Hadley

Losing Vision as an Artist

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, artist Chloe Duplessis joins us to share her creative journey with vision loss. Welcome to the show, Chloe. How are you?

**Chole Duplessis:** Thank you. Thank you. I am well, and I'm overjoyed to be here with you, Ricky.

**Ricky Enger:** And I am delighted to have you here as well. I've had a wonderful time just getting to know you a bit through other sources and learning about your work. And now I have the opportunity to ask you some of the things that I've been curious about myself. So, it's really wonderful.

**Chole Duplessis:** Beautiful. Beautiful. It's always interesting when people say they've come to know me through the work. That gives me such joy because I'm very interested in finding out exactly what your interpretation is of the work. So, I'm so excited about the questions that you have today.

**Ricky Enger:** Wonderful. Well, let's jump right in then. And I think before we really talk about your journey and the questions that I have for you, can you just give us a bit of background, tell us a bit about who you are and if you wouldn't mind also diving into your diagnosis and the story of that.

**Chole Duplessis:** Certainly. Well, I am an artist, a curator, and a historian based in Colorado. And I'm also the founder of Duplessis Art, and we are a working art studio and cultural consultancy. So essentially, I create work that is anchored by accessibility, equity, and healing. And that looks like, depending on the season of year, an actual exhibit that may be up anywhere from a weekend to two or three months to shows that actually travel. When they travel, I have the tremendous opportunity to actually have an artist talk, engage with communities all over the country around this work. I think what's unique about the work is because I am a historian by trade, all the shows that we do are one, accessible, but also secondly, they anchor and elevate the space, the rooms that we're in, these beautiful opportunities of community by elevating the stories of lesser known persons of color.

So, this may look like people who are ancestors. For instance, like Harriet Tubman, Cathay Williams, who I actually have a show that's traveling the country right now called Sister Soldier. She was the first woman of color to serve in the United States military. She was also the only known female Buffalo soldier. So, a lot of people have no idea who this amazing human was. We love those stories. Those are stories that I create art around. And again, taking into account the importance of accessibility. There's a tactile dimension to the work. There's always an audio version of the work. Just little things that we do to ensure that people can experience it, because as someone who is not just a person of color, but a wife, a mom, and someone who is navigating disability and vision loss, I am well acquainted with seasons of my life where there are things I wanted to really embrace or learn or do more, but there were limitations there.

So that simply just means that someone has not considered my experience, and because I am well acquainted with my experience, there's an opportunity for me to do that. We try to do that through the work. And I've been creating art for about 15 years or so professionally. I actually started in photography and then branched out into digital collage because I was living in New Orleans. And for anyone who has lived or traveled to New Orleans, it is this beautiful melting pot of just accessible culture.

From the moment you land or drive into the city, you may be in someone's second mind, you may have someone offer you food. It's just a really beautiful place with really beautiful, resilient people. And the photographs that I was taking and the collages I was making in that season were to really mark these occasions. So, I did that for a number of years, and then when I went into the professional realm for my work, working in government, working in community, I pushed my love of art to the side. It was just my beautiful stress reliever or opportunity to curate joy, so to speak. So, I did not do it. No one knew that I was actually doing this other than those who were very, very close to me until many, many years later.

**Ricky Enger:** And we'll get into sort of what happened after your diagnosis in just a bit, but can you talk a bit about your vision loss? I know that your vision loss is actually not the first experience that you've had when it comes to vision loss, right? You had someone close to you who also had vision loss, right?

**Chole Duplessis:** Yes. I was diagnosed exactly five years ago. And I am forty-four. So I had a late diagnosis of Stargardt disease, which typically, if you are familiar with Stargardt disease, most people lose their vision between the ages of 12 and 16. So I received my diagnosis much later in life, but I was already well acquainted and familiar with what it meant to have someone that I cared deeply for, navigate vision loss, because my mother has RP, and she was diagnosed when we were in middle school. I just remember there was a season of her being very dutiful and driving and PTA and all the things for us. And then over the period of maybe two or three years after her diagnosis, she was no longer able to do those things. So, she still was extraordinary, and to this day shows up for us in so many beautiful, loving ways.

But she did not drive from the age of twenty-six on. And as her vision began to decline, as young people, me and my two siblings, my brothers, we grew up with this awareness of just little things that we need to do to be of support to my mother. So that commitment, that passion to support persons navigating disability came naturally because of my mother's experience. And then when I went on to work in the workforce, oddly enough, I would always find myself, Ricky, in situations where I was being called upon or appointed to serve on behalf of persons with disabilities. I kid you not.

**Ricky Enger:** Wow.

**Chole Duplessis:** Yeah. And no one really knew that my mom was legally blind. Because my mom ran a beauty shop. She was active in our church; she was active in the community. So, unless you were close to her, you had no idea.

So, I just thought that was something that as I began to grow and progress in my professional journey, if there were ten people in the room, I was the one that was called upon to advocate or to represent the office. So much so that even in my first... I'll call it my first high profile position, because every position has value, but in this position, I had a lot of visibility. I was executive assistant to the mayor of my hometown, and I was also chosen to be the person from the mayor's office to manage the Mayor's Council on persons with disabilities. So here I was, late twenties thrust into this opportunity to engage with beautiful persons of all backgrounds, navigating all types of disability on a citywide level. So, I just think that my life has kind of prepared me for where I am right now in terms of having a measure of understanding that things do shift and change, but that I believe my life is very... It's divinely led and that it's helped me manage the news of my diagnosis.

By the time I got diagnosed, I was already thirty-nine. I had a filled life. I lived, I traveled, I had different experiences. I could not necessarily feel sorry for myself because honestly, Ricky, I was driven before my diagnosis. My diagnosis not only freed me, but really amplified that drive to do and see more, particularly because we had, at the time, a three-year-old child. We had just had a daughter.

So, in my mind, when I get the diagnosis, the very first thing I think of is one, how do I show up in this season? Because everything I've worked for the past 20 years to create, I thought required sight. I was wrong. It required vision, and that's a function of the heart. And I say that often because I really, really mean it. But the second thing was, how am I going to navigate the awareness that there may come a time when I am not able to physically see our daughter? So, I will tell you that for me, that was the toughest thing. That was the toughest part of my diagnosis because it will be my reality ultimately.

But rather than kind of sit in that seat, after much prayer, I spoke to my husband and I was like, let's just go. Let's just lean in. Let's lean in, let's show up. So, we just take every day as an opportunity to do the things and to value all of the things. There's no wasted space. There's no wasted energy. You want help tying your shoes, you want to learn this, you want to walk outside, let's hold hands. All these things that even now that I'm down 40% of my vision that is fuzzy because that's what Stargardt does. They're fuzzy. Some things are not in focus. Some things are just blurs of light. But for now, they're here. And when they're not here, they won't be here. But the memories will be here, hopefully.

**Ricky Enger:** Absolutely. And you actually used the words courage and clarity when you talk about this in other places. And I think just as you have really shared part of your life story, it's clear that you really were prepared in some ways because of your experiences to face this in a way that, courage, and clarity. Who thinks that when they get news like this? But you did that, you leaned into what you had, and you took the time to embrace where you were. You talk about actually how your diagnosis granted you the permission that you needed to fully embrace your creative calling. So, you had kind of put it aside for a bit. Can you talk more about that? How did this diagnosis make you say not, "Oh, I can't do this very visual medium anymore," but instead say, "Oh, I'm going all in?"

**Chole Duplessis:** With Stargardt disease, your essential vision is compromised. So, your ability to focus gets increasingly more and more difficult until it eventually goes away. When I started practicing my art professionally, I actually started, not in photography or in collage. I started working in digital. And people could not believe that because they were just like, you're legally blind. How are you working in digital? Well, it's the benefit of technology. You can take something that's the size of a fingernail and amplify it three or four hundred times. The detail that you have through technology to create digital art, sometimes, is even sharper than if you had twenty-twenty vision. It was outstanding.

So, I did that for a number of years when I first started my practice. And then I knew, because of the research that I had become acquainted with after my diagnosis, that eventually I was going to lose central vision, then peripheral vision, and then it was going to fade to black. So, I said, you can wallow in this season, or you can prepare yourself. And I had a real conversation with my husband, Sean, who is a tremendous partner and just a voice of support.

And I said, "I have been given a gift in the midst of this challenge that I know I'm going to lose my vision. A lot of people are not afforded that. What am I going to do to show up to prepare myself for the season ahead?" So, I shifted from digital to fabric because with fabric, I can now set up a system that allows me, based upon the ends of my fingertips, to actually categorize the type of fabric, the size of fabric, and how to show up and create work. I've already shifted. Once I found out last year that I had lost over 30% of my vision and I was nearing 40%, I said now is the time. I've only been working in fabric openly for about two and a half years, but this is where we are now. So, I'm no longer even doing digital unless it's a special commission.

**Ricky Enger:** Right. And when you were doing digital, what kinds of either tools or just anything about the mechanics of it that you think were different because of your vision loss that you might not have done if you could see better and believe that you always would?

**Chole Duplessis:** Well, believe it or not, I use Canva. If some of your listeners are familiar with Canva. It's just a really beautiful app that most people use when they are entrepreneurs or small business owners or business owners with big budgets who don't have capacity to hire someone to do digital for an event. You can do flyers and promotions and graphic design, and it's very, very accessible. So thankfully I started working in that before I started to lose big waves of vision. So, I was familiar with it.

And then I do a lot of work, sometimes, in Adobe that allows me to shift backgrounds and change colors and things of that nature. When I was working in digital, I would marry collage with photography. I would take pictures that I'd taken years and years and years ago and then go in and lighten them, darken them, or pull the pigment off of them completely or restructure them, chop them up digitally into pieces and put them back together. Almost like a puzzle of sorts.

I wanted to ensure that the work I was creating was work that connected with people on a heart level. That's very important to me. And as I continue on this journey with vision loss, it grows more and more important to me for that to be the case. So, we decided a few years ago to have audio tours for every exhibit that we do. Every time I release work, there is an audio component. And for that, we just use basic recording software that you can download for your phone. So, believe it or not, only two or three tools. We don't use a whole lot of stuff to create the work, and I'm still creating the work. I'm the primary creator for Duplessis Art. My husband is our project manager and also installs all of my shows. So, when I do big physical pieces, he's the person that is patiently hanging these pieces thirty feet in the air.

**Ricky Enger:** What I love as I'm hearing you talk about this, is that you're always going back to making your art accessible, making it inclusive. And I know that as a person of color, your art is absolutely influenced by your experiences and that aspect of your identity. How has that shifted, or how has your art been influenced now that you have added another aspect to your identity, which is a person with a disability, how is that affecting what you create or even how you create it? What's the influence there?

**Chole Duplessis:** We began to shift the work from just being work that we would exhibit to work that actually engaged people on a physical level, and that was accessible. And in this season of my work, as I lose more vision and dive deeper into individual stories of the ancestors and of beautiful elders of color that are lesser known, that contributed in extraordinary ways, I am more focused on creating a series of beautiful period rooms that allow people to have a glimpse into their own personal experience like we just did with the Sister Soldier touring art exhibit.

When you go to see the exhibit, you literally walk into a room that is curated like a sitting room from the late 1800s with aspects of original art and fabric that honor this amazing human, the first female buffalo soldier, well, the only female buffalo soldier. So that is how the work has shifted over the years.

Now, when I first started making news, I had a dear friend of mine who was a journalist, reach out to me and say, "I'm deeply proud of you. The work is very strong, and I want to offer you some advice." And because I care deeply for this friend, I said, "Sure." And she said, "You don't have to tell people, Chloe, that you are blind or going blind." I said, "What do you mean?" She said, "Well, I saw your press release for this show that's coming up, and it says, legally blind artist and historian creating da da da da da."

And I said, "Okay." She said, "But what I want to tell you is the work is strong enough to where you don't have to divulge or share or promote the notion that you are losing your vision, that you are now legally blind and will lose your vision."

And I sat with that for a few seconds, and I've known this person since I was literally in elementary school, and I said, "I appreciate that, but I want to share something with you. This is not a twist. This is not a pitch. This is not something shiny to bring people to my work. This is my reality. And if I omit that, then I minimize my work. I minimize my diagnosis, and I do not allow myself the opportunity to show up for myself and others in this season of life. I also know that even in this day and age, many people navigating disability feel invisible. They feel that they're not considered or prioritized. What does it say if I do the same? The work I'm creating now is a reflection of where I am in my journey and would not be the same work were I not losing my vision."

If I was not losing my vision. I have every faith, Ricky, that I would not be creating the same work. And I shared that with her, and she began to weep, and she said, "I am so sorry. I never even considered that." I said, "I know because you haven't had to, but there's something that you have navigated in your own journey that you've had to consider omitting." So, this work and this season of work, as we enter into 2024 and move forward, it's not just for me to be truthful in documenting my vision loss through the art and honoring these ancestors through these stories and these shows and these exhibits and artist talks.

It's a reclaiming of sorts, Ricky. It's a reclaiming. Everything that I sit right now with, every tool in my arsenal, whether it be a physical tool, a paintbrush, a computer, a needle, a spool of thread, or whether it be an emotional, mental tool or something that my grandparents and parents sowed into me, my faith, those tools. Everything I have right now is the result of my community and the result of this pursuit of community and faith. And my faith suggests that as long as I'm still here, I have work to do and there are people who will come to support the work. And that has been my testimony. If you had told me five years ago that I would be living in Colorado, making national news creating art, and doing it full-time with my family and my small child, and that the work would travel into places that were not traditionally supportive of people of color or those navigating disability, I would say, "Okay, let's see."

**Ricky Enger:** That is so incredibly powerful, just talking about how people with a disability can feel invisible or overlooked. And I know that there are people listening who are struggling with that diagnosis, and whether they are an artist or they have some other creative outlet that they're looking for, maybe they're feeling a little bit of trepidation and thinking, I can't do this. Things have changed too much for me. What advice would you give to someone who is struggling to reclaim that thing that they love, that creative outlet that they used to be good at, and they think it's lost to me now.

**Chole Duplessis:** Once you have it, you never lose it. It's always with you. Ricky, those are the lies that people would have you believe. First of all, you're always supported. That's the first thing. You're always supported. Even if you feel alone, you're never alone. Additionally, anything that has been near and dear to your heart over the years that maybe you placed by the wayside because of work, commitment, responsibility, family, all the things, you can return to, you can return to. One of the things that I am really, really intentional about sharing, every opportunity I have in this season with those who are open to listen is let this be a season of reclaiming for you. And look, in this day and age right now, you made it through a pandemic. How many people can say that?

**Ricky Enger:** Right.

**Chole Duplessis:** We obviously made it through a pandemic. And so, the reality is many of us know people or whole groups of people who did not, Ricky, for whatever reason. Maybe it was COVID, maybe it was something else. But about five or six years ago, when all this began to kind of quietly shift, many of the people that we loved and held dear were still here with us. Some of them are not. But we are. So, by virtue of your existence, the fact that you can actually hear this podcast right now in real time means that you are still here for a reason. You are here to create. You are here to nurture, to sow into others. And the only way to effectively do that is to sow unto yourself. Be unapologetic about your self-care. Be unapologetic about your need to connect to your creativity or to nature or to music, or to whatever brings you joy.

Make these things a part of your daily practice early in the morning, late in the evening, whenever you can find the time. Because one, that helps manage resentment because you're not just sowing it to everyone else, which is a real thing, but also, it begins as a gift. It's a gift you're giving yourself. It's a small joy. And here's the thing, for many people who are creative, for those of your listeners who are listening, a lot of people have this notion that unless you exhibit work, put out music, or publish the book, that you're not an artist. Two, that you're not creative, that's not true. The fact that you actually have this capacity, this desire, this longing, this loving is all that you need. It's all that you need. So, wherever you are in your diagnosis, maybe you've lost someone that's near and dear to you. Maybe you're in a different season of life, whatever you're navigating, just know that you don't have to wait for a big shift to embrace who you are and to really start this season of reclaiming. You simply have to choose to do so.

**Ricky Enger:** Love it. Wow. Thank you so much for that and for sharing your story and your journey, and you're clearly passionate about what you do, and that comes across. And for people who want to know a bit more about you, we will have a link to your website and various social media things in the show notes. Any final thoughts you want to give us before we wrap up and bring this to a close?

**Chole Duplessis:** Certainly. Well, thank you again for the opportunity to speak to your beautiful audience. I just want people to be encouraged. I know it's tough. I want you to be encouraged. And I want you to remember that your life has value and has worth, and that in the words of my beautiful seven-year-old daughter, Zoe, oftentimes those things that people would have you feel that put you in a category of less than are the things that amplify who you are. So, my vision loss is not to be minimized because it has changed my life and will continue to change my life and the lives of those that I love. But my vision loss, because I've chosen to view it that way, is my superpower. So, tap into your superpower because you have one.

**Ricky Enger:** Fantastic. Thank you so much, Chloe, for stopping by. I've really enjoyed our conversation.

**Chole Duplessis:** Thank you.

**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@hadleyhelps.org. That's P-O-D-C-A-S-T at hadleyhelps dot O-R-G or leave us a message on 847 784 2870. Thanks for listening.