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Episode 49- Navigating Romance with MDA Ambassadors

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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.

Well, it is February, and romance is in the air. So, today I have three of our incredibly talented MDA ambassadors with me to talk about all things dating and marriage. Because ladies first, we have Nora Ramirez, who lives in California and was diagnosed with SELENON-related myopathy at the age of nine years old. She's one of four siblings with SEP1-RM, and Nora is a dog mom, a woman after my own heart, of two, and a wife, a daughter, and an aunt.

Next up we have KL Cleeton, who is an entrepreneur, get this, a poker professional, so interesting, I don't think I've ever talked to a poker professional before, and an influencer committed to empowering individuals to realize their potential. He focuses on startup development and motivates others to overcome their limitations, achieving more than they could have imagined.

And last, but certainly not least, I have Justin Lopez, who is a 30-year-old disability advocate and operations manager. Diagnosed with limb-girdle muscular dystrophy, or LGMD2B, at the age of 13. Justin has dedicated much of his life to advocating for disability rights and promoting inclusivity in both personal and professional spaces. As a son, brother, husband, and father, Justin understands the importance of community and support.

Thank you all so much for being here. Everybody who's probably listening is ready for us to get on with the show and talk about all of the dating, and marriage, and relationship tips. So, lots to talk about. I'm going to jump in. So, since we're here to talk about relationships, of course, as I already mentioned, each of you are ambassadors with MDA and are clearly accomplished individuals. Would each of you mind letting me know, let's just confirm your status, married, single, otherwise. Justin, let's start with you. You're married, correct?

- Justin Lopez:** Yes. Married and have a son, who is actually turning three in March.
- Mindy Henderson:** Oh, my gosh, such a fun age. Wonderful. And Nora, let's go to you next.
- Nora Ramirez:** Yes, I'm married. We've been married for seven years, and our two dog babies.
- Mindy Henderson:** Wonderful. What kind of dogs? Super important.
- Nora Ramirez:** A Maltese girl and a Bull Wolfhound boy.
- Mindy Henderson:** Oh, my gosh. So a little one and a huge one.
- Nora Ramirez:** Medium. Yeah.
- Mindy Henderson:** Medium? Okay. Wonderful. And then KL?
- KL Cleeton:** So, I am not married, but I am in a wonderful relationship with someone from the Austin area, and it's a long-distance thing, but we see each other as often as we can, and we're coming up on eight months.
- Mindy Henderson:** Great. Okay. So, let's just jump into it. I'm going to let whoever wants to go first go, someone's got to be the brave one, but tell me a little bit about your experience. Let's talk about dating, navigating dating. We all know dating in general comes with challenges. It's not easy for anybody. But then living with a disability, every now and then, it can make things just a little bit more complicated. So, what's your dating journey been like? Who wants to go first?
- Justin Lopez:** Yeah. I can go first. I would say, and mine was a while back, I've been married for five years now. I've been with my wife since 2016, so it's been a while. But I would say that dating was, even going through high school and then into college, it was unique. It was more of, I tried to keep it as traditional as possible.

When my condition would come up at the time, I initially began to hide it, actually. Stated that it was more of a leg injury, which I did have, but obviously, when I had the leg injury, it progressed, and we learned what it was, which is limb-girdle. But at the time, I really just kept it as, "Oh, it's just a leg injury." And then depending upon how deeper the relationship gone, that's when I opened up and explained more of my condition.

Mindy Henderson: You know what? You make a really good point, because I think that sometimes the society that we're living in, we have to downplay bits and pieces of who we are, whether that's a disability or something else, I think that it's a theme that probably can resonate with a lot of people, not being allowed almost to embrace all of who we are. Right?

Justin Lopez: Yeah. And I would say, just to add on to it, I lived on campus in Ohio, I went to Bowling Green State University, and so I would be walking to class, and at the time I was walking, I may have crutches or something like that, and someone may stop me and ask me like, "Hey, what happened there? Are you okay?" And for someone who's just asking simply what's wrong, I might give them a short answer, "Oh, yeah." I tore my ACL or something like that." Versus someone who really wanted to sit down and actually understand. So that also gauged whether I give you maybe a short story or maybe a long-term story too. So those are things that also played a factor.

Mindy Henderson: Yeah. Well, and to that end, I don't want to put words in your mouth, but no one is entitled to our story. And so while I say that, it's a shame that I think a lot of people in a lot of ways have to feel like they have to hide or downplay pieces of themselves. I think a lot of times we want someone to earn the right to know our story as well, even though it's not something that should be tied to shame. There's a trust factor there before we share. So, Nora, let's go to you. What was dating like for you?

Nora Ramirez: I feel like for me it was challenging just putting myself out there, even aside from my disability, my personality is very, even more back then, very shy and very just scared of people and the world, and everything. So, I tried to focus on that, and I tried to not even try to think about my disability and how I look, and what questions they're going to ask, about all the what-ifs and what nots. I try to not think about that. I already have this struggle to even get started. So, that was my main focus on building confidence and just going on dates, whether they were friend dates or getting to know each other dates. And working on that was my main focus. During dating stages, I never brought up my disability, even though it was visible and noticeable a lot of things. I needed to ask for help sometimes, but they didn't ask questions. I never had anyone I dated ask questions, and I just didn't bring it up myself until that's when things got serious and we were in a relationship, and that's when I opened up to him about it.

Mindy Henderson: Yeah. I see a theme here beginning to emerge. So, I'm going to come to you in just a second, KL, but Justin and Nora, did you guys date a lot? What volume are we talking about?

Nora Ramirez: I did in college. Yeah, I did. I wanted to really get to know what things I liked and didn't like in a partner and dating, and all of that. I think I was scared of committing to something that doesn't work out, and it's like being vulnerable with someone, and then it turns out we're not compatible, so I wanted to do a lot of practice just dating, but they were just casual dates.

Mindy Henderson: Well, I think that's important anyway. Like you said, knowing what you want, what you don't want, what's important to you, that takes a minute and it takes a lot of experience and dating different people. Justin, did you date a lot?

Justin Lopez: Yeah. I would say I definitely did. I would say that similar to what Nora just said, as far as we are people, we are just as people as everyone else, so learning what you like, what you don't like about an individual and trying to find that connection that's genuine. But I also think a connection that you can trust, even at a higher level, in comparison to maybe other relationships or traditional relationships. Because obviously, as we embark on our journeys with the ones that we have now, it requires a lot more additional confidence in that significant other to do some additional responsibilities, different things of that nature. So, I would say that definitely early on, I was definitely dating a lot as far as getting to know people, things of that nature. And then towards my later years of college, I really wanted to settle down and find someone that I knew that I had a lot of trust in. I did.

Mindy Henderson: Yeah. That makes sense. So KL, tell us a little bit about your dating journey. I know that you've got a girlfriend, it sounds like you've been together for a little bit, but did you date a lot before this?

KL Cleeton: Well, you talked about trends. I'm going to now [inaudible 00:11:51] trend, and do the exact opposite of Nora and Justin. So, my disability, I have spinal muscular atrophy, technically type two, but it's only because I have outlived type one.

Mindy Henderson: I see.

KL Cleeton: It's fine. So, my disability, my relationship with my disability was much more in the forefront. Most of the listeners probably are aware of what SMA is, but for those who aren't, I compare it to something like being paralyzed from the neck down, but I feel everything, but I have no movement whatsoever. So, because of that, my fear, my struggle was that burden of confidence. I was going to be a burden for a romantic partner and nobody could ever really see past the wheelchair and the super skinny arms, and all of that good stuff.

And what I found was the few times I did put myself out there, it just led to heartbreak after heartbreak. Not in the, like you see in the movie where they a [inaudible 00:13:22], they show up and throw eggs on your head. I'm not saying it's definitely like that, but just, oh, we're [inaudible 00:13:32] friends, things like that. But eventually for [inaudible 00:13:38] time and work on myself, what I

found was that I couldn't expect other folks to find me desirable as a romantic partner, if I didn't do the work to find myself worthy of that sort of compassion and that sort of romance, [inaudible 00:14:05].

So, I did that. I spent a lot of time on that work. And then whenever I did meet [inaudible 00:14:14] and we met online like basically everybody does nowadays it seems like, especially in a post-COVID era, I took a new tact, I took a new mindset into that. There was no expectation of like, oh, I'm looking for something or someone. Basically, it was just getting to know somebody new and in the process of that, getting to know someone, I was completely open and completely vulnerable in a way I hadn't done before. And that I was really lucky because that allowed me to get to know this person and for her to get to know me on, not a superficial level, but on a deeper, personal level.

And she knew about my disability literally from my message one. I was very open about everything. You could see my [inaudible 00:15:29] and my avatar, and my [inaudible 00:15:33] headshots and things like that. So, it wasn't like a surprise or anything. Yeah. That was my journey, my path, was first, convincing myself I deserved that sort of love and then changing my own behavior to make it where other people were able to see that I felt like I deserved it as well.

Mindy Henderson:

And that's so important what you just said because I also live with SMA and so I can relate to so much of what all of you are saying, and I've had my own experiences and things, but I think that, I've talked to a number of people over the years who have been forced into that self-acceptance as part of their dating journey. And I think that there's actually, that can be a little bit of a gift, if you want to turn this all on its ear, I think there are other people out there who may never get there with the self-acceptance and self-love, and all of the things that, like you're saying are so important, that need to come first before someone else can love you.

And so I think that that's, maybe, one of the sort of hidden gems or hidden gifts that some of us in this community come by because of the journeys that we're on. So, you've all touched a little bit on how you approached sharing about your disability with a potential partner. Are there any specific strategies or conversations that you found helpful in opening and understanding, and creating an open and understanding environment from the beginning or near the beginning?

Justin Lopez:

I think that it was very important to talk about what situation that explained what muscular dystrophy was from the beginning and making sure my wife had a solid understanding of what it was. Because obviously with muscular dystrophy there's an umbrella, a variety of different types. And so understanding my particular type was important to be able to explain because I think what we envisioned down the future was that, if in a situation where she needed to explain it to someone and say, my dog is going off, she would need to be able to talk about it and understand it. So, I think we talked about exactly what were limitations and what did those look like too at the beginning.

Mindy Henderson: What about you Nora?

Nora Ramirez: Yeah. For me, communication is huge. So, I feel like I made sure to set up just communication in general once we got serious, me and my husband after the dating stage, and worked my way up to telling him about my disability. And then when I did it didn't feel, it was still a little scary, but it didn't feel as, because we were already used to communicating and being able to talk about anything, nothing was off topic. So, then when I was talking about it with him, it was going down bullet points, it felt like, I just teaching him.

So, I was [inaudible 00:19:21] a mini class about muscular dystrophy and then I made sure to ask him if he had any questions because I didn't know if I talked too fast or if it was just too much information and he didn't hold any of it, so I made sure to ask. He didn't have questions and then we just continued normal. But he still continuously learning because some things it's different to talk about it and hear about it versus see it and experience it. So, [inaudible 00:19:51] a lot throughout the years and learn a lot and now he's a great advocate.

Justin Lopez: I think learning as you go along because, at least for me, no one else in my family ever had it. So, this was a learning thing for me as well. And at the time when we first started dating, at least when my wife and I started dating, I was still walking, I was able to take walks and steps and things like that. And then I progressed into using crutches a little bit more, then using [inaudible 00:20:19] and then [inaudible 00:20:20] to use to a wheelchair, then a wheelchair now to where I am now, which is a power chair. S, she's seen the journey of it all from the beginning. So, that was interesting and learning as a couple, how the dynamic shifts.

Mindy Henderson: Nice. KL, talk to me about first dates because, just to kick us off, when would go on first date, there can be a lot of anxiety there, particularly as a wheelchair user or somebody with a disability. It's all of the question, how am I going to get there and are we going to sit somewhere that's accessible, are they going to want to do something that's not accessible to me and all of those kinds of things. How, in the past, have you approached first dates and what kind of wisdom can you give our listeners about handling those situations?

KL Cleeton: Yeah. So, obviously, first of all, fellow SMA, I did not know that, high five, you and I. Yeah. I think that what it comes down to, I'll just use my first date with [inaudible 00:55:54] as a really good example because I think it was a really positive experience, but for some really key reasons that I think are reproducible. First of all, she's amazing, so there's that.

Mindy Henderson: I feel like you like her just a little bit.

KL Cleeton: Just a little bit. But also, I'm not going to lie, very fortunate that she is able bodied, but she works in or worked in the accessibility [inaudible 00:22:22]. She is a developer that worked on digital accessibility for a large portion of her

career. She had some basic knowledge and understanding. This is really, really helpful. But even more than that, having a partner that is just curious, interested in problem solving, interested, not in what can or can't we do, but "Hey, this thing isn't really doable, is there something we can do that's adjacent or adapting [inaudible 00:23:03] so we can do it?" And so what we ended up doing was our first date was very unusual by societal standards because, well, first of all she flew from Texas to where I live in the middle of Illinois. So, already she's making a massive leap of faith to that I'm not serial killer or something like that.

But because of the weight of that 1,000-mile distance, we talked a lot about everything before we ever came to visit. That was the last step to, is this real? Is this a thing that translates? We did something stupid, we drove over to St. Louis, which was about 100 miles away, which was a really big step by itself because she had to be shown how I need to be moved, if something needs to be adjusted, she had to learn some caregiver stuff. But she was like, "This is, forget it. My eyes are open. I know what this means. I'm not coming at this blind." But because of that communication and because of that understanding [inaudible 00:24:45], it made it so much easier.

And we went over to St. Louis, we had ice cream, we went to children's museum that was closed for the day, that had opened for a fundraiser. So it was a bunch of [inaudible 00:25:02] in children's museum. It was fantastic. And we've got photos obviously from that first day. I think really the reason that was so positive, from my perspective, and the reason it's replicable for other folks is because it was foundational on two basic things, which is curiosity and communication. And because each of us had both of those things, I think it made the evening something we'll never forget.

Mindy Henderson: She sounds special. I feel like you should hold on to her.

KL Cleeton: I plan too.

Mindy Henderson: Nora, what are some of your favorite first date activities from back when you were dating?

Nora Ramirez: Some of my favorites were, because of my overthinking part, restaurants that I was familiar with, that I knew what food had, how the layout was. So, I think I was in charge. I like to take control of where it would be just so I knew and I didn't have anxiety about being there. I also love nature. So, another one of my favorites was going to the park, specifically the parks that I liked and the areas and tables, and chairs to sit at. Because I think it also helped that there's things going on in the park, there's people, there's dogs chasing a ball, there's kids, there's even just the wind blowing on the leaves. So, it was a good space to be able to talk, to get to know the other person. And when there was silence, it didn't feel awkward because there was things going on. We could watch what was going on around us while we thought of something else to ask or to talk about.

Mindy Henderson: Very low pressure. I like that idea. That's a good one. So, Justin, I'm going to shift gears a little bit and ask you a different question, if you don't mind. So, let's talk about conflict for just a second. Conflict is natural in relationships, but it sounds like all of you are in what they refer to as inter-abled relationships. And so there are times, even if, and I don't know what your specific situations are, the three of you, but even if your significant other is not your primary caregiver, there are times when maybe you've had a horrible fight, but then you need help in the restroom or not to get too personal or getting into bed or something like that. And that can be a vulnerable time to need to speak up and ask for help, frankly. Is that something that you've encountered? And if so, how do you navigate it?

Justin Lopez: Yeah. Definitely. I would say that, like you said, in relationships, conflict happens. So, it's definitely, it's inevitable. And dealing with that situation where my wife is my primary caregiver, it definitely comes up where a pride thing has to also come into factor where you have to acknowledge, okay... And sometimes I think it helps the conflict I think because it's like you can't be mad forever, we have to come to an agreement because at the end of the day, maybe, "Hey, I need to get into bed" or "Hey, we both need to go get something to eat" or we need to go to an event or whatever the case may be. So it does work out sometimes.

I think what also needs to happen is that communication, like you said earlier, in the relationship, understanding that where we're going to have separate opinions and we're going to debate on things at times, but knowing that as a foundation of, hey, caring for one another regardless of the situation still needs to happen. It is important. But definitely there's been some times where that's been a learning curve for both of us, where my pride, I wouldn't accept my pride sometimes, I'll admit it, where I would end up, whether it's staying up a little bit later because I didn't want to ask to go to bed because we just finish something, finish argument or whatever the case may be. But it definitely does happen. But I think the best thing is just to be able to communicate through it. It is important to happen and understanding from that standpoint.

Mindy Henderson: Love it. Does anybody else have anything they want to add to that?

KL Cleeton: I don't know. [inaudible 00:30:07] ever in a million [inaudible 00:30:06]. No, I agree with Justin 100%. I think that, and the idea that, the caring aspect is tying to the cheat code to conflict resolution because like you said Justin, I still need to eat, I still need to have a drink or my face scratched or whatever it is. And so if we have a disagreement about whatever it may be, usually it's something really stupid and I'm the idiot, who's wrong, but at the end of the day it's forced to not be able to sit there and simmer and stew because eventually, I need to have a sip of something to drink [inaudible 00:31:05]. Eventually, we're going to be eating and she's going to be feeding me. And so it's hard to continue to let that simmer.

Justin Lopez: I will say though, there have been those silent moments of helping me feed [inaudible 00:31:26] or helping me get into the bed, there's been those silent agreements to help like, "Hey, I'm here just because I'm helping you, but we're still arguing."

KL Cleeton: You know what? Your significant other to absolutely be your champion to help you and whatever, and they can still be pissed at you at the exact same time. They are not either or.

Justin Lopez: Yeah.

Mindy Henderson: There you go.

Justin Lopez: Yeah. [inaudible 00:31:53] doesn't give you a pass, for sure. 1000%. And like you said, it's always our fault, right? Always our fault. Always.

Mindy Henderson: I'm so glad y'all know that.

KL Cleeton: [inaudible 00:32:06] know anything about that. She's never fault because she is the leader in the relationship. And so Justin and I, you and I are on the same page then.

Mindy Henderson: Very nice. Well, let's talk a little bit about people outside of our relationships and I'm going to let whoever wants to chime in here first, go right ahead. But I think there's times a stigma or a misunderstanding around the romantic lives of people with disabilities. Have any of you faced challenges in how people outside your relationship perceive your relationships and how do you address those misconceptions to foster a more inclusive or open mindset about dating and marriage?

KL Cleeton: I know I just got done talking and I promise [inaudible 00:33:13].

Mindy Henderson: Go right ahead.

Justin Lopez: Go for it.

KL Cleeton: [inaudible 00:33:14] would be absolutely livid if I didn't share this story because its equal parts horrifying and hilarious. The first time I went down to visit her in Austin, we did all the things [inaudible 00:33:32], but one particular evening we went to dinner just she and I, to a more upscale suburb of Austin. It's like where the Bushes live and all of that neighborhood. This restaurant had a beautiful, it was up on a real high hill that overlooks of below lands. Beautiful. The hostess was very kind, put us at a table right by the window. We ordered our flight of wine; we're having a good time and I'm not able to turn my head to the right. So, [inaudible 00:34:20] always sits on my left. And I did not actively see this, but I was getting real time updates, every, I don't know, probably a minute and a half.

Because there was a gentleman and his pregnant wife that were having dinner at the table beside us. And she is talking about, I don't know what, I'm going to assume new baby things or whatever it was and he is not absorbing a single syllable of what she is saying. And I was informed that the reason that he was not absorbing anything was because he could not wrap his mind at the table next to his. He was like, the way [inaudible 00:35:08] describes it was, he went from, "Oh, that's nice. Kid in a wheelchair and his assistant out for dinner. Oh, that's weird they ordered a flight of wine. Oh shoot, he's kissing her. Oh my God, that's more than a kiss." It just was like, the wave of emotions that this poor guy was going through. And we laugh about it even to this day. [inaudible 00:35:46].

Mindy Henderson: Justin or Nora, have you guys found yourselves in a similar situation or a dissimilar situation?

Nora Ramirez: I've just noticed stares, [inaudible 00:36:01]. I've had strangers come up to me and ask what's wrong? What happened? But other than that, I don't know what they're thinking. That could be thinking things. But [inaudible 00:36:13].

Justin Lopez: Yeah. I would say me and my wife's situation is even a little bit more dynamic because we're an inter-able, inter-racial couple. And so with that one too, my wife time and time again gets ask if she's just a caregiver for me, which is, depending upon the day, the time of day, that might not be the right question to ask her. It might get a little disturbing, but I think that, that definitely does happen though when it comes to the staring. Some people have had enough courage to come up and ask, which is interesting. And I think we just try to be respectful and understanding and say, "Hey, we're a couple, this is what happened."

There's actually been, more recently, in the last, later years where we've had our child and he was just born and people would come up and even ask, "Oh wow, that's your kid?" And they would just assume, assume that we're not able to have kids or things of that nature. And so that does happen. But I think, in public we try to keep it very educational to them because I think sometimes, I think people just don't know and it's okay if you don't know, if it's not in your day-to-day activities or you don't see it as much. So, we try to help people as much as we can. But it's definitely come up sometimes where we either, like I said, they've asked whether, "Are you a caregiver to him or what's going on there?" And we have to explain it.

Mindy Henderson: Yeah. I like that. I think that's a very gracious, all of you are very gracious in your outlets about it, and I'm glad to hear that there hasn't been anyone that's been horribly offensive about things like this. I think the only thing I would add is, in situations that have come up for me, I've taken the approach of just convincing myself that maybe they're looking because they're jealous that they're not with me. And so that's what I've chosen to believe sometimes.

Justin Lopez: Yeah. I will tell you that I've been perceived as other individuals, we went on our honeymoon, some of them thought that I was a professional athlete and that she was with me. And so we went along with that for a day or two. We thought that was funny. And so things like that happen, like you said, where people would stare and then we just go along with it. But we definitely keep it within ourselves and we laugh about it on the back end.

Mindy Henderson: Exactly.

KL Cleeton: I do like what you said about using it as an opportunity to educate them. Because I think we can do that and keep it light and funny at the same time. It doesn't have to be an either-or thing. It can be a [inaudible 00:39:27] thing. And I think, like you said, a lot of times folks are just, it falls into two tents what I gather, they either can't comprehend it and those are folks that won't be able to be educated as easily. But there are folks who are just legitimately curious and have that curiosity. And I'm a big believer of curiosity should be rewarded and not critiqued. Otherwise, how can we ever imagine wearing something new?

Mindy Henderson: Yeah. Absolutely. And you make good points because not everyone has disability as part of their life. And if it's not part of, I heard a saying once that I'm probably going to butcher, but if it doesn't exist for you, it doesn't exist. And so I think a lot of people who come into contact with something that might be new for them, while, I want to make it clear, it's not necessarily our responsibility to educate them, but it sounds like we're all like-minded in that we get it. We understand that this may be a new idea for them. And I think that if we're having fun, if we have fun with the situation, then the person's going to come away from it having had a good first experience, and a good exposure to something that they maybe didn't know about before. So, I would throw that in too, which I think is an extension of what all of you have said.

Unfortunately, we're almost out of time and I've got so many more questions. But as a relationship evolves, and I think Justin, you've alluded to this in some of your other answers, but not alluded to, but you were actually quite frank about it. Physical or health challenges may also change over time, particularly with a neuromuscular condition. So, how have you and your partner adapted to shifting needs? It's a hard thing to generalize, but whether it's emotional, physical, or logistical changes that need to happen or shifts that need to happen, how do you make those shifts to ensure that your relationship remains strong throughout the changes?

Justin Lopez: Well, I think the first thing is just having a conversation about how we're feeling about that situation and having it between us first, before we let any outside factors, family, friends, other opinions come in and crowd the judgment, and maybe cause conflict, or not even call conflict, but just change opinions because it can't happen. So, I think that we initially just talk about it as a couple first, talk about what things, either A, if we feel comfortable with sharing about the situation or doing or B, talking about how that affects you as a person, because I think that that's super important.

I think as I was transitioning from, I think the later stage of me going from maybe a [inaudible 00:43:17] to a chair, it was difficult for my wife to understand exactly what was going on and she's more of a, how do we fix it? How do we get it resolved? And it wasn't going to be a one size fit all kind of fix. So, again, it comes with more communication and more just education around it, so then that way she feels comfortable understanding exactly like, "Hey, this is the situation that we're in." And making sure that she feels that she has all her answers that she needs to be able to move forward.

And then also just, I think the other aspect of it too then is maybe letting up in other aspects of the life. So if she's taking on more responsibility at home, whether it's more chore responsibility, maybe we do bring in an additional caregiver to relieve some of those other responsibilities and things of that nature. So, it's a balance of, as something comes in or an approach happens, how do we make adjustments to, I guess, improve and make sure everyone's comfortable with the situation?

Mindy Henderson: I love that so much, that it's not about one person, it's about both of you and how you're both affected and what you're both experiencing, and making sure that all of those, both sides of the relationship are being accounted for. I think that that's really great. Nora, what about you? You've been married for a little while now. Is this something that you've gone through with your partner?

Nora Ramirez: Yeah. Definitely. Because throughout the years there's always, I feel like, something new, every few months or every year, a new symptom or just a new change, a new device I have to introduce to my life. So, it's been a learning journey for both of us. And I think just us remembering that we're on the same team and that having, a lot of the things that Justin said, good communication and addressing things before anyone else has time to say anything about it or before anything else, just being open with each other, especially me being very open about how I'm feeling, so he understands.

I have to remind myself that he can see things, but he's not feeling them, so it's not the same type of understanding, going through something as seeing it or hearing about it. So, it does help him be able to put himself in my shoes if I explain exactly how it makes me feel. And if I can openly tell him what things he can do. So, it takes the guesswork out of it for him, [inaudible 00:46:19] how he can help, I can let him know what I think, and trial and error maybe [inaudible 00:46:26]. So, we'll both brainstorm ways to, both of us, better adjust to the change.

Mindy Henderson: That's really good. So, I have to follow up that question with asking you, it sounds like communication is paramount in your relationship. Were you and your partner always, were you naturally good communicators or have you had to work on it? And do you have any advice if someone's not a naturally good communicator?

Nora Ramirez: We were both open to it and open to, we still continue to learn and to better our communication, and expand on it, and all those things. And it helped that I'm really into psychology and I went into that field to get my degree in it, but also, his personality style, he was open to the things I was teaching him. And for example, we have him take, us together, the love languages quiz. It opens up a new level of conversation and does take, we find things about ourselves that we didn't know. So, things like that. And having also, starting from the dating stage and boyfriend/girlfriend stage, I liked playing the, I don't know if it's called 21 questions, the game where we just ask back and forth. But we would play often enough to where the questions got deeper because we had to get more creative with the questions. We couldn't ask the basic, what's your favorite color? What's your favorite hobby anymore?

So, that also, I think, gave us practice, practice of asking deeper questions, how we word questions and being open to answering everything that nothing was off topic. You tend to address things or talk about things before we need to. It's easier or after, if something happens. I know I still struggle, well, for a while I struggled with, if I get upset, my go-to is like, I don't want to talk. I just want to close off. I just want to, wasn't sometimes even anything that he did, it was just like he didn't read my mind or he didn't read my mind [inaudible 00:48:49].

Mindy Henderson: I hate it when they don't read your mind.

Justin Lopez: We're sorry.

KL Cleeton: [inaudible 00:49:00].

Mindy Henderson: You guys are so good.

Nora Ramirez: Yeah. Being aware of it and then apologizing and fixing it. So it's just, I guess my advice would be don't be scared to communicate just because you don't know how to. Practice, it will get better and it will get a lot easier, and it will prevent a lot of conflict, a lot of misunderstandings, and a lot of things that are just not needed in the relationship.

Mindy Henderson: Such good wisdom and advice. Which leads me to the last question that I'm going to have time to ask all of you. And I think that we just need to all hang out every Wednesday afternoon and-

Justin Lopez: Sounds good.

Mindy Henderson: And be best friends because you guys are awesome. No pressure. But I am going to ask you as a parting gift to our readers, KL, what's your best piece of, and I'm going to come to each of you, but KL, what's your best piece of advice that you would give our community or our listeners, who maybe is just beginning to date or maybe is struggling in their dating life?

KL Cleeton: I think the biggest thing that is universal is just understanding that two basic foundational things. A, that you are indeed worthy and deserving of that sort of connection. And if you don't believe that, that leads to the second foundational thing, which is finding that sort of acceptance for yourself, in yourself before you can hope to have somebody else find that in you as well. And I think that's true of whether you have a disability or not. I think that covers the banner of the human experience, which is, you need to recognize that you are valuable as a human and you need to recognize that in order for other people to see that you are valuable and worthy, you have to be able to understand that, and truly believe that in yourself. The MDA community has a whole bunch of amazing resources, people that you can connect with, people that are going through similar experiences as you, that can give you that feedback. And so you don't have to do that alone, but in order to find love, you have to find the love for yourself first. Yeah.

Mindy Henderson: Love it. And I have to agree, I think, genuinely, I think this is the best community in the whole entire world. I love everyone that I've gotten the pleasure to know, all of you included. So Nora, let's go to you next. What's your best piece of advice?

Nora Ramirez: I go back to communication, I guess because that's what I've seen has worked the most and has helped the most. And not being afraid to put yourself out there, doesn't matter, any type of disability, it shouldn't interfere with dating because we're humans. And also, it's okay to ask for help during dates.

Mindy Henderson: Yes.

Nora Ramirez: The biggest obstacle is usually just putting yourself out there, whether it's dating or being vulnerable, in a committed relationship, whatever it may be, the first step is the hardest. But it does get easier, especially with practice. Whether it's practicing dating, practicing communication, practicing being vulnerable.

Mindy Henderson: So, true. And I am going to re-emphasize what you said about asking for help on dates. If they have a problem with that, you probably don't want a next date.

Justin Lopez: 1,000%.

Mindy Henderson: Yeah. So, I love that. And communication is the secret sauce, for sure. Justin, I'm going to give you the final word. What's your best, give me your best shot?

Justin Lopez: Yeah. I would say control what you can control, I think that's the biggest thing. Control the controllables, that's what I would say. So, that way you could be your best version of yourself on that date, so that way it's strictly about the connection, whether it's a genuine one or not. If it means that making sure that you're in an accessible spot for dinner, let's do that. Or if it means that, like Norris said, having it in the park or going to a movie theater, whatever it is,

finding something that's a comfortable setting for you to be truly yourself, that way it'll allow the data to actually take place.

And then you can be able to make that relationship either flourish or understand that like, "Hey, baby, it's just not compatible." But I think that you control those things first, initially, and then the other things that are uncontrollable, you get to a place that you find out the elevator is not working that day. Let that be a part of the story then and let that flourish into what could be. Those are things that are uncontrollable that are out of your hands. So, just do that and then you go from there.

Mindy Henderson: Amazing. You guys are absolutely fantastic. I can't thank you enough for spending part of your afternoon with me today and for sharing your wisdom with our listeners. And happy Valentine's Day to all of you.

KL Cleeton: You too.

Nora Ramirez: Happy Valentine's Day.

Justin Lopez: Happy Valentines Day.

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.