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Hello to everyone tuning in and welcome. My name is Martel Catalano and I am honored to be sharing with you this presentation on Living Mindfully with Vision Loss. This presentation is for those living with vision loss themselves, and is also beneficial to family members or professionals living or working with those with any kind of vision loss, or really any kind of chronic or life-altering illness or disability.

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Over the next thirty to forty minutes I am here to explore some topics you may be familiar with – things like stress and mindfulness – and also get into some more subtle or specific discussions – things like self-worth, identity, and everyday practices. Together we will find ourselves getting closer to a place where we can meet vision loss with curiosity and compassion, how we can make peace with the cards we've been dealt, and how we can find some metaphorical light in a world that often feels very (metaphorically and literally) dark.

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But first, a little bit about me because you may be wondering who I am and why I am here to talk about all this. So again my name is Martel Catalano and I am known first and foremost as the Co-Founder and Executive director of a non-profit called Beyond My Battle. At Beyond My Battle, we help people reduce the stress of rare disease, serious illness, and disability through emotional support and educational resources rooted in mindfulness, awareness, and compassion. Services and resources offered through include educational materials, virtual support groups, the Beyond My Battle Podcast, and more – useful to both people living with and caring for those with health-related uncertainty.

I also have Retinitis Pigmentosa or RP, and was diagnosed at age 13 with this life-altering condition. I became an expert at subconsciously crafting problems – ones that I could solve or mend – to distract myself from the real problem of going blind – one I couldn't fix. I lashed out, put up walls, and refused to reflect on the TRUTH that I had a disease that causes gradual vision loss. It was just too hard. Depression and anxiety seemed easier to me, so I lived like that for quite a long time.

When I was about 25 though, I realized this was no way to live. I couldn't recall the last time I felt truly happy – or happy with myself. My health was a mess, my relationships with loved ones were volatile. I realized how stressed I was, and that my own denial and negative bias I had built up – which we will get to later – was causing my life to go by without me living in it. And somehow I knew deep inside that the only way to truly experience my life and not let it pass me by was to be honest with myself and others about having RP. It wasn't a light bulb moment like it sounds, but I got very serious about self-examination and self-inquiry – asking myself the difficult questions of why I disliked myself, why I felt a constant sense of shame, and how these subconscious beliefs lead me to outwardly believe things like that I was unlovable or a burden – as well as filling my personal toolkit with ways to reduce my stress.

Which is where the mindfulness came in. I studied with yoga and meditation teachers for years to come to the realization that anyone listening to has studied yoga knows, that it's not about poses on a mat, but a mindset. It's about cultivating a practiced presence. It's not about the cliché “letting go” of our worries, but rather “letting be” – accepting our life for how it is, which in

turn frees us from the shackles of how it SHOULD be. Long story short, I ended up starting Beyond My Battle with a friend of mine in 2018 to bring this message to the millions of people like ourselves. To educate and support people with the emotional or psychological battle that is oftentimes so much harder than the physical one. Which is why I am here today. I know what it's like to lose your vision. I know what it's like to rebuild as a family who lived in denial or anger about it for years. And I know what it's like to investigate our subconscious that holds us back from our potential happiness and consciously create a life that is less stressed, sad, frustrated, and anxious.

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Before we touch on mindfulness I feel it's important to touch on stress. Learning about stress and the different ways it presents itself in our life was truly step one in my personal journey because we can't reduce something if we don't know how it feels or behaves.

During my studies, I was able to form a relationship with a researcher, professor, and psychologist named Dr. Stuart Shanker. Shanker's framework for understanding stress changed my life and if you were at Visions 2018 in San Diego I spoke about this framework called Self-Reg a lot there. Using Self-Reg, I first learned what stress really is – the process of our body burning energy to maintain balance – and use the framework to understand the different KINDS of stress so I could better understand what was going on for me, since sometimes it felt really indescribable. Learning about the 5 kinds or “domains” of stress helped me be able to notice when I was stressed, start to figure out why, which then helped me communicate about it and ultimately reduce it. The 5 domains of stress are...

Biological: glare, darkness, tired, sick, hot/cold

Emotional: fear, anticipation, excitement, isolation, anger

Social: peer pressure, embarrassment, relationships, love

Cognitive: digesting information, planning

Pro-Social: empathy/feeling for others (like for our parents, spouse, kids), feeling like a burden

An example I often give is for people with RP we can't drive, so we have to plan out our days or weeks around public transportation or rides from others. This is COGNITIVELY very stressful, all the planning, and on top of it there is PRO-SOCIAL stress from feeling like we're asking others to take time out of their day for us. When we don't know this, we might be really upset or rude to people – I know I was – but when we know this, we automatically feel more in control.

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So, knowing about stress is really central to our journey if we are going to reduce it. And if you want to learn more about that I think the 2018 presentation is still online on the FFB website. But I want to now talk about this mindfulness approach to stress reduction. We hear the word mindfulness a lot today, but what does it really mean?

Well, the definition I use is paying attention or being aware, moment to moment, with curiosity and without judgment. That's it. It sounds so simple, but in fact, practicing mindfulness is quite difficult because the natural state of our waking mind moves around, weighs things against the past, plans out our futures, and spirals into all sorts of rabbit holes of thought. If you don't believe me, try it right now. Let's take a minute to just be totally here, observing each second (ONE MINUTE GOES BY).

You probably noticed during that minute some thought come up, right? We live our days like this, even when we're just sitting and relaxing. We are thinking about anything other than the moment so often that 99% of the time we don't even know we're thinking. In many ways we need to plan things or else we'd never go anywhere or achieve anything. But we certainly don't need to do this all the time, and decades of research now prove that by taking just some time each day to practice being present with focused awareness, that we end up, happier, less depressed, less stressed, more focused, and our health can improve in ways ranging from lower blood pressure, to reduced gastrointestinal problems, to even warding off additional illnesses. When we practice mindfulness – which we can do in many ways and I will get to shortly – we break that habit of being unaware of the present.

By breaking this habit we become more aware of the now, and while this sounds nice and good, that's not really why it's so beneficial. Sure, we love to feel alert and attentive to the present moment, but by increasing our awareness of the present we actually are cultivating a general awareness of so many things – awareness of why we respond to things in certain ways, awareness of what triggers us, why it triggers us; awareness of feelings of connection to others – or disconnection. When we tune into the present moment more frequently, we become more in-tune with our likes, dislikes, opinions, aversions, judgments, perceptions and possibilities. This is all very beneficial when we are living with a medical condition like one causing vision-loss, that is so out of our hands. And same for the family members of someone with a medical condition! We begin to awaken to how we feel and why, which can drastically improve communication between family members or loved ones, and serious improve the way we look at life overall.

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So the analogy from mindfulness pioneer Jon Kabat-Zinn I like to use when talking about or teaching about mindfulness is: Our thoughts are like a river, they are constantly moving, and we are swept up in the stream of thought nearly all the time as it runs rampant or maybe even turns into a waterfall. Mindfulness is the act of swimming over the bank and watching the stream of thoughts go by, listening to them, observing their patterns, and learning from them. I say this because as much as I talk about mindfulness with people – which is often correlated to meditation which I will touch on shortly – many think it has to do with completely emptying the mind. I hear all the time that “I just can't get my mind to turn off” when in reality mindfulness is very much the mind being on – it's just being on HERE not tomorrow or yesterday or what's for dinner or that thing you wish you'd said to your ex. And that's why it IS difficult because it IS practice to get your mind to be here, but it's not emptying it all. So as we learn about how to incorporate mindfulness practices into your life to live more mindfully with vision loss, just remember to not beat yourself up if your mind isn't turning off. It's not supposed to.

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Like anything, mindfulness is a practice. If we want to learn a new language we have to practice it. If we want to learn guitar we have to play it. If we want to get great biceps we have to exercise them. Mindfulness is like working out a muscle, too, but the muscle is your brain. That's why I want to share some ways to cultivate a mindfulness mindset. Some of these are widely known and some I've put my own twist on.

Curiosity - know that life is a forever-unfolding landscape of the unknown. While this sounds scary, maybe, at first, when we realize that we can't predict our futures or know what is to come, we allow things to just be the way they are and open our minds up to them.

Non-judgment - when thoughts or sensations arise, we work to not label them or judge them as good or bad, something we like or dislike, but rather just as is.

No goals - when we approach anything with a purpose in mind like "I'm going to get relaxed now" we automatically apply an expectation or desired outcome. Release any expectations and just be with whatever comes up. If you get tense, observe the tension, and so on.

Compassion - when we judge ourselves less we can have greater compassion for our lives and our own selves. At the end of the day, this is the way things are and we are doing our best with

Patience - enjoy the process. Anything that arises in our practice is an opportunity to be with it fully.

When we meet our mindfulness practice itself in these ways, we begin to live in accordance with them. Meaning when we judge our mindfulness practice less, we judge ourselves less; or when we gain compassion for our mindfulness practices, we grow in compassion for ourselves.

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Well, I have been talking about mindfulness practices but what are they? Remember that mindfulness is really just observing or paying attention, moment to moment, with curiosity and without judgement. So while meditating is certainly something we can do and where the research I was mentioning before comes from, we can practice mindfulness in many ways. Some popular ones are mindful walking, which some people even call walking meditation. Many times when we walk, we are paying attention to thoughts about where we came from, where we're going, or what's for dinner tonight. When mindfully walking, we focus just on walking with - we become aware of the changing weight, sensations, and speeds from one leg to another. We might notice the heel when it makes contact with the ground, then how it transfers to the ball of the foot. We might observe the pause between steps. Or how does the rest of our body moves while you walk? Going back to the last slide, we don't judge what we find, we just notice moment to moment.

Another easy mindfulness practice is mindful eating. There is so much literature on the many benefits of not just slowing down but tuning into our food - we pay attention to the texture of what we put in our mouth, or maybe even how it smells before. When we chew, we notice how many chews we take, or how the texture changes, and so on. Next time you eat, try it out.

Mindful talking is another practice that sort of starts happening on its own as we become more present. We might start to slow down our speech in order to more deliberately choose words. We might focus on the tone of our voice more, and certainly part of any conversation is listening, where we might observe how we feel when we listen to another. A bonus of mindful talking is usually that our conversations are calmer, more supportive, and less reactive, which is great when you're a part of a family where an illness or disability is present!

Lastly, the quickest way to become present is by tuning into our breath. It is always there for us, and takes just a few seconds. We can use our breath to become immediately aware of the here and now by observing a few inhales and exhales; using them to tune into bodily sensation, smoothness of breath, feeling the belly fill and empty, breath coming out the nose, and so on. This is my go-to exercise and immediately informs me of my level of stress in that moment; I

know that when I am stressed, my breath doesn't flow as smooth and I feel like I can't fill myself up as much. Placing a hand on the belly or chest also helps us find embodiment with the breath with directs our awareness to the present physical sensations from the breath's movement.

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And here are some more intentional exercises, meaning they may not necessarily happen every day like walking, eating, or talking, but we can incorporate them to continue to build on our practices.

One way that mindfulness really helps us as people living with or caring for someone with vision loss, or any chronic illness for that matter, is becoming okay with the inherent unpredictability our lives are faced with. Living with vision loss means large-scale uncertainty or unpredictability like how quickly we may lose our vision, or if we will be able to do big life events. Smaller scale uncertainties include going to a venue or doing something your friends are doing pending the lighting or accessibility of it, having to cancel plans if you can't get somewhere independently, or injuring ourselves from a fall. So, we benefit greatly from accepting the unpredictability that is life. Our minds, however, like things to be certain - they like predictability because it feels safe. Yet, uncertainty and unpredictability are the reality for everyone, and us moreso, so we are best served by getting comfortable with it.

Cultivating a Don't Know mind is a practice from my friend and author of How to Be Sick, Toni Bernhard. It comes from a long line of mindfulness practice that goes back thousands of years and is a great way to remind ourselves to question what we think to be a truth, and come back to the moment. When I say what we think to be a truth I mean just small things like "Will I be able to travel to my friends house alone this weekend" to larger things like "Will there ever be a cure for my condition"? We don't have answers to these things today, and that's okay, so we are best not to make an assumption one way or the other. We spend a lot of time making up stories or assumptions about the way life will go for us or our loved ones, but it's best to know that we don't know much of anything, at the end of the day. Any time we find our mind going down those rabbit holes, saying things like "I am never going to be able to do this" we can ask "Am I sure?" We realize we don't really know, and then not-knowing becomes okay. When we are faced with lots of not knowing, like with vision loss, this is a great benefit.

Toni also talks about an exercise in her book she dubbed the Drop It exercise. It is intentionally bringing in adverse thought into our mind and then intentionally dropping it, or coming back to the now. We can practice this to strengthen that muscle I mentioned earlier. Bringing something scary or sad into the mind and then bringing the awareness back to the present sounds, smells, or sights around you very quickly builds that muscle.

And lastly, mindfulness meditation is not only a centuries old practice but one so well documented there's no arguing its power. Mindfulness meditation takes everything we've reviewed here today into one simple act of paying attention - just to our mind. Instead of paying attention to food or steps or words, we pay attention to what is happening inside our mind, moment to moment, and whenever we notice it stray from here, we bring it back. We do this over and over and over again and there is no wrong way to do it and no way to screw it up. In fact, our mind HAS to wander for us to bring it back. You might find that your mind wanders 100 times in a 5 minute meditation and that is perfectly okay. We can use any cue, also, to help us come back to the present moment, like our breath or sensation. The key is to meet the thoughts

that arise without judgment - we don't get upset at the wandering mind, we just notice it and come back. Let's try it now for a couple minutes so you get the idea.

Closing the eyes or having a soft gaze down the bridge of your nose, come to a comfortable seat. Notice your body where it makes contact with the floor, perhaps feet touching the floor, or your legs on a couch or chair. Notice your hands and where they are, maybe placing them somewhere softly. Noticing your shoulders and observing if they hold any tension, relaxing them if that feels good. When a thought comes up, we don't push it away immediately pretending it isn't there or isn't worthy. We observe it for what it is in this moment, trying not to label it, and then coming back to the present, perhaps using the anchor of your breath to reunite with the now. When more thoughts come up, do the same, maybe even say "that's a thought" no labels, and come back. Trust in yourself to continue this practice for another minute (ONE MINUTE)

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As I wrap up my presentation here today I want to leave you with something.

I am sure many of us here have heard someone say that another person is suffering from a disease or illness. I can't count the number of times I have had someone refer to me as "suffering from Retinitis Pigmentosa". Every time I heard this, I politely stop them and remind them that I am, in fact, not suffering and that suffering is an assumption on their part. However, I did suffer for a long time, and I know that the pain and turmoil I experienced helped guide me to where I am today. In the first slide of my presentation today I have an image of a lotus. For those of you who can't see the lotus, it is a flower that is often surrounded by lilly pads, and this one is light pink in color with a nice yellow center. The lotus is a very symbolic image because it starts growing beneath the surface of very murky and muddy water. It has to fight it's way through that unclear, dark, dirty water to emerge at the top, where it then and only then is able to bloom into what is a beautiful flower that embodies a sense of calmness and peace. We ARE going to have hard times living with vision loss or loving someone with vision loss. I want you to know that the struggles we endure make us ultimately come out the other side so much stronger and more vibrant. We can allow our vision loss to be a teacher if we let it, guiding us through the muddy water to a place of greater awareness, compassion, and inner peace.

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I invite you to keep in touch with me either personally or by following the work we do at Beyond My Battle with applying mindfulness to illness, disability, or caregiving. At BeyondMyBattle.org you will find educational tools, e-books, the podcast, virtual support groups, and much more. Or you can reach me through my website at MartelCatalano.com for inquiries, 1-on-1 mentoring opportunities, or just to get in touch. Thank you all for watching and be well.