#

Hadley Presents

The Impact of Vision Loss on Marriage, Revisited

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, Hadley's Director of Community, Marc Arneson talks with couple Karen and Danny Leonetti about the impact of vision loss on a marriage. Welcome to the show, everyone.

Karen Leonetti: Thank you.

Dan Leonetti: Thank you.

Marc Arneson: Great to be here, Ricky.

Ricky Enger: Yes, so glad to have everybody. It's a room full of cheerful people, which is my favorite thing ever. Marc, you are no stranger to this show. We've talked before about how a couple might deal with changes and especially those that are brought about by vision loss. But we had one example of that, but every couple is different, every person is different, every vision loss journey is different. So, I think the more people that we can get to talk about that the better, just to get all of those perspectives, so really looking forward to this. Before we jump into these really great questions that Marc, you have for Karen and Danny, let's just get a quick intro from everybody, so, Marc, we'll get just a brief sentence or two from you.

Marc Arneson: Ricky, is just to mention my title is Director of Community here at Hadley and what I do is I get to know people. I hear lots of fascinating and interesting stories, and I try to bring that back to Hadley and see if there's a way that we can do something to help.

Ricky Enger: So, Danny. Why don't we start with you and get just a quick little intro from you?

Dan Leonetti: My name's Dan Leonetti and Karen and I have been married 38 years. We live in Black Mountain, North Carolina, in the Western North Carolina mountains. Thrilled to be here, and the friendliness of everybody, and the four seasons of the change in weather, it's just awesome being here.

Ricky Enger: Yeah. North Carolina's a great place to be. I'm not in the mountains, but beautiful, beautiful place up in the mountains, so welcome to North Carolina. I've been here for little over 20 years myself. So, Karen. How about you? Let's just get a quick intro from you as well.

Karen Leonetti: So, I'm a almost-to-be 30-year cancer survivor, thriver of Non-Hodgkin lymphoma, six-inch tumor on my heart from pesticide poisoning we think. So, through living with my wonderful husband, he has helped me to survive and to live this dream, so that's what we're so excited to speak to everybody about. We're just really glad to be here, to share the good news about survivorship, and how we deal with vision loss, and all the things that go with it.

Ricky Enger: Love it. I'm so looking forward to learning your story. With that in mind, I'm going to turn this over to Marc. Marc, you have some awesome questions to ask and love to hear what you guys have to say. So, let's do it.

Marc Arneson: Yeah. Thanks, Ricky. I do. I'm super excited about this. And Karen and Danny, again, just thanks for being willing to do this. So, Karen, maybe we can start with you. I was wondering, as you think about your vision loss and this adjustment and journey that you've been through the last how many years, are there things that you have done or maybe that you do, or maybe there's things that you've said to help Danny understand how he might be able to help you with some of these things?

Karen Leonetti: My situation is a little bit different maybe on what everybody's situation is, but I believe that my vision loss was really slow. I had 15 weeks of chemotherapy in Sarasota, and then a bone marrow transplant in Moffitt Cancer Center, and then 15 days of radiation in Sarasota when I went back home. And one of the big, big things that Danny had to sign off for me as my caregiver was all kinds of side effects: hearing loss, tingling, fingers tingling of the toes, neuropathy, and vision loss. And we were willing to sign off on all that. So, all that to say that things happened quickly and slowly at the same time.

Danny was able to see when I was frustrated when I was... And at that point we noticed, but we didn't know that my vision was declining. He'd noticed when I dropped something, I'd be feeling all around the floor. I believe when we moved to the mountains, as Danny stated is when we started seeing signs that things were different with my vision because I was in the same home for a while, so this wasn't a new space.

So, Danny would tell me, “Oh, it's over there, honey.” And I'd say, “But please don't say over there, can you say,” and Danny will tell you a little bit about some different things he helped me with, but directions, directionally say, oh, it's on... We have two different color countertops, we have a wood countertop, but we have a granite marble top countertop on the other part. He'd say, “It's on the granite countertop, not on...” He tries to give me real directional things, your question of how he... It's just, we learned together little by little. And like I said, it just seemed to morph slowly, but seemed overwhelming at times.

Marc Arneson: I can imagine it felt overwhelming at times. And it does seem like you guys came together as a team and just you figured some stuff out. Danny, do you recall moments that helped you understand what Karen's experience was and what she was going through?

Dan Leonetti: Yeah. It's hard to explain to people vision loss. When people think about vision loss, they think blindness totally. There are large spectrums of vision loss. Karen's been to many doctors, getting her eyes tested. The interesting thing that we have a doctor here in Asheville, North Carolina, and the name of the business is called Tunnel Vision. And we went there to get her eye exam, many different doctors, of course, eye exams. But we went to this guy, he really doesn't advertise himself as a high specialist in low vision. He is an ophthalmologist, so he brought out... The most frustrating part for me is, what does Karen see every day?

He goes back in his office; he comes out with a little card the size of a credit card that has little circles cut out of it. And he says, I want you to look through this third circle and cover your other eye. He said, this is what your wife sees. Because you don't have this credit card... I want you to do this tonight, you too, you take a paper towel roller, empty paper towel rller, hold it up to your eye, blows the other eye, that's what Karen sees. That brought me to the realization. This is what my wife sees, straight on circle of somebody's head. If she's looking at your head, she sees just your head.

She doesn't see to the left, to the right, upper left, upper right, lower left, lower right, down below her feet, nothing. It was devastating to have to figure out how I'm going to help her. Being married 38 years, and walking down that aisle, and before she was ever sick, and whatever it took, I take care of her. And then of course this all led into the most beautiful thing in the world, and she'll tell you, about her leader dog for the blind. And she'll tell you all about that and how that's changed. I can't imagine how it's changed her life, how it's changed my life.

Marc Arneson: So, Karen, I imagine, as you know, 38 years of marriage, you start to fall into certain roles, right? You do things around the house that are your duties around the house or your chores around the house. And even within your relationship, I imagine you established certain roles. Can you guys talk a little bit about how maybe that's changed since your vision loss?

Karen Leonetti: Danny and I have always had an equal role exchange, I believe. It wasn't like one person was the boss, or one person was the kitchen person, and one person was the lawn person. Since my vision, I can't see spots or things like that on laundry, so Danny does that 100%. And we go grocery shopping together and he has to... God bless him, he's so patient, and he has to go and get the things that he knows he needs. And then he'll come back to me.

And I'm still in the aisle with Shanti trying to read a label because they make the label so difficult for low vision people. It'll be orange print on a purple background, which has a plastic wrapper that is reflecting glare from the light. It makes me feel frustrated because I feel he shouldn't have to spend so much time reading things to me, but he does it without complaint, he does it with joy in his heart. And that's just the amazing part, that's his personality. I'm very blessed that he has that personality.

We have vacation rentals. We clean together. And he has his things that he cleans, and I do the kitchen and bathroom. He comes and checks my work because I feel things literally with my hands so much that I am a very good cleaner because of that. And so, Danny, he checks the shower and the toilets for me. And then he checks the fridge and the sink. And we're good to go. He just checks my work. He doesn't ever make me feel like I'm not doing a good job. I mean, even if he saw a little bit of toothpaste knowing he'd probably just wipe it up and say, “Awesome, honey, what a great job.”

We both like to be outside, so he might be cleaning his wheels on his car. And I might be in the garden because the garden I have found is really my happy place. I don't like to be disturbed while I'm in there, that's my little zone, and it's the only thing I can do totally 100% by myself. He's very cautious. If he's helping with unloading the dishes, he makes sure that the glasses are on a lower shelf instead of something that could fall down if I hit it or something. So, he helps me with so much and never makes me feel like I'm not participating or helping.

Marc Arneson: Well, that's interesting. So, Danny, I'd like to hear your perspective on that as well, but Karen, I think you had said something about sometimes you need to ask for Danny's help and it can be a little frustrating, I think, if I heard you correctly. I'm curious, we have a workshop that we put together on ways that you can ask for help when you need it and then turn down help when you don't. Have you learned some of those things as you have journeyed through this together with Danny?

Karen Leonetti: Definitely. Through the... There's the mini centers and there's all kinds of... The vision, the low vision support group. Well, in one of my classes we did in the low vision centers through the state of North Carolina, I learned about advocacy and I'm a pretty good self-advocate. One time we were going into a restaurant out of town and there were over to the right, the hostess had us come through and over to the right there was a whole lower restaurant area, dining area that was empty. And she turned to the left and proceeded to take me when I still just had my cane and not my guide dog. She proceeded to take me up the step to the upper dining area.

And I stopped and I said, “Excuse me, I would like to stay down here. I have a cane and I have low vision. It would be safe for me to stay down here.” So, she said, “Oh, okay, I didn't realize.” But I think it was a teachable moment for her. Oh, I need to, as a young person in the hostess field, be cognitive of my patrons' needs because I definitely had a special need. And that was right after I had a full class on advocacy, self-advocacy. So, I have no problem asking for help. It's nice to be able to feel that way, that I can just ask for it when I need it.

Marc Arneson: Yeah. Have you and Danny been able to navigate some of those moments where you've been able to, when you feel you need it, you ask for the help, but then there's been times perhaps when you wanted to advocate for yourself.

Karen Leonetti: Well, it's so interesting because just as we were preparing for the podcast today, I was moving downstairs and Danny was on the other line coordinating with me, telling me where the outlet was. You know, “Oh, honey, plug into this outlet, it's by the stairs in the corner.” So, he's always gently guiding me. And I just I love that. That a husband can gently guide a wife without making her feel insufficient. Just a guide, a loving, helpful husband. It's very beneficial to me.

Marc Arneson: I love that, gentle guidance. Danny, I am curious. Through Karen's vision loss and with some of the different roles within your relationship or within the household changing, how has that been for you?

Dan Leonetti: Karen does very, very, very well on our property. Moving and navigating around without the dog, without a cane. We've been here 10 years. She knows where the structures are, the housing structures, her garden. She does very, very well. She buys seeds from a certain company that has the seed packets are black background and white lettering. It's the only seed company that has these. And she has learned, she loves that brand, she buys them, she reads it herself, and she doesn't ask me.

Inside the house, the remote control. These are things I've learned since 2008, is when I pick up that remote, and when I change the channel, and if I leave the room, I put the remote right back on the center console of the love seat. She goes right to the love seat; she knows where it is. Even though she has five degrees of vision, like a paper towel roller, she can look all over the house, it may take her 30 minutes to find it. But I've learned that when you put things back, when you have a low vision life, she'll find what she's looking for. It's amazing how your body adapts to her needs. And I'm always there if she needs me. Since her beautiful leader dog Shanti has entered the picture, my life has changed.

Marc Arneson: I am curious. So, there's often talk about, with vision loss, there's this adjustment process that a lot of folks go through. And I'm curious, when I hear you guys talk about things that you've figured out, do you ever get the sense, okay, we've arrived, okay, we've got this down, we've figured this whole thing out? Or do you feel it's still a little bit of an ongoing process?

Dan Leonetti: There's always a learning process. We're getting it down every day, better and better, but there's always a learning curve or a better way to do it. Karen lives for right now; she's living right now for this particular hour. I live a little bit ahead of her and I am trying to make things better all the time, watching what's in the future that could happen, that may never... She always tells me, “Don't worry about it, it may never happen.” But I'm one of those ones that's always prepared to be safe, and she is very positive and lives in the right now.

Marc Arneson: Karen, I think you were going to mention something about that as well. This idea of we figured this whole thing out or do you feel it's still a learning process as Danny had mentioned?

Karen Leonetti: Until we really realized that I had a low vision issue, I mean, the first year here, nine years ago, I didn't even share it with anybody. For the first time, I shared with a teacher friend of mine, that she was working and works at a preschool, of my vision loss. Danny was waiting outside. He had to move the car because I didn't have a disabled tag or anything like that at that point. He had to move the car, when I went back in, came out of the store, he wasn't where I had left him, or he had left me. So, I was looking, I put my foot halfway out in the road, looking for him.

And this teacher friend who we had just left five minutes before screamed in this teacher voice, “Karen, stop!” And this person was about to back into me. Didn't even see it, didn't even see it. It's interesting because you just, at that point is when it started and because I was truthful, this is what's going on, okay. Now I need to do something about it. And that journey began. The part where it feels like we arrived is when we received Shanti.

At first it was, she's an aid for me. She's considered a medical piece of equipment. She's allowed in every public place, on every airplane, or transit. But the piece that we didn't prepare for was the therapy that she gives us. When I get angry, which happens quite often, it's always, and Danny understands this, it's “Honey, I'm angry because I'm triggered.” And he's, “I know, honey, I know.” And it's something like I can't see this darned recipe on the back of the pancake mix. Why can't they put it in black and white? And I get angry, but Danny knows my trigger. But when she arrived, it just seems like so much stress was removed.

Prior to all of this, with me having the privilege of owning her, when she became part of our life, I had completed my white cane training because I had to have orientation and mobility training in the state of North Carolina. I had to prove that I could take care of her, and I could travel by myself. All that helped us to arrive that, okay, Karen has a problem. Really to answer the question of when did we feel we arrived? I think it's when Shanti arrived into our life. I do believe that.

Marc Arneson: It sounds like you have so many strengths in your relationship and in your marriage. I'm just curious, through this journey, through vision loss, do you think it's strengthened your relationship in any way?

Dan Leonetti: I do. And that's because, before Shanti got here, first of all, I would get very, very angry that she has to go through this. I never forget her telling her mom and dad that she wanted to have some more freedom. Danny's always there for me and I hate to ask him every five minutes to take me here, take me there, do this, do that. And she says, I'm applying for a guide dog. I just can't tell you…I mean, there are times, after times, after times we have a simple little thing like there's three driveways. Sometimes I park our car over here. Three different places I'll park the car. All she does is she puts on the harness, and she says, Shanti, find the car. Shanti finds the car. Shanti goes to the right rear passenger door. That's where her kennel is. And I'm sitting in the driver's seat waiting this whole time. I used to take her by her hand and I used to walk with her. And she would just trust me wherever I go. Now, she's trusting her dog.

Marc Arneson: I am curious. Is there any advice that you would give to other couples who are facing a similar situation?

Karen Leonetti: Being gentle with each other. The advice would be to be gentle with each other, and understanding, and not to take anything personally, and to communicate. Danny, if I blow up because I can't find my darn black bold 20/20 marker, I just need to breathe, calm down, ask for help. Say, “Danny, have you seen my marker?” And he may say, “There it is, that's on the floor, underneath the chair, next to the window.” So, he's really good at giving me directions.

Over the past, probably three to four years, I've been writing down things that we thought of doing to help. And my plans are to create an eBook soon with pictures of maybe a white coffee mug with coffee in it and a dark coffee mug with coffee in it. And which one can a low vision person see better? It's a white coffee mug with dark coffee. So, that's our plan, it's just finish that eBook to be helpful to spouses, or parents, or siblings, things like that.

But it's just being gentle with each other, being understanding that it's not something personal, but just slowing down. I think God gives us everything we need. And if we need to just slow down, and be closer, and see each other, quote, unquote, better, deeper level and communicating. It's just having time to communicate, explain things, and be there for each other.

Marc Arneson: I think that's great advice, Karen. And I think that's great advice for any couple, regardless of what they might be managing and dealing with. And in the last 38 years, they figured out a lot of really cool things and have an amazing, amazing relationship.

Dan Leonetti: If I had advice to give anybody, find a place to have, be happy, and just laugh about... Because it is what it is and it isn't going to change. So, figure out ways to make it better and figure out ways to deal with it. And this is why Leader Dogs for the Blind come into the picture like this. Get a dog, it will make your life... Whether you're a single or whether you're married, it will make your life change forever.

Marc Arneson: Yeah. It sounds like Shanti was an amazing blessing for you, guys.

Ricky Enger: And we didn't even hear from her on the microphone today. Sometimes dogs love to be on podcasts. I know my cat does, any chance she gets she wants to just jump up and meow. For the two of you as well, love the humor, I know I can tell both of you are just smiling as you tell your stories. Sounds like you've really figured things out, support each other in the best ways possible, so I'm so glad. Thank you for stopping by and sharing your story.

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.