



Episode 31: ALS Podcast with Brooke Eby

June 16, 2023

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Mindy Henderson: Welcome to the Quest Podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest family of content. I'm your host, Mindy Henderson. Together we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities, and those who love them. We are here for you to educate and inform, to demystify, to inspire, and to entertain. We are here shining a light on all that makes you you. Whether you are one of us, love someone who is or are on another journey altogether, thanks for joining. Now, let's get started.

Ladies and gentlemen, today my guest is Brooke Eby. Brooke was diagnosed with ALS in March of 2022 after four years of confusing symptoms in her leg. She has almost 70,000 followers on Instagram alone and was recently featured on the Today Show. She hopes to spread awareness of ALS to as many people as possible, and my favorite part, to laugh along the way. Ruth, thank you so much for being here.

Brooke Eby: Thank you for having me.

Mindy Henderson: I am so excited to talk to you, and I have to say you have, as indicated by the intro that I just read for you, you have the most fun personality, and I

was watching the Today Show a couple of weeks ago, and I saw your story and you just have this likable way about you. You kind of can't help but like Brooke.

Brooke Eby: That's so nice. I hope people agree with you.

Mindy Henderson: Oh, I suspect they will by the time we're finished. So I'm going to dive in because there's so much to talk about. Let's start with your diagnostic process. Like I said, it sounds like it took about four years for you to get your diagnosis, which is not uncommon with ALS. That can be a tricky condition to diagnose for a variety of reasons. What was that journey like for you to get your diagnosis?

Brooke Eby: Yeah, you're right. It did take four years, so it was a long process. It started with me in 2018. I started limping. I felt like my left foot just felt funny. I couldn't push off. Every time I would step, it felt like it was just flopping down, but I've never heard the term foot drop or anything like that. So, I basically went to my sister, who's a doctor, and we just did a little living room test, and she was like, "Yeah, you've got foot drop.

You probably pinched a nerve, something muscular is going on." So, I went to the doctor and that was step one of a thousand of getting a diagnosis. I think ALS, it's a rule out diagnosis, so you have to cross off every other potential option, but in addition to that, it's the worst diagnosis you can get. I mean, you're told you have it, and you might have two to five years on average. So, I think doctors want to be sure that it's ALS before telling someone they have this terminal diagnosis. For me, I don't look like what you picture when you hear ALS. I think a lot of people picture their grandparents or friend's, grandparents who might have had it. Typically male, I think is what people picture because Steven Hawking and Lou Gehrig, the faces of this disease are older white men.

And so, I think for a doctor, it's not what you picture when I'm walking into your office. I'm younger, I'm female, I don't have any genetic markers of it. I think everyone was just hoping it was something else, but after four years, it's kind of couldn't be anything else. So, I was officially given the diagnosis.

Mindy Henderson: Wow. And I've got to say, I had the privilege of hearing a doctor speak last year, and this doctor is a world-renowned ALS specialist in Houston. His father was actually Lou Gehrig's doctor, and in listening to him speak about this condition, he said, and I don't know if this is a term that he coined about ALS or if it's widely known, but he said that ALS is known to be nice guy's disease. And have you heard that before?

Brooke Eby: I have. People comment that sometimes on my social media saying, "The best people get ALS." Yeah, I'll take it. I mean, I'm sure [inaudible 00:05:15] coping mechanism, but hey, I will take it.

Mindy Henderson: Yeah. Well, and we're going to get into your mindset and your outlook in just a minute, but I had to say that before I forgot to mention it because it struck me that he commented that just the nicest people, and maybe that's because the nicest, kindest, most generous spirited people can handle it. I don't know. But yeah.

Brooke Eby: I am totally in the boat of, I think everything happens for a reason, which I think a lot of people with any kind of diagnosis might hate when you say that. I think they're probably don't say that. I 100% believe it, and I always think certain people were picked for a reason. Steve Gleason picked for a reason. He has changed the whole landscape for benefits for people with ALS.

Brian Wallach, he has changed the entire legislative landscape. And then for me, it was a different type of face than people are used to seeing, and I just said, "I'm going to go for it with social media." So, I consider more of myself the awareness side of things. And so, I think all of us were selected for a reason. I doubt everyone else believes that, but in my mind, it's a very organized system of who's sick.

Mindy Henderson: Well, and I think it's a healthy way to look at things. I didn't share with you before we started this interview, but I actually live with neuromuscular disease myself. I live with a condition called Spinal Muscular Atrophy, and so I've been in a wheelchair my whole life.

Brooke Eby: Oh my gosh. Wheelchair girlfriend.

Mindy Henderson: Yes, yes, yes.

Brooke Eby: I'm in mine right now.

Mindy Henderson: Oh, nice. I have a Permobil. How about you? Let's compare models.

Brooke Eby: Mine's an EZ Lite Cruiser.

Mindy Henderson: Oh, okay.

Brooke Eby: I know this sounds super cool.

Mindy Henderson: It does sound cool.

Brooke Eby: I'm just wanting it. I borrowed it in January and I've yet to give it back because I can't live without it now.

Mindy Henderson: Yeah, yeah, I understand. But yeah, I think that, and like you said, people's outlook on these things are different, but I think that if you can look at it the way that you just described, or at least find some purpose in what's happening to you, I think that that's a healthy road path to take. So that's the mindset that I've tried to adopt myself. So you talked about how you are not what people might picture a lot of the time when they hear about ALS, and I think a lot of people may not even realize that you can get ALS in your 20s or 30s.

Is there any difference in diagnosis or in the way the disease progresses based on your age?

Brooke Eby: Not as far as I know. So, in terms of progression, I think that's one of the scariest parts about ALS is we don't know why people progress faster than others. So, I'm in a group called Her ALS Story. It's all women diagnosed before they turned 35.

Mindy Henderson: Oh, wow.

Brooke Eby: And the group grows. I mean, we're at 50 some members now, and we're adding two a month it seems. And we've seen four of our members in the two years since the group. One year, maybe since the group was created, we've had four members pass all in their 30s, some early 30s, and there's no difference between those four and then the rest of us. We cannot figure out why certain people progress faster than others. So, I don't think there's a difference in how we progress.

Sometimes I think it's tricky because I am so loud about my ALS and I think people say, "Oh, well she's younger. That must be why she's progressing lower." But it's not the case. It's just I happen to be a slow progressor, and therefore I can use my voice to spread awareness. But the advocacy landscape is so tough with ALS because people die so quickly that we don't have enough time for people to spread their story and spread awareness. In terms of the diagnosis, I mean, anecdotally, it does seem like we get diagnosed slower. It takes a longer time, but I don't want that to come across as me placing blame on the medical community because I do think it's just more rare for a young [inaudible 00:10:02] to get it. And like I said, no one wants to end a 30-year-old woman's life by giving them that diagnosis.

So, I think there's different reasons for why it might take longer, but I don't think there's research around how long it takes to get diagnosed. It's just stories that I've heard.

Mindy Henderson: Yeah, interesting. So being as young as you are with your whole life ahead of you, once you received your diagnosis and you had ruled out everything else, I mean, what is it like to be 30 ish and to get that diagnosis?

Brooke Eby: It was insane. I wish I documented more of it, but I was in such a state of shock that I couldn't even look at my phone because I knew my friends and family were checking on me and I had no idea what to say. I remember the moment perfectly when I knew it was ALS. I went to probably my sixth or seventh EMG, which is a test where they put needle... You know. I can see-

Mindy Henderson: It's not fun. Yeah. Yikes.

Brooke Eby: Yeah, I can see you shaking your head, but they stick needles in your muscles, and then basically have you flex those muscles to see if it's responding in the right way to your brain saying, "Move your foot."

That's not a medical description at all, but for the layman, just know that there's needles in your muscles and they can judge there's something behind it. But I had probably my sixth or seventh one, and they stank to begin with, but each one I had prior to, they had only seen denervation in my left foot. And so, this time the guy was doing the test, I figured it was going to be the same thing as the last six. So, I was making small talk, we were talking about shows we were watching, it was just any other day. And then at the end of the test, he rolled his chair right next to me and I'm like, "This is cozy." And he was like, "I don't like what I'm seeing here. I see it in your right foot now too." I think I immediately started crying.

I remember him having to grab the tissues, although I am not sure I even knew I was crying at the time. And I texted my sister and her husband, both doctors being like, "It's not looking good." And they were like, "What the hell?" And then that drive home was just me and my sister. My sister and I panicking on the phone. And that started a two-to-three-month period of shock and survival. Those were the times that I wish I documented because people can see me now and I'm upbeat, but it took time. I was grieving everything I thought my life was going to be. I was picturing myself having a family, my career continuing, and I just started thinking about those things one by one of, I guess I'm never going to do that. I don't know how long I have. It's just a really weird concept to wrap your head around.

So, I think after two to three months of that, I kind of just stopped trying to think how long do I have? It really doesn't help to think in that way. And so, my brain adapted. I learned over time, but I don't want to give anyone the impression that this has been my attitude from the beginning because it was bleak. I ate so many M&M's. I can't even quantify the pounds of M&M's that I ate. And I think I read a book a day because I was just trying to escape. But yeah, I mean, a year and three months later, I can look back at it and I just want to give myself a hug. But I'm in such a different place now.

Mindy Henderson: It's incredible. It's incredible. You're so good with words. And you said something a minute ago, I think you should write a book and you said, "Shock and survival," and that would be the perfect name for your book. I just want to throw that out there in case it hasn't come to you. You've got your title.

Brooke Eby: Yeah, free idea. Thank you.

Mindy Henderson: Yeah. It sounds like your family and friends maybe were aware of what you were going through and the progression that you were going through with doctors and ruling things out. You mentioned texting your sister and her husband, but once you knew, how did you share it with friends and family?

Brooke Eby: I hated sharing it.

Mindy Henderson: Yeah.

Brooke Eby: [inaudible 00:14:59] so much. It was the thing that could take me from feeling stable to just a full breakdown. So, in the first week or two after I heard after that one doctor's appointment where he said, "I don't like what I'm seeing," I immediately told my sister, and my sister is a saint, and basically said, "Do you want me to tell the family?"

And so, we conferenced in my parents, and we told them. And then we did the same thing with my brother and his family. And actually, that was a moment that makes me giggle in hindsight, because my sister and her husband are doctors. They speak in medical terms when it comes to this stuff. And we were trying to explain it to my brother, and I remember he just cut us off and he was like, "English, please," [inaudible 00:15:53] thing.

And then after that, I like one by one told my closest friends, my closest circle, usually through FaceTime, and I would start crying before I could even get the words out. And they were like, "What is happening?" They knew something bad was happening. Most of my friends had known I had been limping for four years. And so, it was tough telling someone, it feels like it shouldn't have to fall on the person going through it, because I'm like, "I am putting this horrible weight on someone else's shoulders now when I'd rather just shoulder it myself." And it just felt evil to be like, "Hey, let me ruin your day for a second."

Mindy Henderson: Oh my gosh.

Brooke Eby: So, I started telling my closest friends, and then I actually, I told the group of friends that I grew up with through text, and their responses went from funny to hilarious so quickly that I was like, "You know what? I think I could make a really funny video about this." And that way I could just

share it with people, and one fell swoop and not have to do these individual calls.

Mindy Henderson: That's a good idea though.

Brooke Eby: I mean, there was a lot motivating me to make a TikTok, but that video, I think was my first one that really went viral was me telling my friends over text because I told them, "Look, I'm using a cane now. I don't know how much longer I'll be able to use the cane, blah, blah, blah."

And rather than any sort of sad responses, my friend wrote back, "Can I sign your cane?" And then one by one, each of my friends would, I would also like to sign the cane. And then someone sent me a picture of the Six Flags guy with the cane dancing, and it was just, it made me tear up because I was like, "Man, they're not treating me any differently than-

Mindy Henderson: I love it.

Brooke Eby: So yeah, that started my first viral TikTok video. And I think everyone just likes to see that no matter what happens, your friends are going to rack on you no matter-

Mindy Henderson: Yes.

Brooke Eby: I'm getting choked up just thinking about it. It was so cute.

Mindy Henderson: It sounds like you have amazing friends that have largely the same kind of personality that you do.

Brooke Eby: I mean, they're funnier than I am tenfold. And so after that, I started posting the videos to social media, and then I kind of stopped having to have the one-on-one conversations where now instead, people are coming to me already having me being able to process it on their own and then say what they wanted to tell me as opposed to, what do you say when you're best friends is like, "I have this horrible diagnosis." It's like, you almost want to say, "I'm going to give you a day. Call me whenever you're ready." So, I think the social media piece helped a lot with that because I was like, "Go figure out how you want to process this. Know that I'm okay and we're going to figure this out. I just want you to be in the know of what's going on with me." So yeah, I don't even remember the question you asked.

Mindy Henderson: No, no, no.

Brooke Eby: [inaudible 00:19:15] You tell me when to stop.

Mindy Henderson: No, this is perfect. And I'm trying to wrap my brain around how brilliant your solution to sharing this news was and I've never heard that strategy

before, and it's so smart because you're it's hard on both sides. You're already dealing with the diagnosis and the life change and all of that, and having the weight of sharing the news over and over and over.

And then like you said, it's hard news for someone else to hear. So, I think that that was so smart.

Brooke Eby: I mean, I think of myself when someone tells me if I have a friend who's like, "My grandparent just passed," I'm so bad at responding to that. I feel like my instinct is to make a joke or to try to make light of it and be like, "Well, I can't wait until he haunts you." But-

Mindy Henderson: That's exactly what I'm going to say the next time a friend tells me news like that.

Brooke Eby: Well, I feel like I never have. And two of my best friends are therapists. So, they have the responses of, "Do you want me to offer solutions? Do you want me to..." They know the right way to respond. I feel like I've never been good at responding. And so, I'm like, "I'm going to make an outlet for people who are bad at responding like I am, because I think it's a really hard skill."

Mindy Henderson: Yeah, it's so true. That's amazing. So I would be remiss if I didn't also ask you about the wedding that you talked about on the Today Show, because it sounds like that was something of a pivotal moment in your journey and sort of resetting your mindset. Do you want to share that story?

Brooke Eby: Yeah, no, it's a life defining moment that I was aware of in the moment of how big it was. So, I got diagnosed in March 2022. My best friend from college, I call everyone my best friend. One of my best friends from college was getting married in May, and I was a bridesmaid. I'm like, "Oh, crap, I have two months to figure out how to act normal about this." I was still at the point where if someone asked me about it, I would start crying. I wasn't in a stable position. And so, a bunch of my college friends were going to be at this wedding, and I was coming in with a walker, which how uncool must I have felt.

I was so self-conscious, just wobbling my way into the wedding with a walker in a bridesmaid dress.

Mindy Henderson: If anyone can pull it off it's you.

Brooke Eby: In hindsight, I look at the pictures, I'm like, "I still looked cute," but at the time, what a nightmare to say, "I'm going to go in front of my entire college group with a walker and just hopefully not have to answer too many questions because I'll start crying." And luckily, my two best friends in the world were going to that wedding real, I mean, all of them were at the wedding, but my two best friends walked in with me at the wedding,

and I looked over and I was like, "Can we just leave? I don't want to do this. I can't do it. Let's just go back to the room and hide." And my friend Jackie, who was all over my social media now with, "What if we just make it fun or it could be embarrassing or it could be really, really fun."

And we joke because three hours later we were like, "How do we get more attention on us by using this walker?" We started having so much fun. We were making people limbo under the walker. The bride was under the walker. I was giving people walker rides. I was the hit of the party, and I was just like, "Dang, people don't care about mobility aids, or they probably know I'm going through something just based on my physical appearance alone right now that they just want to have fun and see their friend." And so, after that wedding, I got COVID.

Mindy Henderson: Oh, nice.

Brooke Eby: Yeah, I got a nice little gift from that wedding. But yeah, it was a really long COVID, it was four weeks of just a really bad flu. I don't know if I hallucinated or what happened, but I took a bubble bath to try to break my fever.

I opened up the notes app on my phone and I started writing down things that I have found funny in the prior two months since being diagnosed. So, when my doctor was like, "You should gain weight. You should eat anything you want." My family was like, "You're so lucky." And we all started cracking up because we're like, "I guess that's not the word we should be using." But it was just little moments like that where I was finding any kind of reprieve from the depression. I'd been in. I wrote down this list and I showed it to Jackie at our next brunch date, and she was like, "We're making you a TikTok. We got to figure this out. There is something there." Yeah, I think the wedding was the spark that flipped my mood a little bit. And let me say, "How can I start enjoying this a little bit?"

Mindy Henderson: That's amazing. And I think it's also a testament to just the idea that if people love you, they love you.

Brooke Eby: They do not care.

Mindy Henderson: Yeah. No, but I think for the most part, it sounds like if not in all the parts, it sounds like the people that were there for you before have been there for you after.

Brooke Eby: Yeah. I think I've talked to some girls in my support group who have said they've lost friends because they weren't supportive, and they weren't helpful. I think for me, I'm 34 now. I was 33 when I was diagnosed. I think I had almost weeded out those sort of superficial friendships prior to that. And my group of friends, for the most part, I've known since I was in

kindergarten. Jackie and I have known each other since I was four. And then a couple of my college friends are sisters to me at this point.

And so those are the ones that I care about. That is my circle. And beyond that, I was like, "If more people want to be added into the circle, great." I haven't seen anyone pull away by any means. I will say if you want a dose of humility, your nieces and nephews, if you have young nieces and nephews, they will deliver it to you. Anytime I'm thinking, "Wow, I'm cool." I look at my TikTok following, my nieces are like, "You're not cool." If you ever need to be brought down to Earth, kids will do it.

Mindy Henderson: It's true. That's so funny because just last night I watched, have you seen Michael J Fox's documentary STILL on Apple Plus? You should watch it. It's awesome. But he said something to that effect also about his kids. He was like, "If you want to be brought back down to Earth," he said, his kids were like, "Could you just stop moving for a minute?"

Brooke Eby: I know.

Mindy Henderson: So yeah.

Brooke Eby: My niece the other day was sitting on my lap in the wheelchair and her legs fell asleep, and when she stood up, she's like, "Man, it's like I have ALS," because her legs were getting a wobbly. I'm like, "Oh my God." I mean, they're all under 10, so they don't even understand [inaudible 00:26:51] ALS. And we try to keep that from them for the most part.

Mindy Henderson: Right.

Brooke Eby: But man, they can find humor in anything.

Mindy Henderson: Seriously. That's so good. So-

Brooke Eby: You're going to have to edit it out so many times that I'm saying best friend, it's getting confusing.

Mindy Henderson: I know. I love that you have 87 best friends. That's amazing.

Brooke Eby: I know. They hate it though. Two of them text me afterwards and being like, "Heard you say best friend a couple times."

Mindy Henderson: I thought I was your best friend.

Brooke Eby: Yeah, no, it's competitive out there.

Mindy Henderson: Yeah, seriously. So how do you implement this mindset of joyfulness and humor? On a bad day when there are challenges and things, are you

always able to find the joy, or are there moments when you just can't do it? Or if you do, if you have figured out how to always find the joy, how?

Brooke Eby: Yeah. I mean, wouldn't say I have full bad days. I would say I've had bad moments. So I'll give a couple examples. If I fall and I can't get back up, which I can't get back up when I fall, that is a 100% hit rate, I guess is what [inaudible 00:28:10]. If I fall, I'm not getting up. Those moments are really bleak. Those moments when I just feel so helpless. Same thing when I transition into a new mobility aid, when I went from a cane to a walker and then a walker to a wheelchair.

I mean, that all happened in under a year of being diagnosed. I think nine months I was in a wheelchair. Those are the moments when I get upset because it's just a reminder that ALS is always taking, it's not a stagnant disease. It's always taking something from me. And so those are the moments I would say where I get down. But I think I recover pretty quickly. And I think a lot of that is because of the people around me. I've never been able to take anything seriously. I've never been a deep type person. Poetry, I don't even understand.

Mindy Henderson: I was going to ask.

Brooke Eby: No, I don't understand poems to this day. Deep stuff is not where my brain goes. That is not where I like to live. I want to live in funny land. So if I'm having a bad moment, I'll either text a few of my friends, call a few of my friends, or I'll put on, it used to be Harry Potter. Usually when it's cold out, it's Harry Potter. The rest of the year it's like a silly show. It's like Kimmy Schmidt or Crazy Ex-Girlfriend, which is my favorite show of all time.

I put that on and just kind of distract myself until it's over. But I don't know. I think your question a lot of people have, which is like, "Do you film a TikTok video and then go back into a depressed state? Do you turn off the video and then start crying?" And the answer is no. I think this is me 95% of the time. It's just sometimes ALS will surprise you with something and it'll catch me off guard and that'll get me. But the thing I keep coming back to is this is my path. This is my purpose. It would be really easy to get depressed comparing, seeing my friends having babies, seeing them kill it at work.

Those are the moments where I think a year ago, I would've broken down. Now I'm like, "That's amazing for them." I'm also doing amazing things just in a different, totally different-

Mindy Henderson: Oh, you so are. Yeah, absolutely. And I really commend you. I don't know, I may have said this already because it's so true, but I really commend you for using your voice the way that you are and bringing awareness to the topic. And I think also just affecting people along the

way and teaching other people how to find their own joy and how to maybe shift their own mindset. And as I was writing questions for this interview and thinking about what I wanted to talk to you about, I came up with the concept of a joy muscle that you have to potentially build over time when you are faced with something hard, or even, I mean, life, no matter how you slice it, life is hard for everybody.

And so, we all go through challenges and hard things. I know you said that you have always been sort of a joyful person who finds humor in everything, do you think that there's a joy muscle that if you're not sort of innately, naturally that way you can train yourself to build?

Brooke Eby:

I love that idea because with ALS, all of your muscles atrophy. And so, I think the contrast of building the joy muscle up, well, the rest of your muscles depleted. I love that visual. I don't know. I mean, I think if I'm looking at my support groups, it's largely filled with very grateful people. I think everyone has, I mean, we all have the same brain in a sense where it's going to protect us as much as it can. For me, that means not thinking about what could have been or the future.

I don't go there. And I think a lot of that is just my brain protecting me. So, I think that everyone is more resilient than they think, it's just how they want to approach it. I don't blame anyone for not putting their story out there. That is such a personal choice. I'm very comfortable sharing. Obviously, you're probably too comfortable, but I think other people find purpose in other ways. I have friends who are really interested in advocating for research, and they're really detailed in learning more about research, others who want to focus more on legislation. I think a lot of people with ALS see the challenge that the disease has. I mean, it's so underfunded. They're no survivors. So, we don't have these survivor groups to help advocate for us. And so, I think we all have a purpose ahead of us, and we just use our different strengths to approach it.

Mindy Henderson:

That's a really great perspective because I was going to ask you, like I said earlier, we all have challenges and hard moments, whether it's ALS or something else. And I think that it's innately hard in something difficult in challenging times to maybe find the humor if we're not naturally that way, and to turn something bad into something more positive. And so I think that it's a hard thing for a lot of people to do anyway. And I love that what you said about everyone has their own gifts and ways that they may use a situation or look at their situation, but do you have any tips for anyone who might be going through something hard right now? If they're really struggling to find the positive side, what would you suggest they try?

Brooke Eby:

That's such a hard question. In your last question, I don't know how you're going to have to edit this, but something really interesting happened. So, the New Yorker is doing an article about ALS, and the journalist who

wrote it interviewed four of us living with ALS, and I think I was the last one to be interviewed. And I was talking about how lucky I am because I'm a slow progressor. I've got a good family, I'm still working, blah, blah. And he was like, "Brooke, you're the fourth out of four patients to call yourself lucky." So, every single person, I think is finding a silver lining in how they're lucky, which I just thought was incredible. And I was like, "Man, I hope he uses that somehow in the article."

Mindy Henderson: That gave me goosebumps. Wow.

Brooke Eby: It's a weird... And maybe that goes back to nice people get ALS. I don't know. But I don't think anyone gives themselves enough credit. When people come to me and they say, "I can never approach this the way that you do."

I'm like, "How do you know? Give yourself some credit. Because I didn't think I would. I knew I liked goo being goofy, but I didn't think I was going to approach a terminal illness with goofiness." No one expects it for advice. I mean, I think for me, the best thing to fall back on is purpose. I think if you get into the mode of comparison or into the mode of people are going to judge me, anything that sort of comes with the stigma of having a disease, or maybe it's not a disease, but it's something else that you're going through. I think everything has a purpose. And that's what keeps me going. I know that my whole life was training for the years that I'm going to be able to advocate for this. And so, I'm able to map those moments of training to what I'm doing now, and I'm like, "Wow, I really believe this was all meant to be."

But beyond that, put on a good show. Eat some Thin Mints. Those are my coping mechanisms is I eat a box of Thin Mints at night.

Mindy Henderson: [inaudible 00:36:51] you.

Brooke Eby: I don't know what's going on there. I can't stop. It's truly an addiction. But yeah, I mean, I think give yourself credit is my first instinct, because I don't think anyone trusts themselves as much as they should.

Mindy Henderson: Yeah, that's true. The word control popped into my head too while you were talking, and I think it's, I mean, I'm not a psychol a psychologist, I just play one on podcasts. But I think too, if you can let go of what you can't control like are other people going to judge me? You can't control that they are or they aren't. And I think it can be important too just to recognize what is in your span of control and to let go of everything else.

Easier said than done, I'm sure. But yeah.

Brooke Eby: I totally agree. But I don't even have to actively do that. I think for me, my brain does that for me. And I [inaudible 00:37:55] on my brain, it's an entirely different species inside of me, but the things I can't control, how

fast I'm going to progress, what I'm going to look like in five years, am I going to lose my voice? Those things I don't even think about, it doesn't cross my mind. And so, I think that's hard to explain to someone who's not going through something serious, but like you said, letting go in a sense of you don't have to actively say, "I can't control that." I think you just have to let go a little bit and trust that your brain will do it for you.

Mindy Henderson: That's true. That's a great point. So-

Brooke Eby: It's so hard to explain. It's so vague and meta, but hopefully it makes sense.

Mindy Henderson: But I think just the nature of what you just said, just let happen what's going to happen, at least in part, and I think you expressed it beautifully. I know that you are also a big proponent of ALS research and looking for treatments and things. What goals do you have in all of this? What do you hope will come of your public sharing of your journey?

Brooke Eby: Yeah, it's gotten more specific over time. So, when I started, the thought was just awareness. That was the one word. But a few months into that, I was like, "I don't really know what that means," because now I have this platform and this following of people who say, "Utilize us, deploy us. We are resources."

Mindy Henderson: Oh, wow.

Brooke Eby: So, you really have to start thinking, "What do I want from people? What can actually move the needle here?" And so, I keep coming back to really this one conversation I had with, there's an executive at Salesforce who's a huge ALS advocate, and he has been a guardian angel to me since I've been diagnosed. But one of the first conversations we had, he said, "It's a money problem." He's like, "I looked at it from a business lens. It is a money problem, it's an underfunded disease." And so, to me, that translated as like, "Okay, how can my community on social media help address this?" So I started making call to action, which I think are really hard to come up with and advocate, but as of lately, it's been one, call your congress person because there is a medication that's going to have an advisory committee in September called Neuron that has a lot of promise for early stage stage ALS patients.

So, call your congressperson and ask for that to be accelerated. I made that ask and a week later, the ad come was scheduled. I have no idea if it's related, but I fully give TikTok some credit.

Mindy Henderson: I think it's suspicious.

Brooke Eby: For moving the [inaudible 00:41:03]. And then the second, I've been doing fundraisers on my Instagram for research organizations for labs, and so

I'm asking people to donate on my Instagram and to share it with their friends. I think the more people are Googling ALS, if we can get a little uptick in that, I'll consider it a success. And then lately, I've been thinking how do we go bigger and how do we open up new revenue streams? So, I'm starting to target high net worth individuals and celebrities with my videos. I haven't put one out yet, but I put out a video saying, "Tag the celebrity that you want me to do a one-minute pitch to [inaudible 00:41:44]."

Mindy Henderson: Oh, nice. I love that.

Brooke Eby: So, people are writing Elon Musk or Taylor Swift or the Kardashians. And so, for each of those, I'm trying to think of a creative way to get their attention. So, for Taylor Swift, my niece who's 10, has an incredible singing voice. And so, I'm going to rewrite a Taylor song about ALS and have her sing it and see if we can-

Mindy Henderson: Oh my gosh, I can't wait.

Brooke Eby: I think it's a cute... People want to feel part of something. And so, I think for people to come and see that video and then be able to tag Taylor Swift, it's like I helped a little bit. And so little things like that. I mean, at this point, it's like me just going rogue and hoping something sticks to the wall. But those I would say are really the things I'm asking of people right now.

And that's my goal is like ALS, we're going to get a cure. Whether that's in 100 years or two years is directly correlated to money. The faster we can get money into these research labs; I think it'll just do speed to the next result. Whether that's a breakthrough on the science side that I'm not even going to understand, then that'll get to a breakthrough on the patient side, speed to impact is my number one goal.

Mindy Henderson: That's amazing. And you're so right. I mean, research is expensive. I've learned a lot more about the science and research that goes into developing these drugs over the last few years. And it takes, I mean, billions.

Brooke Eby: Yeah, it's like 2 billion a drug, I think on average.

Mindy Henderson: Yeah.

Brooke Eby: And the drugs that we have today, I'm able to take three of the drugs available today because they're not the genetic type of drugs. They are expected to slow down progress by a few months. They are not exciting drugs. I mean, it's exciting when anything happens for ALS, but the impact is not super exciting.

Mindy Henderson: Yeah. Well, I'm glad that you're benefiting from what we have available today. And I think that clearly people like you and the circle that you run in, I think that you're going to do amazing things for the progress of this condition. I am so proud to know you and happy to have been able to have this conversation with you. Final thoughts as we bring it home, what advice would you give to somebody out there who may be listening who may have just received their ALS diagnosis or have a loved one who was just diagnosed? What would you say to them?

Brooke Eby: The first thing I tell people always is to find a support group because that saved me at the beginning. You don't know where to start. I mean, whether it's an ALS diagnosis or maybe an anxiety diagnosis, it could be anything. I think finding a community of people going through the same thing is such a moment to exhale because you're like, "I finally can ask the questions that I didn't know who to ask to, and I can look around and see people who might look like me going through this," so you don't feel like such an outsider living [inaudible 00:45:08] world. So, find support and find a support group is number one. And I think two is that there's a role for everyone. Let yourself grieve for as long as you need. Mine was three months, but I'm a freak, and I think it probably should be like a year if we're looking on averages. But take the time you need to grieve and then use it as a purpose.

Again, not just ALS related. It could be for anything like SMA or whatever you're diagnosed with. I think if you're interested in social media like I am, there's a role for you there. If you're interested in legislation and going to the hill and advocating there, there's people to help you do that. There is a role for everyone. Or maybe you don't want to leave the house because you're uncomfortable. There's things you can do there too. I have friends who write blogs about ALS because they're like, "We're not comfortable talking in front of people, so we prefer writing." I also have people who sit around and call their congress people every day, depending on what your strengths are, use them to your advantage and turn it into a purpose, because otherwise it's really easy to slide into why me? But I think it should be more like it's me for a reason.

Mindy Henderson: Yeah. Oh my goodness. I can't think of a better note to end on. That was so well said, and I just can't thank you enough for sharing your time and your story and for being vulnerable and showing us all how to laugh. And again, just thank you for your time.

Brooke Eby: Thank you so much. It did kind of feel like therapy. I got to say. You are good at armchair psychology.

Mindy Henderson: Well, maybe I will make my title official then.

Brooke Eby: Yeah. Yeah, you should.

Mindy Henderson: Thanks, Brooke.

Brooke Eby: Thank you so much. This was fun.

Mindy Henderson: Thank you for listening. For more information about the guests you heard from today, go check them out at mda.org/podcast. And to learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved, and to subscribe to Quest Magazine or to Quest Newsletter, please go to mda.org/quest. If you enjoyed this episode, we'd be grateful if you'd leave a review, go ahead and hit that subscribe button so we can keep bringing you great content and maybe share it with a friend or two. Thanks everyone. Until next time, go be the light we all need in this world.