##

Hadley Presents

When a Parent Loses Vision: A Conversation With Adult Children

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 impact of vision loss on a family when a parent has been diagnosed. And joining us, are siblings, Jack, Cathie, and Paula, along with Hadley's Chief Program Officer, Ed Haines. Welcome to the show everyone.

Jack: Thanks, Ricky.

Cathie: Thank you.

Ricky Enger: Wow, so glad to have everyone here. It is a full house, which is fantastic. We've been looking forward to discussing this topic for quite some time, and we figured the more the merrier. Before we get into Ed's fantastic questions, and just getting to learn a bit more about the family dynamics, and how vision loss impacts those things, why don't we get a quick intro from each of you? Let's start with you, Jack.

Jack: This is Jack Merriman and I am one of five siblings. I'm on the call with you today with my older sister, Paula, and younger sister, Cathie.

Ricky Enger: Excellent, thank you. And Paula, how about a bit from you?

Paula: My name is Paula Loret de Mola, and I am the oldest of the five siblings. And I live approximately 45 minutes from my parents.

Ricky Enger: Great, thank you. And finally, last but not least, Cathie.

Cathie: I'm Cathie Rigazio. I live in Minnesota, so I don't get the experience with my parents, like my siblings do. But I was just visiting them for two weeks, so I did see quite a bit those last two weeks.

Ricky Enger: I imagine so, and I'm sure there's a lot with phone calls back and forth, as well. Thank you so much for joining us and we're glad to have all of you here. Before we jump in again to Ed's list of questions, I just had one. I know that vision loss comes in all shapes and sizes and can happen to people of any age. There are parents of toddlers and school age kids who lose their vision, middle aged parents with kids in college, and parents who are seniors. Can we just get a description of what the particulars are with your mom? When she was diagnosed and what the diagnosis is, and just a bit of that background. Paula, we'll let you take that one.

Paula: My mom was first diagnosed in 1979. She was 48 years old. She had been doing a needle work project that was becoming more and more difficult. She went to the eye doctor and her eye pressure was extremely high, I believe it was 50. She had surgery on that eye, and subsequently was diagnosed with glaucoma. She progressively lost vision in that eye along with eye color. She still had vision in one eye. But then after that, we found out that the initial glaucoma diagnosis was incorrect, that it was more high pressure. Regardless, she still was blind in one eye. She did fairly well, until not too long ago, when she was diagnosed with macular degeneration. She was diagnosed first with the dry eye, which she was delighted with, because that was "the good" macular degeneration, and hers did progressively get worse.

When she was undergoing the macular, I realized we needed some help, and there was not much help out there. You went to the ophthalmologist visit, they gave you the medical piece, but there was no, "Well, what can we do? What kind of support can we put in place? We need a bag of tricks." So, I became connected to the Spectrios Low Vision Center, and they actually were very good. We went for the first time in 2014. At that time, we became aware of specific assists, which have been very helpful. I think that the macular piece now is going a little bit faster than any of us anticipated, but intellectually knew was possible. And so, that's why we're reaching out to try to find better ways to give her a better quality of life.

Ricky Enger: Certainly. And wow, it really runs the gamut of progressive vision loss, and not just one kind of vision loss, but two kinds. She initially lost vision in one eye and then progressive vision in the other, so just really a lot of different experiences as time has passed. And I think what you've talked about with the ophthalmologist giving the medical diagnosis, and then off you go, it's up to you to figure out what happens next is, sadly, a common thing. And I think that as we continue here, those things will get covered in a bit more detail. With that, I know, Ed, you have several questions, so I'll just turn it over to you and we'll proceed then.

Ed Haines: Thanks so much, and I should say I'm so excited to have this conversation. Since we heard from Paula, I'll just let Cathie lead with this next question. Cathie, did you find there were differences in how you, as siblings, reacted to your mother's vision loss in her good eye, her most recent vision loss?

Cathie: I mean, we are more cautious with her. When we take her out, someone's always with her at all times to make sure she can get to where she needs to sit down in a restaurant. Or, even just when I'm home for a short visit, helping her with her coffee, downstairs, or just doing little jobs without taking away her self-respect, because she still likes to do a lot herself. We're all just really cautious of her feelings but are her eyes for her too.

Ed Haines: And how about you, Jack? Did you find there were any differences in how you reacted to your mother's vision loss, say, from Paula or Cathie?

Jack: No, I think it's pretty similar, Ed. I think probably the big difference is you don't really understand it until you live it. Unless you're there every day, or if you're there on a regular basis, it's hard to really comprehend or understand exactly what's going on. To Paula's credit, she's been really good about keeping everyone informed and up to date, so there are "no surprises." We also have a younger brother who happens to live in the same town as our parents, who lives, maybe, a mile away. Between Paula and Dan, they see our parents regularly, almost every day. So, I think when you see them every day, it has a different impact on you than when you see them once a week or once a month.

Cathie: And I think with mom, she wants to still do a lot of stuff, and that's hard for her to understand that she can't do it. We still let her do what she wants to do without treating her like you can't do that. We really worked hard not to do that to her, that you can do it.

Ed Haines: I'll throw this out to any one of you. When your mother was first diagnosed with macular degeneration in her good seeing eye, what were some of your initial concerns?

Paula: I'll jump in on that one. Initially, I was concerned that she was eventually going to be totally blind, and that made me even more anxious to figure out how we could do this. When she was given the diagnosis of macular degeneration, the wet diagnosis, which was the progressive one, the ophthalmologist stated that, "We're not going to let you go blind." Well, that's a lovely thought, but intellectually and medically I know that's not a guarantee. My mom continues to hang on to that and you can't take it away. I don't know that she's not ever going to be completely blind, but she's already seeing the differences, the changes. You might not wake up completely blind, but what you can see is severely limited.

Cathie: I think in the beginning I was like, "Okay, she'll be all right. It's mom, she'll be fine." But now what worries me is they're aging. My dad's much older than her and they're still in their house, and I'm afraid we can't ever take her out of that house because she knows the surrounding area so well. And that is a fear that I have. If she does eventually go blind, and dad's not around to help her, what are we going to do next?

Paula: Aside from the physical limitations of partial blindness, blindness, there's also that emotional piece that I have struggled with how to get help, to help her with that, to help us with that. It's an acceptance. It feels like the stages of grief in some ways. I still struggle with how best to help her with that, because it's not going to get better. I feel like we just need more in our bag of tricks, and we're stuck sometimes on that emotional piece.

Jack: When the macular degeneration became known, I think everybody started thinking about, "Okay, what do we do?" As Paula described, it wasn't a single solution to it. Everybody started thinking about it. And candidly, that's when we reached out to Hadley. My wife had been actively involved with Hadley for 20 plus years and we reached out to somebody at Hadley. We got ahold of you. Hadley has reinforced one, a lot of the concepts and practices we've already put in place, but two, and probably more importantly, in answering your question, gave us more ideas and suggestions on how to handle this. The periodic emails that we get from Hadley about, "Have you thought about this," have been really helpful. And we've started sharing those with our mom and I think she benefits from them.

Cathie: Knowing to put those little dots on her remote control, or her light switch is so good for her too, because then she feels in control. And it gives us a little peace that, "Okay, mom can do this. She's doing okay." We are so appreciative of all that you have done for us.

Paula: I know that the whole thing is a process, accepting help, accepting the reality, accepting the possible future, and some of it is easier to overcome than others. So that said, because she's older, there’s more resistance, sometimes resistance, to the help, and that's been frustrating for me personally, because if the help is out there, let's just run with it. The help is there, the assists are there, and now let's just figure out how best to use them.

Ed Haines: You're right, Paula, it is a process, and people obviously just have to be ready for assistance on their own to be able to make the most of it. It's those little victories, like labeling the remote control. Things like that give people the impetus to move on to something else. I'm thrilled that she's taking advantage of resources that are out there. Paula, maybe I'll ask you, when she was given her initial diagnosis of macular degeneration, was she given any information about what to do next from her ophthalmologist? And then, how long from her initial diagnosis did it take for you folks to learn about low vision services?

Paula: She was given no information on what to do. We had already been to Spectrios for help after the glaucoma diagnosis, so that was before the wet macular diagnosis. No, no help, at all. I remember sitting in the ophthalmologist’s office thinking, "Oh my gosh, now what do we do?" And I'm an educator. I taught kindergarten for years and I'm used to having a game plan, and there was none. There was none offered. I resorted to furtively glancing at the brochures that were behind the door looking for anything, and that's how I found Spectrios, and then I reached out to them. And then, luckily, we were blessed with the Hadley piece, as well. But no, nothing was offered. We were on our own.

Ed Haines: Well, that's not an uncommon experience, unfortunately, but I appreciate you articulating that. A couple of you have talked about offering your mom assistance. What is your approach when you offer assistance to your mom? How do you handle that to help her be receptive to assistance?

Cathie: Well, one of the videos that you had sent out, which mom and I watched last week, was how to walk with her. It was always me holding onto her, but I think she's supposed to take my elbow, right?

Ed Haines: Yeah, your arm above your elbow, right.

Cathie: I need to practice that, as you can hear, but that was a really good thing to have that information on how to lead her.

Ed Haines: And Jack, how about you? How do you approach when you want to try to help your mom, how do you approach that to help her accept your assistance?

Jack: It's probably more basic than what Cathie described, but I'll just ask what can I help her with? If we're walking, having watched that video, I'm trying to have her grab my arm. But candidly, most of the interaction that I have with them is at home, around the kitchen or the dining room table, so there's not a lot of going out. If we need something from the house when I'm there, oftentimes I'll just go get it, so that my mom or dad don't have to get up and walk up and downstairs to go find something.

Ed Haines: Do the three of you, or your other siblings as well, talk together as a group about the future, about the possibility of her losing more vision and what you think you'll do as a family?

Paula: We have begun Zoom calling on a regular basis. And that's wonderful, because that's an easy way for me to update everybody on the latest eye appointment. Things that are going on. Cathie and I have done the research on assisted living, which neither of my parents are interested in, so I don't think that's going to be a huge option. We need to talk more about what are our home care possibilities, if and when, that becomes a necessity. So those monthly phone calls have been invaluable.

Cathie: They are really helpful, our monthly calls, because sometimes we weren't all on the same page. It really helps the other ones who may not be on the same page to hear what we're seeing. So, I think the Zoom calls have really helped us a lot.

Jack: In our circumstance, we have three people, three kids, that live within an hour, hour and a half, of our parents. We have one, Cathie, lives out of state. Our brother, Mike, lives out of state. Obviously, it's a little tougher for them to be there day-to-day, or even a week-to-week. But by doing the Zoom call, everybody, with some regularity, is totally up to date about what's going on and what the priorities are, and candidly, what everybody is doing. Before we started the Zoom calls, Paula would go to my parents' house. She's probably there once a week or so, maybe twice a week. We didn't know what she had done. She didn't know what I had done. We didn't know what our younger brother, Dan, had done, so this just gave us a chance, every three to four weeks, to bring everybody up to date about what efforts have taken place and what people are working on.

Ed Haines: Well, that sounds like a terrific practice. Definitely something that you could recommend to other folks, I'm sure. I was just wondering, what are some of the strengths that your family brings to this situation?

Paula: One of the strengths is we were a tight family growing up. We were all connected. We all have strengths that we bring to the table, and, as adults, those have become a little bit more obvious, the skills that we do bring. I think that's been a help. I think we just honestly love them and want them to experience all the best they can, all the days that they have here.

Ed Haines: Well, thank you. That's a wonderful sentiment, certainly. What advice would you give to other families who have parents with vision loss?

Paula: I would advise seeking out the help, try to do the research, find the people that can help. Like Mr. Rogers says, "Look for the helpers." It's time-consuming and a lot of times you feel adrift, but it's a necessary thing to do to help them. The other piece is it's not just the physical piece about how do we help her sit in a chair and find the best way to watch television or whatever, but that emotional piece. And that's something that I continue to struggle with, because I feel like I'm failing her there. I don't know how to help. I don't know the best things to say all the time. Sometimes I just introduce an idea, knowing it's not going to be accepted right away, and I continue to do that knowing that, eventually, she'll get there and that will help everyone. So, I think just seek out the help, because it's not easy to find.

Jack: What I'd throw in there, Ed, is one, I've realized that this is not going to be solved and you're not going to have nirvana and success in 30 days or 60 days. This is going to be a lifelong responsibility and exercise that we need to deal with. Two is, you got to start small, look for small wins. That way, when mom sees it helps her, she's more willing to try the next one. And as Paula said, sometimes you try it and it gets rejected, but you can't forget about it. You just have to be patient and try to reintroduce the idea, or the concept, again down the road. But it's that long progressive path that you have to take in order to have success. What I've noticed is when some of these ideas have been implemented, what it helps is with her sense of confidence, her sense of individualism, and that even though she has lost sight, and her sight is limited, that she can still function and survive and be productive every day.

Paula: The conversation, Ed, that we had with you a few weeks ago, where she actually was able to talk to someone who knew more about it than any of us, and validated her concerns, her fears, what was actually going on, was so wonderful. And so, I thank you for that support. When we go to the ophthalmologist, as I said, you had said it's a seven-minute visit, and that is right on target. That they do what they need to do, they come, and they say what they need to say, and then you're on your own. I don't look for anything different there anymore, but knowing that's normal, doesn't make it right, but now I'm not so annoyed by it. So just being validated and having someone hear her was very wonderful, so thank you for that.

Ed Haines: Well, you're very welcome. It was really a pleasure to meet with her and it's great to hear.

Ricky Enger: Yeah, for sure. I think that's probably a challenge that a lot of people face, especially parents who are used to being the ones in control, and the ones who are giving their children advice, and the ones with all the answers. It must feel especially vulnerable to then be in that position of how do I talk to my children about how I'm feeling? How do I express some of these emotions? And then, how do we, as a family, figure a way forward? As you said, Jack, just that individualism is maintained, and at the same time, help can be given and accepted, either immediately or perhaps over time. Any final thoughts that any of you want to leave our listeners with? We've covered quite a bit, but there may certainly be something that we haven't touched on that you'd love for other families to hear.

Cathie: Well, just like it takes a village to raise a child, it takes a village to help your parents as they get older. I mean, I'm just so thankful to have my siblings to be able to talk to about this, and to have Hadley to be able to reach out to, now, to get help. You all just have to work together. And you're going to have hard days. I mean, it gets hard. It's sad. It's just good to have people to talk to.

Paula: In a family situation, you recognize each other for the strengths that they have, use those strengths in different circumstances. Not everybody has close proximity, but a phone call, a FaceTime call that we can arrange, things like that. So, use those strengths that people have to help out when you can.

Jack: In our circumstance, Paula has been the primary source for taking our parents to the doctors, in this case, for the eye doctor. And I think on one hand, especially when there's multiple siblings, or multiple people in the family that want to help, you really need to have one person lead the effort. But everybody else has to be willing to hear what's going on and participate in the follow-up. As Cathie said, she can't be there every day, but as we need to do research on a particular topic, she's more than happy to do that. But I think it's important to have one person be the point person responsible for the effort, and then everybody else needs to add their expertise where they can, when they can.

Cathie: And I think being the out-of-town person, you have to be careful not to expect the people who are in town to do it all. I mean, I can't always say, "Well, Jack, you need to do this. Paula, I think you should do this." I mean, you really can't do that to them either, because it's a lot, so you have to be really careful not to give your opinion if you can't help with it.

Ricky Enger: I love hearing that, just figuring out those logistics and making sure that everyone is doing what they can, and that everyone feels appreciated and supported. I think you really hit the nail on the head when you talked about your family's strengths. It is about communication and recognizing what each person is best at, and still being willing to jump in, and help where you can. Thank you for that. And thank you also for sharing your experiences and your stories with us. So happy that Hadley has been of help to all of you and to your parents, and hope that continues. As Ed said, "It's what we're here for."

Paula: Well, we looked for the helpers and we found it. We thank you.

Cathie: Yes, you're our new best friends.

Jack: I think we have you on speed dial.

Ricky Enger: That's what we love to hear. Thank you all so much.

Cathie: Thank you.

Paula: 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.