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Hadley Presents

Jalapenos in the Oatmeal: Digesting 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, blogger Jeff Flodin joins us to discuss his journey of vision loss. Welcome to the show, Jeff. So great to have you.

Jeff Flodin: Thank you for inviting me to join you. I'm just sitting back and relaxing. Thanks.

Ricky Enger: That's a great thing to do. It's a Monday morning as we record this. And so, sounds like you're starting the week off right.

So I was delighted to discover your blog. And then I realized, okay, wow. I have like 12 years of great content to get through. So really excited about that. But for people who don't know about you just yet give us a little background. Tell us about yourself.

Jeff Flodin: Thanks, Ricky. In the summer of 1986, among other things, I was driving a '71 Volvo, jogging about 20 miles a week, hiking in the Superstition Mountains, taking photographs with a Canon camera in Kodachrome 64, reading at least one book a week. And I was 35 years old, and I was one month shy of being married. And I was diagnosed with RP and told I was going to go blind.

My initial reaction was I thought it was the end of the world. I catastrophized to the point of how would I support myself if I could no longer drive? And the "ifs" became "when" because the prognosis was pretty clear. How would I learn when I could no longer read? How would I avoid leaving the house dressed like a clown? Predictably, you've probably heard stories which are all the same, but they're all different.

I turned in my driver's license three years later, was declared legally blind four years after that. And it's been a steady progress, using the term "progress" loosely, to the point of now, 36 years later, I have light sensitivity. Haven't seen a face, including my own, for 15 or 20 years. In some respects, I've beaten the aging process, because I can't see what I look like.

You know, it's been a process. It's been a real test of patience and endurance. I've learned some very valuable things about patience and tolerance and problem-solving. All in all, I would've preferred to learn those things and be the person I've become with sight rather than without sight. But all in all, I'm in a place, in my head and heart and body, that it was not the end of the world, and it didn't even come close.

Ricky Enger: Well, there you go. And you've actually chosen to write about some of that stuff, which is great, sharing what you're going through with the world. And I love the title of your blog. Of course, it's just begging for an explanation though. Your blog is entitled "Jalapenos in the Oatmeal: Digesting Vision Loss." And that just has such interesting imagery. And so, I'm curious, how did the title for that come about?

Jeff Flodin: Well, it was 12 years ago when I was asked by the staff at what was called the Guild for the Blind, now is Second Sense in Chicago, to write a blog. They said it made sense, if they were going to revamp their website, to have a blog and have that blog be written by a person who was visually impaired. And so they chose me. And I sat down, and I brainstormed titles for the blog. I had some very practical ones like “Vanishing Point.” And then I had ones like, “How Can I Tell if This is a Real Skunk?” or “What I Say When I Lose Something.”

I think I'm trying to project to you, Ricky, and to people listening, that one of the things that has helped me is not to take myself too damn seriously; that a sense of humor really evens out the overarching anxiety and tendency toward victimhood and self-pity and so on.

And I'm using those words because in 1986 when I was diagnosed, I was 10 years into a social work career. And I continued that career. I'm continuing that career to this day, in terms of facilitating low vision support groups. In the blog, there are funny ones, and there are tragic ones, and there are tear-jerkers, and there are knee-slappers and so on. And “Jalapenos in the Oatmeal: Digesting Vision Loss” was the one I chose, primarily because I thought it operated on more than one level. One, on the practical level, kitchen mishaps, throwing jalapenos instead of raisins into the oatmeal, those kinds of things do happen. But also, maybe on a more figurative level that, in life, we don't know what is around the corner. And so, that's what I chose. And that's what I hope is conveyed.

What I wanted to try to accomplish with this blog was, on a personal level, I'm a strong believer that self-expression is not only beneficial but therapeutic. I think that when you can put thoughts into words, fears down on paper or in the computer, as it were, that it is part of the grief process; that it is part of the process of putting a name to a feeling, putting feelings out there. And I had hoped not just for it to be a self-indulgent diary or journaling; not so much for myself. But there was a very important twist of consciousness for me when I was faced with the invitation to join a low vision support group in 2008 in Chicago. I'd been living with RP for over 20 years, and I thought, well, I haven't been doing the greatest job in the world, but what am I going to learn from sitting around a table, listening to a bunch of other people talk about their trials and tribulations?

And then I thought, well, maybe I could be of help to somebody who's new in the process. And that was a sea change for me, in terms of my selfish consciousness. I get the biggest kick out of talking to people who are sighted, who read the blog, and then tell me, "I had no idea what it was like." It's stretching the audience from the people who have low vision and tune in because maybe it'll help them feel better or get an idea of or give them a laugh. But educationally, 90% of the sighted public wants to be helpful. The trick is, they just don't know how sometimes. You don't grab somebody and pull them across the street just because the light's changed.

So, that's the story behind the blog. And as you said at the outset, Ricky, it's Monday morning, and we're off to a good start. I send the blog to Second Sense for posting on Monday morning. And so, this morning, I had written a blog in the last couple weeks. And I send it, and it just got posted. So, we are off on a good start, and it’s still Monday morning.

Ricky Enger: Yes, indeed. And I know what I will be doing after this recording. I'm going to go check out what this morning's post is.

You've talked about living with RP for a little while now. So, you've had some practice, I guess. The interesting thing is that, for a lot of eye conditions and RP specifically, for some reason, there's always something happening. There's research, there's going to be gene therapy, there's some new drug that's going to do some miraculous thing. And there's always something that is just over the horizon, which is great because it gives people some hope that things might be different, that they might regain some of that sight that they're losing. And yet, there is now. There's living with what is. And it just seems like it would be difficult to find that balance between having that hope for something that might be, and at the same time, being able to live with and accept what is now. How have you found that balance yourself? Or is it still something you're working on?

Jeff Flodin: Oh, it's something that's working on. I am a work in progress. Just as my eyesight is progressively getting worse, in my social work career I came up against an organization that said, "Keep your eyes on shore, but row like hell." In that respect, yes. Since 1986 in my annual eye exams, the doctors have said, "Keep the faith because there's research going on." I've been hearing that for a long, long time. And I appreciate the research that's going on. RP is a retinal degenerative disease. I've learned through Foundation Fighting Blindness and other sources about the research that's going on. I learn about the gizmos and gadgets as my eyesight has gotten worse and I've needed to go from magnification to screen reading, for example, to labeling systems, to gizmos and gadgets that we have had to learn so that we can maintain the level of quality of life that we want.

I had the occasion, about 10 years ago, to look for counseling in the post-traumatic stress disorder area. And I realized that, with progressive vision loss, there is no post-trauma because there is no post in the trauma. It's always happening. And if you can minimize the disorder end of it, you have traumatic stress. Instead of PTSD, you have TS, traumatic stress. That's how you learn to live. And what I have tried to do is put faith in research, faith in bigger and better gizmos and gadgets. And I look at faith as hope with legs, hope with energy. But at the same time, I am subject to the human character defect of denial. And if I chose not to get white cane training in 1995, because I was fully certain that there would be a cure for RP within the next five years, then I would've been five years behind where I needed to be. So, I need to keep rowing the boat, but also keep hoping for that I'll hit shore pretty soon. Now I'm 72 years old, Ricky. And my hope now: for treatment and cure for the next generation.

Ricky Enger: And that sounds like a very realistic thing to hope for, I think. I love the balance between wanting something to be different and hoping for that and at the same time, understanding that you got to help yourself as well. I think that maybe that's one part of adjusting to vision loss. I know that when we talk about adjusting to vision loss, there's this expectation, both for the person doing that adjustment and for people who are watching it happen. There's this thought of, okay. Well, when you reach step five in the pamphlet or whatever, then it's over, it's done, you've arrived, you're all adjusted.

But that doesn't feel likely, I guess. So, can you talk a little about your process of adjustment? And is it a continuous thing? How do you work through that knowledge that every day you don't know what to expect, and there might be something new and unexpected that you're adjusting to?

Jeff Flodin: At the time I was diagnosed, I was 10 years into a social work career. And I had been taught in school, and I had used, in my social work, the five stages of grief developed by Elizabeth Kübler-Ross: denial, anger, depression, bargaining, and acceptance. And I thought, well, I have a good understanding of that. So, I'm just going to breeze through those stages. I'll give maybe the first four, maybe six months each. Okay? So then, within two years, I'm going to be in the acceptance stage, which I thought about as being this big meadow with daisies in it, where you just roll around and everything is behind you, in terms of the trauma and the grief and the loss.

And I was never more wrong in my life. I have learned that, however many stages of grief there are, and I know that Dean Tuttle, in their book Self-Esteem and Adjusting with Blindness, which is a really good book, and it's on NLS and so on, as an audio book, is they have seven stages of grief.

And I think they point out a couple things, in terms of there are some stages where counseling does not help because you're not ready for it. When you're angry, you don't hear very well. And you have to be able to hear and process information in order to continue through the stages. So, that was a life experience for me in which I didn't think it was going to be a snap, but I didn't think it was going to be such that one day, when I was working in Chicago, walking to and from work with my guide dog, I had a really good day at work, so I felt more along the acceptance end of things. And then I started to cross Western Avenue against the light. And I got four or five steps into the intersection and realized that I was crossing against the light.

And I scooted back, with the dog, to the curb. And I went right back into anger and denial and depression. It's, how could I do such a stupid thing? So, the fluidity of those stages and the fluidity of how you feel about yourself and your place in the world are almost constantly going. This adjustment is going to continue the rest of my life. And it's not just adjusting to my eyesight. It's adjusting to the place in the world that people with disabilities have.

What I realized too, in terms of what my responsibility was, was I could rely on sighted guides, and I can rely on guide dogs, and I can rely on technology. But I am the one who has to keep myself up to date with what's out there. To take the next step proactively, like to learn braille from Hadley, which I did. Those kinds of things. I have a lot of friends; I have a lot of support. But I'm the one who has to keep things moving forward.

Ricky Enger: Right. And it sounds like you're doing that with that essential bit of humor mixed in.

Jeff Flodin: Yeah. It's the great equalizer.

Ricky Enger: You mentioned you're 72 now. And so, you've been at this for a little while. And you've learned a lot, I imagine. Some of it was probably not easy to learn. There were undoubtedly some struggles that you faced and came out on the other side and probably some you're still working through. But is there anything that you wish you had heard closer to the beginning of your journey that might have made things easier or different or might have saved you some of those struggles that you've gone through?

Jeff Flodin: I used the analogy when I worked in the hospital in Philadelphia. The scenario that would present itself, which I adapted for my own purposes, was the doctor tells the patient that the patient has cancer. And the doctor says, "That's your diagnosis. And the nurse is going to tell you how we're going to treat it." So, the nurse tells the patient how they're going to do chemotherapy and so on, and so forth. And then the nurse says, "And the social worker's going to tell you how to live with it." It's up to me to find how to go about dealing with this. Some of the things that I have as mantras are, "I am not alone" because blindness is a very isolating condition. "It's not my fault." I have a tendency, if I can't be perfect, to feel that I am deficient. And my eyesight is not perfect. And to the level of deficiency in my activities of daily living or in my psyche or whatever is totally up to me. "Ask for help and be open to receiving it."

Repeat after me the serenity prayer several times a day, about recognizing that events outside of me are beyond my control and asking for the courage to take the appropriate action. A lot of people have some horror stories about being diagnosed and then set adrift to fend for themselves. I think that is something that people have been working on for decades. About how to build in some support systems to the medical end of things.

But there are places out there. There's Hadley, there's Foundation Fighting Blindness, there's gizmos and gadgets. There's support groups. You have to stay connected. You have to find something that gives you pleasure and makes you feel like you are still a useful and contributing member of your pack or society.

Ricky Enger: That's very well said. Thank you, Jeff. All very important things for people to hear. Regardless of where they are in their journey. So yeah, we appreciate that. We will have links in our show notes to any books that were mentioned here and of course, to your blog, Jalapenos in the Oatmeal. Looking forward to continuing to read those installments. Any final thoughts to leave us with before we wrap things up?

Jeff Flodin: Thanks, Ricky. No, thank you for this opportunity to talk to you and the people who tune into this podcast. So, thanks for the chance to talk to you.

Ricky Enger: Absolutely. Thank you so much for spending a little time with us.

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.