Hadley

I’m not alone

Presented by Douglas Walker

**Douglas:** Hello, and welcome to Hadley’s Insights and Sound Bites podcast, where people facing vision loss share insights about what has helped them cope and adjust.

**Ashia:** Even walking around my house would be a challenge because you think you really know your house until you lose your vision completely.

I’m Asia James in Georgia. I was diagnosed with a rare neurological disorder called Benign Essential Blepharospasm and it's where I have uncontrollable eye spasms and I have eye closures and I don't know how long they'll close. Sometimes they close for a few seconds, a few minutes, or hours at a time, maybe about 10 hours at a time. I found out about this, I think it was in September, 2022.

I started panicking because I saw that there was no cure for this, and I was hoping and praying that this was not true. I was afraid to go outside. Even walking around my house would be a challenge because you think you really know your house until you lose your vision completely and then you struggle to figure out where you are.

So, I came across American Print House and I reached out to them. She recommended Hadley and really Hadley had changed my life because I got to hear soundbites of people dealing with issues just like me. Even though our conditions are different, we seem to be going through the same thing with dealing with it, dealing with grief, the stages of grief and acceptance and finding our way out of it.

What gets me through the difficult moments is knowing that there's a community out there that is experiencing similar things. The first feeling for me was feeling that I'm in it by myself. There's no one around to help me. They don't know what I'm going through. But with Hadley, that community, we all share similar experiences, even though they may not be exactly the same, we're similar. And that gives me hope, faith and confidence.

It's said so many times and I hate it to be a cliche, but it's true. Finding out that you're not alone makes the biggest difference in the world.

**Douglas**: Was there something that someone said to you or something that happened along the way that made all the difference in the world in helping you adjust to vision loss? We’d love to hear from you. 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.