Hadley

I’m not as scared

**Tammy:** With just a few degrees of vision left, I'm stuck on the fence between two worlds. I don't have enough vision left to say that I'm very sighted, but I also feel like I'm blind in so many ways, I don't see well enough to say that I see.

**Marc:** This is Hadley’s Insights and Sound Bites, where people facing vision loss share what has helped them cope and adjust.

**Tammy:** Hi, my name is Tammy Sue Blastone from Presque Isle, Maine.

I was diagnosed with retinitis pigmentosa. I kept running into things and I had five car accidents, and I didn't know what was wrong, and so I worked at a hospital where the ophthalmologist worked and I went to see him, that's what he told me. He actually cried when he told me.

So, it took me, believe it or not, two and a half years to give up my driver's license. It was really, really hard to do.

So, career-wise, I was a registered nurse. My vision before COVID hit was down to probably about 10 to 12 degrees. For some reason, after COVID, it went down to five to six degrees.

So now reality's truly setting in. I really was hopeful when I had the 19 degrees that held on for so long. I said, "Okay, they always told me, ‘If it gets below 10 degrees, you're going to lose all your vision.’" So, as I stayed 10 to 12 degrees, I said, "Okay, okay, if I can hold it here, I'm not going to go blind, I'm not going to go blind." But then the reality really hit, okay, I really am going to lose all my vision. So, you don't know what to do with that. I didn't know what to do with that. I probably, still to this day, I don't know what to do with it, but I still have five to six degrees and I'm still struggling.

We moved into a town, we bought a home in town so that I could walk different places now, where I can't drive. I can go to the store, I can go to my chiropractor, I can walk to my doctors, I can walk to the hospital, I can walk to my eye doctors, and that's good except for I started falling.

So, I was talking to my girl-friends and we started talking about guide dogs, and they're like, "Yes, you need a guide dog. Oh, of course you need a guide dog."

And I'm like, "You don't understand." My husband has always said, "No, no dog. We will never have a dog. Never." I've been married to him for 38 years and never, he meant never.

My sister started sending me YouTube videos of Paul Castle, if anybody is familiar with him. He has retinitis pigmentosa. And at the time he had about the same amount of vision that I did. He was showing examples, and he had the guide dog, Mr. Maple, if anybody knows Mr. Maple. He did short little things about how much it helped with his independence, and he just didn't feel good using his cane. He felt like he was on display, and it just didn't make him feel good. But with a dog, everybody loves a dog, and you get independent, and everybody talks to you and they're happy to see you. “Oh, look at the dog.” You're received differently with a dog. And my husband was in the room when I listened to all those videos and all of a sudden one day my husband came to me and said, "You can have a dog."

Best day ever, because I was on a plane in a couple of months to go to Guiding Eyes for the Blind, and that's where I got Bidal. The best thing ever to happen. He is such a companion to me. I'm so independent, I can walk all these places again, I don't fall. He looks out for me. He's always got his eyes on me. I still have a little bit of fight that I have left. We always got in trouble in class for making lovey eyes at each other. He's awesome.

And let me tell you, my husband who said no dogs on the floor within 20 minutes of me getting home with that dog, and he loved this dog like child. We used to laugh at people that had dogs, the dog moms and the dog dads. We give up going into other stores just so we can go into dog stores and pick up dog toys for our dog. Enough said.

With just a few degrees of vision left, I'm stuck on the fence, or I feel like I'm stuck on the fence between two worlds. I don't have enough vision left to say that I'm very sighted. I am sighted, but I also feel like I'm blind in so many ways, I don't see well enough to say that I see. I have trouble reading. I feel like I'm a young elementary child learning to read.

Am I scared about my world going dark? Yeah. Yeah. I've been more scared. I'm not as scared. Bidal really makes me less scared.

Anybody out there with end-stage retinitis pigmentosa, I know you're not having fun. I'm not having fun in some ways, I see my vision changes moment to moment.

It's humbling. It's not fun. But I'm thankful. I'm thankful for the opportunity to share this with you, and I hope someone out there, I hope this touches someone, some small part of it. Hey, have a great day. My dog, he just walked over to me, so I think it's time for him to take a trip outdoors and it's sunshiny out. So, I'm going to go enjoy the sunshine this afternoon. Everybody else out there, you have a great day. Take care. Bye.

**Marc**: You never know who might need to hear your story. If you’d like to share with us, just leave us a message on our Insights & Sound Bites voicemail. By calling, 847-512-4867. Or, you can use your smartphone or computer and email us a recording to podcast@HadleyHelps.org.