking for help, and I would encourage people to ask for help. And that's what we do at the peer program is we teach you ways to communicate so that you can get help and also give help.

Ricky Enger: How do people connect with you? So is it like internet-based or phone-based? Or how does all that work?

Tracy Simon: Yes, we are a phone-based program, so people will call into us and we communicate in that way. And then also we call out as well. So it's not just we're sitting, waiting for the phone to ring. The people that we are connected with, we'll call on them and we check on them. And what we do is we call at least maybe once a week. Depending on whatever the schedule of the individual is, we call them, and we set small goals. We offer advice. So sometimes we just sit, and we listen because sometimes that's all you really need. You just need someone to sit and listen to what you're going through because when you're in a family of all sighted people, and you're the only one with no vision or little vision, you sometimes feel like you're left out.

Eye2Eye is just a call away, you know? And I cannot tell you how many times I call my individuals, my clients. And every time I speak to them, they're like, "Oh my gosh, hi, I'm so glad you called." Oh my gosh, what an awesome feeling that is for me. And that just motivates me to just give them all that I have. They've got my attention. "Hey, I understand what going through, because that's where I am." And we share our stories, in the beginning you cry about, but then together we laugh about certain situations about, like, who moved my scissors, you know? And it's so important, who put the spatula in the pots and pan drawer? Or it's like, where is ... And it drives you crazy because at that moment you're anxious. But when you talk to someone that has had that same experience.

Ricky Enger: Oh, absolutely. Yes. Especially the scissors thing, because my family steals kitchen scissors all the time and I have one set for upstairs and one set for downstairs and somehow they still disappear.

Tracy Simon: Yeah. So that's what we do. You know, we offer support across the board.

Ricky Enger: We will, of course, have the number for the Eye2Eye support group in our show notes so that you can pick up the phone and call wherever you happen to be, and call for support, or even perhaps to get an idea of how you might do something similar in your own area, because peer support is so important. I'm wondering if each of you have just some final thoughts to leave our listeners with as we wrap up the program. Marc, let's start with you.

Marc Arneson: Oh, Tracy. I just want to thank you for joining us today and just being open with your life and sharing with us the last eight years and what you've kind of experienced. And it's inspiring to me that you're using those experiences to really help others who are going through some difficult times right now, perhaps, or dealing with something new in their lives. I think this Eye2Eye program that you are a part of is such a needed program today. Connection is such an important piece for people. You guys are providing that for those who desperately need it in a time where it's hard to do right now. So thank you for joining us. I really appreciate it.

Ricky Enger: Absolutely. And Tracy, any final thoughts from you?

Tracy Simon: First, I just want to thank you, Ricky, thank you, Marc, for having me on. I would like to speak to our listeners. Guys, listen. I know that it's tough, but don't give up. Never give up. Because the moment that you give up is the moment that it stops, and we just can't stop because someone needs you. We are all important. We all play a role in life. And whether big or small, it's still a role. So if you need help, get the help. And don't be ashamed because guess what? You're not alone. And here at Eye2Eye, we're here to help. We're here to help you and to let you know that you matter.

Ricky Enger: Thank you so much for that. Marc and Tracy, I appreciate your joining us for such an important and such an inspiring discussion today. And thank you all 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. Send us an email at podcast@hadley.edu. That's podcast@hadley.edu. Or leave us a message at (847) 784-2870. Thanks for listening.