Hadley

“Not butterflies and rainbows. This is hard stuff”

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

**Nikki:** My name is Nikki Leathers and I'm from Auburn, ME, way up north.

I have a rare autoimmune disease called Behcet's, and it's even rarer for women in the United States to have panuveitis eye involvement with Behcet's, but I'm the one that gets struck by lightning a couple of times.

So, I was diagnosed in 2014. It is a journey of vision loss because I've experienced sudden vision loss where I woke up and had no vision at all.

I've had at least 20 eye surgeries. I've been on multiple biological medications. It was almost a relief in May of ‘23 when I had a retinal vein occlusion and there was no more treatment. And so, then it was a journey of finding technologies and what I could do and not do.

I like Insights and Sound Bites, but sometimes it feels like everybody has butterflies and rainbows. And I try to get a positive part of it, but it's hard. This is hard stuff. There's grief involved. There's things you're going to have to let go of. I can't drive.

You know, I can’t see my children's face or their drawings and it's hard. But I do believe we need to look at any of the small wins we have, any of the positives that we can. But that's with everything. It's not just vision loss.

There is this moment that I've had to face several times and it's been really hard because of having lost my sight, gotten some of it back, and then lost more of it.

I had this hobby called letterboxing where I went out and found stamps in the woods and I would carve stamps and hide them for others. Carving stamps was my thing. And I have had to say goodbye to that and that is hard.

I found ways around it. I got a digital microscope and I could see a millimeter at a time of a line so that I could carve a stamp, and I did.

Part of me still isn't quite given up at all. I might be able to do something with puffy paint or tape, wishing I could still carve.
But when I've had to face that, I just can't do it. Every time that I put the carvers away and the carving material, it's like a death in the family. You know, it's like this love and this passion that I had. I love to, you know, make people smile with it. It was hard.

I mean, it's like it compels you. You can't really help it. But there's also something with letterboxing. I have a friend that I sent hundreds of stamps to that I've carved and she hid them all over the United States. So it does my heart good. It keeps me, you know, keep it on.

Sometimes that support can lead to a problem with dependency. I think that there's just this need to be aware of yourself to do self-reflection and really to know when it's going too far. When you got to say “This is challenging for me, but I still need to do it.”

Because sometimes we want to just hide and let somebody else do everything. But I don't think that has to do with sight loss. I think that's all of us.

Sometimes things are hard and we don't want to do it. And if somebody else is going to jump in and do everything for us, but I don't think it's good for us and I've been there and getting back out of that, it is a difficult climb.And you know, step by step, saying like, I know this is hard for me. I thank you for offering the help, but I need to do this.

**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.