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Hadley Presents

The Beauty of Dusk: On Vision Lost and Found

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, author Frank Bruni joins us to discuss his book, The Beauty of Dusk. Welcome to the show, Frank. Thank you so much for being here.

Frank Bruni: Thank you for having me.

Ricky Enger: It's good to have you back actually. You joined us in 2019 and it was so great to have you here. And since that time, you have written and released a book called “The Beauty of Dusk”. You actually did the audiobook narration as well, which is really great. It always adds a little something to hear things narrated in the author's own voice. Yeah, very cool. You discuss subjects that are so relatable, and I'm so glad that you're willing to explore a little of that with us today. So let's get right to it.

I know that when you were initially diagnosed, it was kind of... It wasn't just like, okay, here's what's happened, here's what's going to happen next. You were actually told that there was a pretty good chance that you were going to lose even more vision than you had already. I'm sure that was pretty frightening, pretty anxiety-inducing. You started talking with other people who had maybe been a little further along in this journey. You talked to people like Judge David Tatel, for example. What did you take from those conversations with other people that really helped you to kind of relax and just get some peace of mind?

Frank Bruni: Well, Judge Tatel's a good example of that. I mean, he's someone who was legally blind in his early thirties, having had sight before then, but that was when retinitis pigmentosa took away the remainder of his functional vision. He was someone who was living an enormously rich and fulfilling life, had reached the pinnacle of the legal profession.

One of the main things that conversations with, and just acquaintance with, people like him did for me is confirm what I suspected, but what you want to have confirmed for yourself regardless, which is that if I did lose more sight, if I went from being someone who had compromised vision to somebody who fit the definition of legally blind, that was certainly going to introduce challenges and complications to my life that hadn't been there before, but it was going to leave me with plenty. I was going to be able to do more than I couldn't do, and I would still be able to have a kind of rich and varied life. He was an example of that, so were other people I met. And also I should say talk to, and the book provides portraits of as many, people whose challenges weren't vision-related, whose challenges were hearing related or Parkinson's because I think we're actually all more connected than we are differentiated by those challenges.

I think that they all are things that happen to you that remind you that these physical vessels of ours are imperfect and sort of can, not to put too fine a point on it but, degrade over time in various ways. I think one of the riddles and challenges of life is figuring out how not to be frightened of that, and then figuring out when it happens in whatever fashion it happens to you, you know, figuring out how to confront it, to greet it, to deal with it. And that was something I learned from Judge Tatel, but also from people whose struggles and whose hardships had nothing to do with diminished vision.

Ricky Enger: Because I think we all have challenges that we face and losses that we deal with. One of the questions that does always come up with any kind of loss, and vision loss is no exception, is, "Why me? What did I do to deserve this? Haven't I paid my dues already? I've already faced a lot of challenges. Why is this happening?" How did you go from that perspective and just make that shift to, "Well, why not me?"

Frank Bruni: I did have that moment of “why me?”, as you kind of correctly surmised and as I think a lot of people do. I rather quickly and instinctively, and I don't know why this was the case because I'm not a particularly kind of cunning or strong or unusually bighearted person, I try to be, but I'm probably not as big hearted as I'd like to be, but I rather quickly and instinctively looked around me, did a kind of different kind of survey of the people around me and the people just beyond them, and I realized that, well, most of our struggles, most of their struggles, are not conspicuous, they're not visible. I had a friend who had an autistic child whose autism was pretty severe and who'd been a challenge her whole life and whose kind of adult future and care were a challenge and riddle constantly being figured out. I had friends who had cared for parents with severe dementia and Alzheimer's. I had friends who had battled various kinds of cancer and lived with the worry that those cancers or some related ones would recur. Friends who'd lost spouses young. Friends who'd lost children. I realized that if you take an honest, truthful, complete survey of the people around you, of the world around you, you realize rather quickly what you're dealing with isn't some singularly awful thing. It's just your thing. Something is going to happen. You're going to meet up with pain. You're going to meet up with struggle. You're going to carry around some hardship. It may not be the one you expected, and it may feel to you like one that's a particularly heavy burden, but struggle is the default setting of the human life. I think when you accept that, when you see that, and in that sense, my vision improved, you can never ask the question “why me?” You ask the much more relevant and truthful question, which is “why not me?”

Ricky Enger: Very well put. Thank you. You have done a lot of writing. Even before having released your book, you did a lot of writing about sort of your vision loss journey from when it started to things that you were experiencing along the way. I don't know if you were surprised or not when it happened, but when you shared that writing, when you shared kind of what you were going through, people did the same. They started telling you their stories. You heard from a lot of people who were either struggling with vision loss or some other kind of loss. I think maybe you've touched on a lot of this already but feeling a sense of community from those interactions. Can you expand on that a little? Was it an expected thing, or what did you get from having people share things with you that you had begun that journey and they shared back?

Frank Bruni: Well, one of the things is what I mentioned in the sense that it is a reminder that everybody's dealing with something. It's almost impossible to call it a community because it's so large. It's humanity. It's not just a community, it's humanity. But one of the things I took away from it is I think too many of us go through life not having the kinds of conversations that I ended up having because I opened myself up and people then had opened themselves up in turn back to me.

I think that when we have a sense that someone is struggling or when we can, in those instances where it's visible, see that someone's struggling, we tend not to ask them how they're doing. I think that's about a lot of things. I think part of it is an excess of courtesy. It doesn't seem polite to ask people what is a sort of intimate, very personal question, but I think it's also fear. We don't want to be on the hook to hear and react to the answer.

We don't want to feel then like we should do something that we maybe don't have the time or generosity of spirit to do. But whatever the reasons, I think there are all of these unhad conversations, these unsaid emotions. What I kind of saw, and I think I would've predicted it if someone had said, "What do you think will happen when you do this," is when you show your vulnerability, when you share your own struggle, your own fears, people see an invitation there that they don't get often enough elsewhere in their lives.

They begin a conversation with you in which they do the same. Sometimes it can be a little intense, even a little too intense. I remember getting an email not long ago from someone who'd read the book and said, "I found the book extremely helpful and inspiring in terms of its argument for how one goes ahead and lives one's life without being consumed by self-pity or anger." But the woman said, "My particular struggle, my pain is that I lost a child to suicide. And every time I try to move beyond that and live life with that in the back of my mind, I feel like I'm doing a dishonor to his legacy, and I feel like I'm evading some sort of accountability or responsibility I have." I did not have a good answer for her, but I felt good at the end of the day. I don't want to reduce it to that, and that's not the main thing. I felt reassured at the end of the day that I'd given her a moment to share that she was feeling that for whatever that was worth.

I want to believe, I have to believe that while I didn't have an answer for her, the fact that she had been able to unburden herself to someone who hadn't been there to unburden herself to before, that felt to me like a positive contribution that I'm really glad to have made if I indeed made it.

I guess to go back to your specific question, I learned, I saw, I think we should all think about the fact that when we open ourselves to people around us, when we share what we're going through, it's a kind of implicit inquiry about what they're going through that can foster conversations that I think help everyone involved in that conversation and conversations that are too often swept to the side.

Ricky Enger: Yeah, absolutely. Just having those moments that we can share with each other, rather than sweeping some things aside or having maybe shallow interactions that don't often deepen into something a bit more meaningful. You do talk about that in your book, how after your vision loss, no pun intended, you look at the world differently. You're paying more attention to nature, or you are noticing those personal connections a little more. Even that you're doing things that before your vision loss you might not have considered taking the time to do. Why do you think that is? How did vision loss really play into that perspective shift?

Frank Bruni: Well, in that sense, I think the shift wasn't about vision loss, but it was about the kind of event that the vision loss represented. What I mean by that is I think that I never in a million years... I'm someone who can be a pessimist. I'm someone who can be consumed by fears, less so now than ever before. You do kind of feel a twinge or something and think, "Oh wow! Maybe I have cancer," or you get some sort of weird medical test, and you think, "Wow! There's a history of heart disease in my family. I'm going to have a heart attack."

Weirdly, I don't think many of us who don't have vision impaired people in our lives sit around thinking, "What if I go blind?" I just don't think it's one of those things that feels so universal and pervasive that it's one of the many things that could trip us up. When it happened to me... And I say that because that is why when it happened to me, it became one of those medical events, one of those life events that underscored for me how little you can predict about your future and how uncertain the future is.

And that kind of leads to that whole cliched concept of limited time, of not wasting your time, of not putting things off into the future. I'm talking to you from my home in Chapel Hill, North Carolina where I've lived for only 10 months. I did the big move here, sold my place in New York, did this huge life change in the aftermath of my vision loss. And that was in part because I felt, as a product of that life event, that I didn't want to put off things I'd consider doing, changes I planned to make someday. I didn't want to put them off too long because I had had underscored for me by this overnight loss of vision that I have no idea what next week is going to bring or next month or next year. I have no idea if my abilities and capabilities are going to be the same then. For me, this became part of the seize the day thing that is an utter cliche, but that I think often happens in the aftermath of a truly unexpected catastrophe, crisis, challenge, put whatever noun you want to it.

Ricky Enger: I want to thank you for something impactful that you said a while back in your podcast with us in 2019, and it's something that we've been able to share a bit. In Hadley's headquarters in Chicago, we offer tours of the building. There are lots of really cool things to discover, but part of what we do is that we invite ophthalmologists and their staff and other medical professionals in to take a look around. One thing that we have is a room where people can get a glimpse of what it might be like, what things look like with different eye conditions, for example. Not to say, "Hey, this is what it would be like if it happened today." That's a bit frightening, but more to just take a moment and say, "Oh wow! Those lights are really bright if you have this particular eye condition." We have that kind of virtual reality thing, and then we share some practical tips about vision loss.

We share tips from our own workshops about how you might accomplish different things like cleaning your house or things that people often wonder about. How would I do that when I've lost my vision? And then we also share clips from some of our podcasts. One of the things that you shared that has been so impactful was you talk about your diagnosis, and you were told what was wrong, but nothing happened after that, right? You weren't offered any counseling. Nothing about vision rehab was mentioned. It was just, "Here's your problem. Good luck." I think hearing those words has been really impactful for the professionals who come in and listen to that. Is there anything else that, if you could say, would make for a more compassionate interaction? What should ophthalmologists and other professionals in this field who are diagnosing vision loss, what should they know or tell their patients?

Frank Bruni: What I mentioned in the other podcast is to me the kind of main thing that I would emphasize today and reiterate, because I don't think it can be reiterated often enough, which is I think ophthalmologists are like any medical professionals. Their tendency, I think, is a very human tendency. We all tend to kind of shrink the world down to a given viewpoint, a given lens, a given expertise. They're looking at things in a very kind of clinical, anatomical, medical way.

As you said in your question, for me, the challenge wasn't just that I wasn't seeing well as I was before, but like how do you emotionally and psychologically adjust to that? How do you make the most of a bad situation? As you said and as I said on the past podcast, I remain astonished to this day that even though some of the physicians I saw, all of them were tremendous physicians, many of them seemed like wonderful people, not one of them ever said, "Hey, this is a pretty disruptive and surprising thing in a human life. Vision is pretty central to what you do for a living, which is reading and writing, and you've lost central vision as opposed to peripheral vision. And that's the worst kind of vision to lose for what you do. How are you adjusting? Do you want a referral to counseling?" No one mentioned, and please forgive me if I'm using the wrong phrase, no one mentioned low vision therapy to me.

It wasn't until months and months later when I was just from my own sort of research talking to a wonderful woman named Nancy Miller, who runs an organization called Visions, which is a sort of social services organization for vision impaired people in Lower Manhattan. That was the first time I heard the phrase, and that was probably six months after the stroke that frazzled my optic nerve.

I don't know why that is because it's such an obvious thing for physicians to do, but I think they're living such rushed lives like the rest of us, they are in kind of reflexive automatic mode. And as I said, everything is seen in terms of, okay, what medical thing do I have or not have for you? Now, they were extremely directed and specific about the clinical trials available to me. In fact, I was shepherded rather quick, instantly into one clinical trial. And then a year after that, I met the criteria for another clinical trial that had come along. I would say, I didn't say this I think last time, I would say as a matter of advice to people, I'm a big advocate of these clinical trials. Yes, you may end up in a placebo group. Yes, you're taking enormous time out, not just to participate in whatever the treatment is, but part of the deal is you're constantly marching back to the doctor's office or back to the hospital for a gazillion measures of you to be taken because you are now a test subject. That is a significant investment of time dedicated to science and potentially a cure. You may be doing all of that without even getting the treatment. You may be getting the placebo.

But what also happens, which I learned, and this is why I would very much recommend people investigate whether they qualify for any clinical trials related to whatever their vision impairment is, for as long as you're in that clinical trial, the physicians who are giving you the treatment and who are measuring you, they are sort of kind of bound by medical ethics to sort of act as your physician in other ways too. No one had told me. I kind of discovered it on my own.

During these trials, if I had a question about something else going on with my vision, if I had a question that was related to, but maybe really something of a tributary to the trial, these physicians were there for me. They felt that they had an obligation of care for me as long as I was in that trial. And that's a not insignificant benefit from being in that whole system.

You also end up picking up in a direct, but also in an incidental fashion, an enormous amount of information and extensive education into your condition and into the just sort of general workings of the eyes if that's the trial or of something else. That would be something I would add to the advice or the kind of heads up I gave before, which is investigate clinical trials and give serious thought to enrolling in one, if you indeed meet the criteria,

Ricky Enger: Thank you so much for that. There was a lot that I actually didn't know or hadn't considered when you started talking about clinical trials. It's beyond just the hope of potentially restoring your vision. There's actually a lot more that can go into it. Again, thank you for that. Thank you for taking a bit of time to just share your story and share your perspective. As you're listening, we will have the link to both the audio book and the print edition or Kindle or however you want to buy it, “The Beauty of Dusk”. It's well worth the read. Again, thank you so much for stopping by. We appreciate you, Frank.

Frank Bruni: I appreciate y5our interest in me and in the book, and I thank you very much.

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.