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Episode 16: Turning Pain into Purpose - An ALS Advocate's Story
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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. Thanks for joining. Now, let's get started.

Mindy Henderson: Today's guest is Sabrina Johnson. Sabrina lost her dad to ALS in 2019. The journey to diagnosis was hard enough, but watching her dad battle a terminal disease forever changed her. After a light bulb moment, she decided to turn her anger into ambition and started to advocate for patients and families with ALS.

Mindy Henderson: In 2021, she began Sabrina Johnson Advocate, LLC, to give those sitting in a lost state of hope she knew all too well, a place to receive support, resources and guidance. Sabrina has also become the Chief Operating Officer of I-Ally, a one stop shop of support and services for family, caregivers and their unique needs.

Mindy Henderson: Sabrina, thank you so much for joining me today.

Sabrina Johnson: Thank you so much for having me.

Mindy Henderson: Absolutely. I'm sure that this is a difficult subject to speak about, and I applaud you for using your voice to help others who may be going through challenges that you and your family know all too well.

Sabrina Johnson: Well, it definitely has difficult moments and something that I've learned along the way is I battled a lot up while going through it. So I feel like I'm a few years out of it reliving a lot of things, but I've also found how therapeutic it is for myself to heal while helping others learn from the fact that I did not heal when I really should have. And that I think is the most inspiring and amazing aspect of advocating for a disease that is not only so near and dear to my heart, but was such a turning point in my life as well.

Mindy Henderson: Absolutely. That's great insight. And something about storytelling, as you're sharing our stories is so, there're so many positives in so many ways. What it does for you and what it does for the person you're sharing with is fantastic. Would you start by telling us about your family's journey through ALS with your dad?

Sabrina Johnson: Absolutely. My dad was officially diagnosed in 2017, but I'd like to emphasize the fact that that is not when the journey began. ALS is a disease that typically takes about 18 months on average for a patient to have the official diagnosis from a medical professional. And looking back on my dad's struggles, as a family, my mom, brother, and I, we pinpoint around the same time as when we started to notice some struggles in my dad.

Sabrina Johnson: So for my dad, it started with some pain in his lower back and tripping, falling. And my dad was a very cautious, overly cautious person. So you start in this moment of questioning like, is he over exaggerating? Is this really as bad as he's saying it is? We're a very close family, and so when you complain, you don't really take things necessarily so serious because we talk all the time. That's what you do. You talk about your aches and pains, the good and the bad, but then when his trips started to turn into falls and started to turn into emergency room visits and stitches and things like that, that's when all of our eyes really were like, okay, there's seriously something going on.

Sabrina Johnson: And the struggle was really watching that starting point of trying to figure out where to go and how to even get to a point to become diagnosed. And that is still something to this day that I see a lot of families go through. With ALS being a disease that does not have one test that gets you this, yes, no, or you go in for a blood test that tells you if you're positive or negative for something, you basically have to eliminate a series of everything else. And it falls into a time where, by the time you're diagnosed, there's no way to not know that you have ALS. And my dad felt for a very long time that he was going crazy because he knew his body was failing and knew something was going on. And every doctor had a different plan of attack, had a different way that they wanted to handle it. And so he was feeling very frustrated because he was being very consistent in what he was saying and how he was feeling, but it was never consistent in what the doctors were saying to him.

Sabrina Johnson: So by the time he was diagnosed, he was already at home in in a walker. He was wheeled into the appointment. And while it was a devastating diagnosis, I think that he had this moment of such relief and clarity, knowing that he was right this whole time.

Mindy Henderson: Yeah. I always say to people, in situations like this, you want there to be an explanation, but you don't want there to be something wrong. And so, I can only imagine what that must have been like for him. And 18 months, for someone with ALS, that's a lot of time. It definitely sounds like his condition progressed over the course of the diagnosis period. Right?

Sabrina Johnson: Absolutely. And yes, 18 months is a huge amount of time, especially when it comes down to the medical world of research and clinical trials and what you can and cannot be a part of. And it's so mind blowing now being on more of the advocating side and seeing things from a different perspective and really realizing how much of a difference even a week could make in somebody's diagnosis of whether or not they can participate in some of the amazing things that scientists and doctors and researchers have been able to put together. And so it's devastating them that time and time again we're trying so hard to ask for help. And by the time you are able to get it, you miss out on some of those amazing opportunities.

Mindy Henderson: And that was the case for your dad, right? Unfortunately he wasn't able to benefit from any of the therapy piece or treatments or clinical trials that were going on. Correct?

Sabrina Johnson: Correct. By the time he was diagnosed, he was already too far progressed to be able to participate. And then, a little while after he was diagnosed, his progression was, to nicely put it like manageable, doable. As a family, we're like, all right, we can handle this. We know that things have to change, but we can figure out a routine. It was about a year after he was diagnosed where then it was like a light bulb moment. I feel like once you flip that switch and start to really speed up your prognosis, it can go very quickly. And that's something that we saw with my dad.

Mindy Henderson: I know that you talked about just the ruling out of everything else, along the way to the diagnosis of ALS. Was there anything in particular that ultimately allowed doctors to diagnose ALS or was it just that everything else had been ordered out and his symptoms and the way that he was presenting looked like ALS?

Sabrina Johnson: I think that by that point, things were ruled out. But I remember, I feel like is one of the most heartbreaking moments as a daughter. My dad was like this big, tough guy, huge muscles, very intimidating man. It's like he never really showed emotions in a way that broke your heart growing up. And sitting in that room after the doctor diagnosed him, the first thing my dad asked him was, could you be wrong? How did you know? Your defense mechanisms go up, you want to just be like, no, you're wrong. You know nothing. You just have this moment of being like, I just don't want to believe you, even though I know that you're right. And the doctor looked at my dad and said, "Tony, I knew that you had ALS the moment I saw you." And that to me was so heartbreaking because he was at a point where his tongue was shaking when he would talk. And when he would get very flustered or anxious, it would twitch a lot more. And his biceps were twitching. To our eyes, it was noticeable.

Sabrina Johnson: So when you're with somebody more often and you notice it, you kind of put a blind eye to it and you think like, okay, maybe I'm going to just not see this, but for a medical professional to look at him and somebody who specializes it to have my dad be basically the screening billboard for this terminal disease was such a heartbreaking moment. And I felt so hopeless in that moment for my dad, because I knew how hard he tried to get help for so long, and then to have someone look at him and just know that there's no way that you're walking out of here without this diagnosis was such a turning point. And I think back to that part of his journey all the time to really kind of ground myself in a way of why I want to advocate for patients and families, because of how devastating it was in that moment of trying for so long and knowing then, now on the other end, what was to come.

Mindy Henderson: Yeah. You and I spoke, I think it was last week. And I got to hear your story for the first time. And I want to ask you a question about this because I know that there are groups of people who are at higher risk for ALS. And looking back, there was a car accident that your dad had just before his diagnosis that you mentioned. Do you believe the trauma from his accident could have played a role?

Sabrina Johnson: It's hard not to at this point. The more people that I have met that have been diagnosed, or the stories that I have heard from loved ones who have lost people to ALS is definitely mind blowing to find out the amount of people that have had some sort of life altering moment where their body was shaken in some sort of way. I feel like I've gotten to a point where time and time again, I am hearing people discuss a life altering moment prior to when their symptoms were showing.

Sabrina Johnson: So in my mind, I have to have this feeling where I want to know more, I want to dive deeper into, it can't be a coincidence, in my opinion. I just feel like if time and time again, we're hearing the same part of a person's journey, which is their body was somehow impacted. It just would be hard for me to believe that that has not been shaking and moving part of their body that is kind of activating it. And it is sad to me that I feel like people have had a life before their body has changed and then have had signs and symptoms, which have led to a diagnosis. It's hard to not kind of tie that in.

Mindy Henderson: Right. The diagnosis journey to ALS is such a topic of conversation these days and how we can reduce the time to diagnosis and all of that. There's just so much to talk about, but I'd love to move on to the next part of your journey. For families who are listening, what would you say is the most important first step that an individual or a family or both can take after receiving an ALS diagnosis?

Sabrina Johnson: One, I would say is first allow yourself to feel, feel in any way, shape or form. As a family, we all felt very different at very different points in time. And I think that everyone should allow themselves a moment of feeling. After that, I cannot emphasize enough the strength in your voice and in your heart. You do not need to settle for a multidisciplinary practice or team. Find what is right for you and your family. And you know instantly if you click with your medical team. And if you do not click, then you move on, find another team and find a team that will turn into your family.

Sabrina Johnson: This is going to be a very life changing aspect for everyone. I like to say that ALS is diagnosed to one person, but this is a disease that everyone ends up with. Everyone ends up with ALS. One person is diagnosed, the rest of the family is still affected by ALS. And so, you want to find a team that is going to care for not only the patient, but also the family. I think that you have to be able to be comfortable enough to use your voice to speak up for the person that is diagnosed. And I think that needs to start with being comfortable enough with where you're at, to find that comfort in yourself to use your voice.

Mindy Henderson: That makes a lot of sense. And you mentioned multidisciplinary care. Can you tell me about the different kinds of medical professionals that were involved in your dad's care?

Sabrina Johnson: Sure. Really cool thing. I think it is the multidisciplinary aspect because you have a big team, which is great. Typically, all over is you will have your neurologist and the nurse. Their nurse is also typically your care coordinator, the one that's going to continue to set things up on the outside of your ALS hospital, when you need to be seen by other places throughout your journey. Then you're going to have a respiratory specialist. They're going to be making sure everything's going okay with your breathing and helping with that part of when things need to change, or when things need to start to be altered and making sure that you are safe and comfortable.

Sabrina Johnson: Physical therapy and occupational therapy, they work together as well with making sure not only with your wheelchair, but something that I never really understood beforehand was the amazing things that occupational therapists could do with helping reteach you how to utilize life with utensils, writing, things like that. So it was really amazing to see how they would come in and teach my dad how to kind of retrain his brain how to brush his teeth differently as his hands and limb started to change.

Sabrina Johnson: You're also going to have a nutritionist and dietician team that comes in, and they're of a huge impact, not only at the beginning, but to help guide you through a transition into how you are going to start to handle the excess saliva that is a huge aspect with patients with ALS, and then how to eat safely. So as your mouth is starting to change, when it is time to start to get a feeding tube and transition that way. They're all then working together to make sure that you are safe and that you are, as your body is changing, that you are aware of what is going on and what will start to go on within your body. But then what I have really learned is they're really teaching the caregivers how to help make sure that the loved one is safe and secure at home as their body is starting to change.

Sabrina Johnson: That was something I did not understand while going through it. My dad got to a point where he did not want to go and see his team anymore. He felt like he was just being told how much worse he was getting. It was very hard for his mental health. But then you come to realize as caregivers that we're not then learning how to handle those changes. And as he was progressing, we no longer knew right then and there how to handle the changes of his progression. I think that the multidisciplinary team, while they're amazing for patients, in my mind, they are so beneficial for the ones that are caring for the patients, because they are making sure that you're aware of the changes that are happening and how to keep them safe as they are changing as well. Because I think that they want to try and hold onto their independence as long as they can, but to make sure they're safe while doing that.

Mindy Henderson: Yeah. And all of that certainly goes back to your earlier comments about really making sure that you have the right care team, and making sure that your team of doctors and other professionals are people who are really going to support not only the patient, but the family and the caregivers and all of that.

Mindy Henderson: I want to go back to something that you said when you, the point at which your dad really didn't want to keep going to his appointments and it was affecting his mental health. How did you all handle that?

Sabrina Johnson: It was hard. My dad was a very stubborn, stubborn man. And so, it starts off at first with like kind of bartering, like let's get through it, let's go. They're very long days, which is hard when you're trying to get someone who doesn't want to go, go to something that you know is just long, but then it also gets to a point where you're kind of in this between a rock and a hard place and what's worth the fight. But what is great about having part of the team is you also have a care coordinator that you can communicate with that we were able to explain what was going on and his fears. She is a registered nurse and a lot of, pretty sure all of them are registered nurses. She would come to their house and still make sure that he was doing okay or checking on certain aspects of things.

Sabrina Johnson: At that point, she was checking on him as well. Then as a family, we were starting to switch things over to more of a palliative and hospice nursing style, and kind of look at more things to get things to come to him. We knew then at that point where we want him to be looked at and to know what's going on. We've never been in this situation nor we have no clue what is going on or what to look for, what our warning sign, or [inaudible 00:22:03] lost for words. It got to a point then where to us, it was like, this is not worth the fight of fighting with him, with knowing then that his mental health was going to suffer before, during and after. That's when we really just started to switch things over to more of the palliative hospice care and started bringing things in more to the home so that he was still being monitored and cared for. And then we as a family... We compromised then as much as we could.

Mindy Henderson: That makes sense. Caregiving can be such a tough job. What advice would you give to other families out there to make the caregiving role, I don't want to say, it sounds funny to say as positive an experience as possible, but to make it as, to sort of streamline it and make it as okay as it can be for everybody. I know that you had a really amazing caregiver that you found, ultimately who really participated in your dad's care, but what would you say to the families who find themselves in caregiver roles and how to make it work?

Sabrina Johnson: Yes. Caregiver burnout is a huge thing. It's scary. It's scary for a lot of people, because I feel like once you get burned out, it's very hard to breath. What I could say and recommend is to not only ask for help, but to accept help. I think that that sometimes is harder than asking for help, is to accept it. Because a lot of people are coming to you with phrases like what can I do to help? I'm here to help, let me know how to help, but we're in a situation where you don't know how you need help and you don't know what you need. You need help, but what kind of help? And so, you get to a point where when people are starting to really offer help in ways where they are offering to bring meals, or let me come over so you could [inaudible 00:24:21] accepted, say yes, and don't overthink it.

Sabrina Johnson: Another amazing thing that I've put together through I-Ally is this care guide of asking for help made easy. And believe me, I'm like the last, this is still to this day a struggle that I have, even with my own husband, is how to ask for help and how to do this. I am no specialists on this, but putting together at the beginning, a list of your favorites and your typicals, I like to call them. So, what is your typical go-to order? Everyone knows when you order pizza, what do you typically order, cheese, pepperoni, sausage. Same with Chinese. Same with McDonald's burger, things like that. Putting together a list then of your family's typicals with groceries. We're a big fan. My kids only eat Yoplait strawberry. Giving them your family, a list of all of your typicals, grocery stores that are around you.

Sabrina Johnson: I live in a small town where Uber Eats isn't around here, but Grubhub is, things like that. This way, it allows people who want to help a way that they know out. They can help you without having to ask. So when they want to come over, they know what you normally get. So they could say then confidently, I'm going to bring you Chinese for dinner and they know what you order. They don't have to ask. And then same on the other end, while I loved when people would want to come and bring food, it was another thing I'd have to think out. I know I'm hungry, but I don't know if I want to burger or chicken tenders. I don't want to go-

Mindy Henderson: [inaudible 00:26:07] can get really overwhelming.

Sabrina Johnson: Yeah. It's such a nice thing, but I don't want to have to think about it in this moment. So having somebody help where you don't have to think is such a breathtaking moment in caregiving. And so, I think that that becomes such a winning moment where you are accepting help without asking. And then people are able to help where they know that they're helping in ways that you need in like.

Sabrina Johnson: I think that right from the beginning, you can just give your family a typical list of even, how do you communicate? I don't want to talk to you on the phone. I don't want to listen to a voice. If you send me voicemail or leave me one, I'm not going to listen to it. I'm just that. So letting them know that. Or like I love emails. Yeah. I will gladly email you a 12 page response. Letting them know things like that.

Sabrina Johnson: And so, it allows everyone to be on the same page. And I think that is the best way to relieve some of that caregiving stress, is trying to get everyone that could be part of this journey on the same page, because you're accepting and asking for help without doing it right at the beginning. And now everyone is just aware of how you work as a family, how it flows, what is going to make this a comfortable experience for everyone, rules and regulations and things like that early. And I think when it gives both sides, the ones that want to help and the caregivers expectations on both ends, it kind of sets the mood to have help in ways that people want to help and that you want people to help.

Mindy Henderson: Yeah. I think that's such great advice for so many reasons, because first and foremost, caregivers need care too. They need to be taken care of as well. So I love your point about you just say, yes, just accept the help. And the way that I've even learned to look at that is I think all of us have been in situations before where we have helped another person. And you know that feels good. I think our knee jerk reaction is to not want to be a burden, not want to be a bother. And so we say no when people offer help, but if you can turn that around and look at it as a gift that not only can you receive, but you can give the other person, by knowing that it's going to make them feel good to be able to help you, it becomes a win-win for everybody.

Sabrina Johnson: Absolutely. I think that is something I have to even remind myself when people are like, I want to help. I want [inaudible 00:29:04] there is to turn it and think about like they want to, it would make them feel very good to help.

Mindy Henderson: Yeah. And it's useful. And it's so hard to watch people that you care about struggle and feel like you can't do anything. So letting them do some things for you and participate is a great thing.

Sabrina Johnson: Absolutely. And I think it's such a great bonding time for friends and families when you're in this drowning moment in your life to really let people in that way where they're trying and they're offering, but you as well have to be willing to accept that.

Sabrina Johnson: I loved this idea that I saw online, where a woman sent a text to her friend. And she said, tomorrow night at 6:00 PM, I'm coming to your house. And I'm going to do like either a, where it was like, send back the emoji that you are agreeing with. It was like, let's say a monkey emoji. And take your kids out to dinner and you can be alone in the house. And then, I don't know, unicorn emoji. I'll bring dinner to the house and we can all eat together. And then dinosaur emoji. I'll have my husband take the kids and you and I can watch a movie and have dinner together. And it was like, one of these is happening, now you choose which one you want. And I love that.

Sabrina Johnson: And that is something that now I try and keep that in mind of how I want to offer help to people where you're letting them choose. Now the caregiver then in their mind is like, okay, I can pick which one I want. Do I want to be alone? Do I want to be with someone? Where am I on this spectrum of help? Also then as the person who's trying to help them putting their foot down and be like, I am helping you.

Mindy Henderson: Yes, exactly. Exactly. I love that. Like I said before, I know that you guys had a really wonderful caregiver who was incredibly helpful to your family during this time. And I think it was kind of by happenstance that you found this person. Do you have suggestions and thoughts or advice for people on where to find caregivers once that time comes?

Sabrina Johnson: First thing is to look for caregivers earlier than you think. Finding a caregiver though is difficult because you need to find someone that's going to be a part of your life. I make joke all the time that my dad loves two women. My dad loved my mom and [inaudible 00:31:52] caregiver then. You have to, not only as a patient that you're very vulnerable with another person, but also as a family that she was there. When I told my dad I was pregnant with my second, she was there for very, she held our hands as my dad passed away in front of us. She was there for such life changing moments of our lives. That to let somebody into such a vulnerable part of your life, all of you have to fall in love with the person that you're having care for someone.

Sabrina Johnson: Finding someone though, there're different aspects. And how we did it was on social media. And just on Facebook, putting that we were looking for a caregiver. A woman that I went to high school with reached out that her aunts who had ALS had an amazing caregiver and it ended up working in an amazing way. I think that the ALS community is such a great and strong and passionate community, that there are so many beneficial support groups, Facebook groups, individuals just on social media in general that, to me, that would be my far go-to, is to just ask, ask by word of mouth on social media and seeing what people in your area, or even at the local ALS support groups have. Because I think that's where you're going to find the most heartfelt caregivers, are from the people that have cared for other people in the community.

Sabrina Johnson: There are also different websites like care.com and different sites online that you can look for as well. I do think though, that trying to find someone that has worked with other patients with ALS is very important. It's such a unique disease that I think it's very nice to have someone that understands it. And we learned so much from Ostra, and she is honestly a huge part of why I'm doing what I'm doing today. Because while I realized how beneficial she was for our family, it took me a long time afterwards to realize how many families did not have an Ostra to really guide them. And I walk around now where I'm like, I want to be Ostra. I want to be the one that teaches you these tips and tricks and that explains the whys in the hows because she taught us all those little things, how to lift their shoulder just a little bit more this way when you're getting them into Hoyer lift or the little parts that make your day easier.

Mindy Henderson: That's fantastic. It's a really good segue actually, to talk about. I want to talk about your advocacy work. Would you talk a little bit about it and how you got started?

Sabrina Johnson: I always love explaining my aha moment because it doesn't get more COVID than this story. Right in the prime of COVID-ness, TikTok came out and that was, what you're doing when you're trying to hide from two young kids. I came across a TikTok video from a woman whose handle is Nurse Hadley, she's a hospice nurse. And she was explaining a conversation that she had with her hospice chaplain, because she was struggling going into homes where families were losing loved ones that were younger. And she had a hard time comforting them because she was becoming very emotional herself. And the hospice chaplain explained to her that if you look at everyone that is passing as them completing their purpose, then it becomes easier to see that them passing is like a celebration. And it's not a bad thing that they have completed their purpose here and they've checked all their boxes and now they get to move on because they can celebrate that they have done what they needed to do.

Sabrina Johnson: So I had this moment then of, what if my dad's purpose was for me to learn all of this? What if he needed to go through this so I could learn this so that I could teach people what we learned, those tips of [inaudible 00:36:22] and little things. So I sat on the couch and I must have listened to that video an obnoxious amount of times. And I jumped off the couch and grabbed my computer and sat at the table. I didn't even say anything to my husband, just grabbed it. And I was like, I'm going with this. I felt like if I said anything out loud, I was going to talk myself out of it. And I just had this moment of really feeling like if I didn't put our story out there, if I didn't put myself out there, that I wasn't allowing my dad's purpose to come full circle. And that just kind of really transformed everything and took off.

Sabrina Johnson: I wanted to start by just putting my voice out there and my story, to help people that felt alone while they're going through any part of ALS. I didn't check any backs. I was in my 20s, a young mom. I was already struggling with the transition of being a teacher before I had kids, just staying at home to living further from family. And now I am told that my dad, who I've looked up to my entire life, I've always been a daddy's girl is going to die. I didn't fit in with my friends because nobody else has a dad that's dying. So like, what do you talk about? I didn't really fit in with the caregiving community, because everything felt very directed towards my mom and her generation. So I felt like I was looking for something and it wasn't there.

Sabrina Johnson: And so, in that moment then, I was like, I want to put myself out there in every way that I have tried looking for, everything that I have wanted so desperately to find in any real search, I want to put on the internet so that if there's somebody else that is sitting there desperately searching to find their box, that they can hopefully find some part of my journey and just have that moment of feeling like she gets it. She gets that part of that heartbreak. And that was kind of what started it, was to just really allow people to know what we went through and to know that they're not alone in the highest of highs and the lowest of lows and that there are some beautiful parts of ALS as well. And that I don't want people to miss out on some of the beautiful parts of it because of the doom and gloom that surrounds it.

Mindy Henderson: Would you talk about some of those beautiful parts? I can't let that one go.

Sabrina Johnson: Yeah. Something that, and this is more of a recent one that I've been sharing is planning for my dad's funeral. I was 35 weeks pregnant, walking to funeral home with my mom and brother and writing his obituary while he's still alive. And you look at this moment where it's like, this is supposed to be such a devastating part. But before we went there to do all of this, my dad and I spent a couple weeks where we were able to have such heartfelt conversations that you don't typically have with your parents, because you're like, even now in my 30s, I get nervous telling my mom stuff because I'm like, am I going to get grounded? Like [inaudible 00:40:10], please still get mad at me. But you're in this time of your life where I'm like, let me tell you about this time in sixth grade when I got in trouble and didn't tell you.

Sabrina Johnson: And so, we were able to just open up about all these things in our lives that you just never think you're going to be able to do. And so, him and I just spent so much time diving deep into ourselves and to have conversations that were so comical and so life changing in ways, because you just know you're never going to normally have that chance. You're never going to sit there and typically open up to a parent in that way, or have a parent open up to their child in that way.

Sabrina Johnson: And when I think back on planning my dad's funeral, I laugh, because my heart skips a beat because it is so comical to me because I think of the funny stories. I think of him and I laughing hysterically about the silly things that him and I both did or how I thought I got away with stuff that he knew [inaudible 00:41:25] to be for that instance.

Sabrina Johnson: So I love thinking about planning his funeral. I love it. To me, it is one of those moments where I enjoyed getting to that point because of being able to have those conversations. You are put in a situation where you're allowed to be you, your loved one is allowed to be them. And you can be the most vulnerable part of yourself that you're never really allowed to be.

Sabrina Johnson: I think that it is such a life changing moment for the family members that I hope that more people take advantage of, and being able to allow themselves to be free in conversations and to open up in ways that they never thought that they would, because I could easily be sitting here talking about how his funeral was this devastating time in my life and all of these really sad, sad things. But to me, it's not. And I love that. I love getting to share that with people and to stress the beautiful part of that, because I want them to have that experience. I want them to be able to sit there and tell them about that time in sixth grade when they got in trouble and to have those laughing, heartfelt moments, because you're not going to get that moment back.

Mindy Henderson: That's amazing. I love that. I want to ask you also, with this advocacy work, what's your biggest goal for your advocacy work? You talked about wanting to be there for other families and wanting to be a teacher and all of that in the ALS community, but are there things that you want to see changed? What's your biggest goal there?

Sabrina Johnson: I would love for one, obviously I feel like everyone's going to say you want there to be a cure, but my big thing is I want the progression. I want there to be something that can slow the progression. I want people with ALS to be able to not look at it as a death sentence and to feel as if each day they can have a little bit more dignity. I also want to be able to fight for them legislatively to have more dignity and fighting for a slower progression and to be able to get people to understand what it is like for someone with ALS.

Sabrina Johnson: I think my big goal comes down to the whole aspect of using your voice, where I want insurance companies to know what it is really like to have ALS. How can you deny certain claims for a family with somebody with ALS if you have no idea if this is beneficial or not. So it goes back to the whole idea of getting people to really see that inside aspect of the disease, where I want people to understand what ALS is from a non-science part. What is the story of ALS? What is it like from the perspective of the family that is really going through it? Because I think what you understand the story of ALS, you have a better understanding of how to then fight and care for ALS.

Mindy Henderson: For sure. What are some of the things that people listening can do to help these things along?

Sabrina Johnson: Use their voice. Let their local representative know one, that they even know of someone that has ALS. And two, that they even know of ALS. That is a big one as well. A lot of people still are unaware of the three letters of ALS. So even just reaching out to your local representative and you can go on house.gov and find who your local representative is. And just even simply say, I am aware of ALS and I would love there to be more ALS awareness in our town, in our state.

Sabrina Johnson: There's so many amazing things going on within the ALS community with MLB having the [inaudible 00:45:48] stay and so many organizations having different events that are popping up. So something as simple as even just like, sharing and posting about things like that on social media continued to spread awareness.

Mindy Henderson: Any purging advice that would like to leave families with who may be listening and are currently going through an ALS journey with a loved one?

Sabrina Johnson: To not be afraid to share their story, during or after or at any part of their journey. I'm a true believer that sharing your story saves a life. You never know who is going to hear something and have that click. I think that letting yourself be vulnerable also allows so many people to be vulnerable to you. And sometimes the best way to learn is by releasing things yourself, and giving yourself a place where you can start to just comprehend what you're going through.

Sabrina Johnson: If you've been impacted by ALS, you are stronger than you know, and you will walk away from this a stronger person. And there is no way that you will not change the world by that strength. So share your voice and use that strength, and I think you'll be surprised by what can come from that.

Mindy Henderson: That's amazing. I love that. I think the last question that I want to ask you, I want to honor your dad. What's something that you would like everyone to know about your dad?

Sabrina Johnson: Well, he was an amazing dad. And a great way actually to honor him and to really learn about him is I just had a children's book that came out this last week about ALS. It's a story around the love that my dad and son had for each other and how my son did not really see ALS in him and still always asked him to be a part of everything and do everything. And so, a portion of each book sold goes towards a couple ALS organizations and it's called Breaker Breaker One Nine, Where's My Little Man At. My dad was a truck driver. He loved being a truck driver. And when he would call me and to see when my son and I were coming over, that was always something he would say, and I have voicemail saved. And that we love listening to it because we love now hearing his voice. And so it's my dad's voice saying "Breaker breaker one nine, where's my little man at?"

Sabrina Johnson: And so that then inspired this whole book that my then now oldest son who's in first grade, his class this year got to illustrate the book that all have come from the love between my dad and his joy for being a papa.

Mindy Henderson: Amazing. Thank you so much Sabrina for being here and sharing your story, sharing your wisdom. Like I said, I know that this is probably hard stuff to talk about, but the fact that you are out there sharing your story and helping other people is what it's all about. So thank you so much.

Sabrina Johnson: Thank you for allowing me to continue to share my story and for helping so many people get to share their stories. I really appreciate it.

Mindy Henderson: Absolutely.

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.