Hadley

The Blind Poet, Dave Steele

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, blind poet Dave Steele joins us to share his story.

Welcome to the show, Dave.

Dave Steele: Thank you so much for having me, Ricky.

Ricky Enger: We are delighted to have you. Here at Hadley, we have actually followed your work for quite a while and really, really love it. Recently we shared one of your poems on our Facebook page and turns out a lot of other people resonate with it as well, so this is perfect to have you on to chat with us, to share your story with our audience, and maybe we can get a little poem from you a bit later in the show. So glad to have you.

Dave Steele: Yeah, absolutely. I really, really appreciate you sharing the poem.

Ricky Enger: I guess before we kind of talk about what you do now, which is you write a lot of awesome poetry and share it with people, this all started at some point and I think it came about because of vision loss that you experienced. Maybe we'll just start with your sharing a bit about what that was like when it happened, what the process was initially for you.

Dave Steele: Sure. So, I have a condition I'm sure quite a lot of your listeners will be familiar with called retinitis pigmentosa or RP for short. RP, for those that don't know, is a hereditary condition in most cases. It is actually a name for a collection of different eye diseases that kind of deteriorate in a very, very similar way. There's no treatment or cure for RP. The way you tend to lose your sight is it starts off generally with night blindness, so struggling from light to dark places and then you start to lose your peripheral vision. Maybe you've heard the phrase tunnel vision, which is similar to RP. It's like a tunnel closing inwards, then you start to lose your central, and often it results in complete blindness.

The way I first heard about it was when I was probably about seven years old, my sister, one of my sisters was the first one to be diagnosed with it in the early eighties. Back then they didn't really know a lot about the condition, but I remember going to my local eye hospital with the rest of the family to be tested, having these drops put in my eyes, which made my vision go blurry, which I now know to be dilating drops because I have them at every single checkup I go to. But other than kind of that appointment when I was seven years old, after that, I didn't really hear any talk of RP. It was just kind of kept from me. There were maybe conversations that went on in the background, but I was too young to know about it. Then I just got on with my life.

Looking back now, I probably have the early onset of it from my early twenties, that struggling from light to dark places but it was a very, very slight adjustment and one that I didn't actually at the time put down to RP. I just adjusted, took a couple of seconds and got on with things.

Then, the way it all changed for me was when I was officially diagnosed around about nine years ago. I was in my late thirties. I used to go and get my eyes checked every couple of years just to make sure I was good for driving and things like that. When I went for a routine eye exam, the optician looked into the back of my eyes and immediately there was this pause and he just said, "Oh, there's been a bit of a change since the last time we saw you. We need to run a couple of more tests." They asked me to do a peripheral visual field test, which is for those that don't know, they put me on this machine and test in each eye. I had to hold this button and every time a light went off in my peripheral vision, I had to click the button to signify that I'd seen it.

The test started and I just sat there holding the button and not clicking it. This realization of what was happening to me all of a sudden swept over me and my wife, Amy, who was my fiancé at the time. I just proposed to her and we were just saving to get married. We had our son who was about seven, eight months old at the time. He sat outside with Amy in his car seat in the waiting room and I had to walk out of the waiting room being told that I had to stop driving straight away and I was being referred to a retinal specialist. Literally about two weeks later I was declared severely sight impaired or legally blind.

Ricky Enger: Wow. Just to go from not realizing because it was happening so gradually to suddenly realizing that, I guess, quite a bit had changed and you were in a completely different place than you were just walking into that appointment. I know one thing that we hear a lot, it's really common regardless of what the reason is for your vision loss, there are always just so many emotions that surround the whole process of vision loss and adjusting to it. I think people process that in a lot of different ways.

How did you stumble on or happen upon poetry as a way to channel some of these emotions that you were going through?

Dave Steele: Well, the way it happened, you couldn't actually write it, it's so strange, my story and the way it's developed. From the moment of that appointment, it was almost like a veil came down. You said obviously, you hear a lot of similar stories from people with regards to how they are when they're diagnosed and a thing like RP is such a very slow and gradual loss that happened over many years, probably from my early twenties as I said. The strange thing is that the brain does this really unusual thing. When you walk into a room, and this is for fully sighted people as well as visually impaired people, when you walk into a room, your brain subconsciously scans what's in the room and often it fills in the blanks for what your eyes can't see. Sometimes people who are visually impaired feel like they can see more than they actually can until they're actually physically tested under these conditions. From that moment of being tested, it was almost like all of a sudden the veil came down and I started to realize that I couldn't see as much as I thought I could and I was probably in denial a little bit.

But what happened after that appointment was a really tough eight to nine months. I was working in car sales at the time and I was also working as a singer. Everything that I did as far as employment involved me driving around and getting myself around independently. The minute I was told I wasn't able to drive anymore, my employer let me go so I lost my job. I couldn't do the gigs that I was doing singing anymore. I couldn't drive up to Scotland where my daughter from a previous relationship was living and pick her up, so I wasn't able to see her for a little while.

We applied for support through the government and the benefits system, but there was a nine month process, procedure, waiting list to get and receive help and a payment. We lost our house. We had to feed our kids on food banks and food parcels for a little while. I was struggling not just with depression and anxiety because of the sight that I was losing because stress adds to that as well, but also for the financial pressure it was putting on my family.

It was when I was at my lowest that I was invited to a support group after speaking to some people online. When I said I'd go to the support group, I was really anxious about going to it because it was going to be my first time being around other visually impaired people, people with canes and guide dogs, it was like a glimpse into the future. But when the organizers of the support group heard that I previously worked as a singer, they said to me, "Would you come and sing some songs and be the entertainment for the support group?" That immediately took away that anxiety for me because that was my comfort zone being in that role.

Yeah, the poetry, the way it came about was literally the night before going to the support group, I was in bed going over ideas of songs to sing and I just thought it'd be really cool if I could take a song that everyone knows but change the words. I chose Stand By Me, by Ben E. King because the opening line of, "When the night has come and the land is dark and the moon is the only light we'll see," that was kind of the night blindness aspect of RP for me. I rewrote the song, changed the lyrics up, called it "Stand By Me RP," and performed it the following day. Immediately when I sang that song, people were coming up to me really emotional saying that the words that I'd written were able to describe how they were feeling about their experiences with low vision and blindness and it was really helping them. That was the first time since my diagnosis I felt like, "Oh, okay, this is something that I could do now. This is something that I could have a place in the world for and be of value."

Because from that moment of diagnosis, I went through that whole thing of loss of confidence, loss of independence, loss of pride, loss of purpose, but hearing the response to that song from people triggered something in me and I got my purpose back. That was where I started to write every day, sharing the good and bad experience of everything that we were going through because music and poetry, it's the same thing to me. It's song lyrics and it has that ability to impact people and make people feel something more than just speaking about it could ever do.

Ricky Enger: What an amazing story. It sounds like you honestly did stumble into it. It was just a thing that by happenstance you were asked to do, something that was within your comfort zone and then you found that what you were doing wasn't just therapy for yourself. I think a lot of people will process things differently, again, where they say, "I have some sort of self-care that I need to do, but this is mine. I'm not really ready to share that with other people." For you, it sounds like you immediately went from having discovered this thing, to it's your purpose and you saw that immediate feedback that this isn't just helping me, it's helping other people. I love it.

Dave Steele: I think with my past, previous to sight loss, I spent a lot of years, my formative years, my late teens, early twenties where I was alone a lot, didn't have a home, I ended up homeless quite a few times. There were times I was really struggling with my mental health, there were suicide attempts. I went through a really rough time and actually those things made me stronger. The way I look at it now is the things that we go through in our past give us the armor and the tools to face the things we get to face going forward. That's why now, fast forward, I have this ability, when I have a bad day, we all have our bad days still, whether you're affected by low vision or blindness or whatever, but when I have what I call my bad eye days and I'm really struggling with anxiety or making an adjustment, I'm now in a place where I can go, "Okay, I can take this negative thing that I'm feeling, I can put it into a piece of poetry, and it will help someone." That helps me and it's a really cool thing to do.

Ricky Enger: Yeah, absolutely. I know that vision loss is never, you go through something and then it's done. You're at the end of it, you've processed. It can be you have a day where you feel on top of the world and then you have one of those days where it just feels like everything is too much. Drawing on that strength of having gone through tough times before I can do this again, is that the thing that you think has really helped you on this journey? Is there anything else that you could point to where on your bad days you say, "This particular thing will help me get through it and I know it's going to be better tomorrow or the next day"?

Dave Steele: Yeah, 100%. Obviously there's drawing on past experiences. The way I look at things now is that it’s never at first the way it seems it would be. We get anxious about going to busy places, places we feel uncomfortable, taking that first step outside of our doors. As a parent, we tell our children the same thing. When they're trying something new for the first time, that actually once you do something, it's never as scary as you build it up in your mind, and that's true about these things that we experience in disability and sight loss and whatever else we go through. Knowing that it's never as scary.

Also, most of the times we really struggle it's actually down to us being frustrated and being hard on ourselves. I tell people, "Just remember that these things that you're feeling are actually perfectly normal and perfectly natural. Don't be too hard on yourself. Don't beat yourself up. Take your time to breathe, grieve, do whatever you need to do, and always know that anything in life, it'll pass. The bad days, they always pass."

Ricky Enger: Yeah, that's fantastic advice. I think we could all be a little kinder to ourselves regardless of what it is that we're going through and just be willing to try it, whatever it is. It's not going to be as scary as ... The imagination is a wonderful thing, but it could be a terrible thing at times as well because you build up so many things in your mind and turns out it was nothing like that.

We have talked a lot about your poetry, but we haven't actually gotten a sample of it just yet. I think listeners are on the edge of their seats hoping that we'll do that. I'm wondering if you would be willing to just share something that you've written with us?

Dave Steele: Absolutely. Of course, I will. This poem is called "Blind Perceptions," and when I originally wrote it a couple of years ago, one of my friends in America said to me that it actually really describes quite a lot of aspects of living with low vision and blindness. I'm sure a lot of your listeners will be able to relate to this. It goes like this.

I know there’s strength inside of you  
though all you feel is numb  
Don’t be afraid as eye sight fades for what is still to come  
You will adjust in these words trust we share these tunnelled eyes  
A mix of strength with anxiousness the same in me applies  
My shins are full of bruises  
and my confidence misplaced  
At time self isolated  
felt the world too much to face  
So I’m here to remind you  
all the times we fail don’t matter  
There’s lots of misconceptions still let’s remind them of the latter  
It’s not that complicated  
change how blindness is defined  
Let’s educate  
articulate  
the many ways we’re blind  
It’s never all or nothing  
many shades and different views  
Yet there’s a stereotype they keep on printing in the news  
No wonder some of us have fears when out in crowded place  
They see the cane  
but can’t explain why we look them in the face  
There’s some of us who stay at home convinced of the excuse  
that because we don’t look blind enough  
there’s a need to be recluse  
Don’t waste your life on people whose opinions are way off  
Just swipe your cane with courage  
hold your head with pride aloft  
So never doubt what we’re about despite what some believe  
Come join me on my mission  
change the way we are perceived  
Won’t let the haze that fills my eyes consume the rest of me  
There’s more to life  
than edge of knife  
despite what I can’t see  
Try not to care as people stare  
with looks of vague suspicion  
But why should I explain to them the terms of my condition  
Though it’s much simpler to stay home  
won’t waste another day  
Their pity’s just an obstacle that’s getting in my way  
Though I am blind won’t be confined by others misconceptions  
This poetry that spills from me  
will change their blind perceptions  
Though anxious chest and days depressed  
have far from disappeared  
I’ve learned to breathe while I still grieve  
control these things I’ve feared  
My kids look on  
not on what’s gone  
but all each day I teach  
For if tomorrow their eyes pay  
life’s dreams are still in reach  
So I’ll not cry as vision dies  
won’t focus on the blur  
No point in holding on to how  
those days and eyes once were

Ricky Enger: Bravo. Love it. Thank you so much. Something tells me there's plenty more where that came from. For people who want to find out what you're doing, what's going on in your world, and of course get access to the poems that you choose to share, where can they do that?

Dave Steele: I'm in a really fortunate position now where literally if you type in "The Blind Poet" onto Google, all this stuff will come up, The Blind Poet, Dave Steele on all social media, Instagram, Facebook, and the likes of. Also, my website is theblindpoet.net. But with regards to literature, I've released four books now and counting, more to come. Three, which were named after that song, stand By Me RP volumes one, two, and three, which are just collections of poetry going right from the start of my diagnosis all the way through. The latest one that came out just last year was my first children's book, which is called Austin's Amazing Adventures, which is a book based on my son Austin. In the book, he's a young visually impaired boy with his best friend his guide dog and it's about helping children with disabilities be better understood and breaking down those needless social barriers and it's short poetic stories. Yeah, so really, really proud of all those. But yeah, if check me out and send me a message anytime.

Ricky Enger: Fantastic. We'll have all that information in the show notes so you all can check it out as well.

Dave, I so appreciate you stopping by, sharing your story, your poetry with us. It is so much appreciated and I've really enjoyed it. Thank you.

Dave Steele: Oh, my absolute pleasure. Thanks for having me.

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.