

Episode 12: Love and Marriage February 4, 2022

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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 all together,

thanks for joining.

Mindy Henderson: And thank you to our sponsor, Cytokinetics. Cytokinetics is dedicated to

supporting the MDA community and to advancing potential medicines for

families impacted by neuromuscular disease.

Mindy Henderson: Today in the spirit of Valentine's Day, we are talking with two married couples

about their dating and eventual marriage. Under most circumstances, dating and marriage can be full of highs and lows, and when you throw a disability into the equation, there can be some unique challenges for the couple to work through. Today we're going to benefit from all the wisdom these two couples have to share. I'm so excited to have all of you with me. Should we do a quick

round of introductions?

Amy Shinneman: Thanks for having us. My name's Amy Shinneman and I'm married to my

husband, Jamie, and we've been married for 23 years. And we have two sons,

Luke and Jack who are 18 and 14. And we met in high school.

Mindy Henderson: Fantastic. And Amy, you have Bethlem myopathy, is that correct?

Amy Shinneman: Yes. I live with a type of muscular dystrophy called Bethlem myopathy.

Mindy Henderson: Gotcha. Fantastic. Well, how about we let Jamie go next.

Jamie Shinneman: She stole all of my thunder. My name's Jamie, I'm a civil engineer. Like Amy

mentioned we met in high school and dated for a couple of years and we did break up eventually, and got back together after our college years, but yeah, there's a lot that we'll get into here I'm sure. But I'm just very happy to be a part

of this and share a little more of our story with you guys.

Mindy Henderson: Excited to have you both here. John, how about you?

John Kerr: Hi there, I'm John Kerr and I'm married to Krystle. We've been married for about

seven and a half years and I work for the state of California and also run a

nonprofit. And I live with spinal muscular atrophy type 2.

Mindy Henderson: Fantastic. And Krystle, would you like to say hello?

Krystle Englehart: Yeah. I'm Krystle Englehart, very happily married to John, and professionally I

am a researcher for the state of California. And yeah, just happy to be here and

share our story as well.

Mindy Henderson: Awesome. I am so excited to talk to all of you and I'm just going to jump right in

because I have so many question for you guys. I would love just to hear your love story. Where did you meet and how did you ultimately end up together?

Amy Shinneman: So Jamie and I, like I said, we met in high school. I was a freshman and he was a

sophomore and we had a mutual class together, but didn't really know each other. And then two of our friends, mutual friends, kind of set us up. And so we kind of started dating from there and we dated for about two and a half years until Jamie was a senior in high school. And about halfway through his senior year, then we kind of... Well really, he decided that we needed to breakup.

Amy Shinneman: So we did, and it was a good thing because we were so young, but we continued

to be friends through... He went on to college and then we really continued with a friendship after the initial shock of the breakup and all those feelings. So we continued to be friends and then we eventually, after Jamie graduated from Purdue, he moved to Memphis, Tennessee to kind of start his career in civil

engineering.

Mindy Henderson: And is that not where you were living at the time Amy?

Amy Shinneman: I was not. So I was still in... We lived in Indiana, and so I was kind of finishing up

college myself and then we decided that I'd never been to Memphis, so I was going to just go for a visit as a friend, and kind of that's the rest to the story. We got back together from there and about what, a month or two later moved to

Memphis myself.

Mindy Henderson: Sounds like it was meant to be. And then how long after that did y'all get

married?

Jamie Shinneman: It was a couple of years. So it was '97, I think when she first came down to

Memphis and it was October of '99, when we got married. Funny, you say meant to be, we believe that as well. And it takes me back to when we did break up through high school and it was, as many high school relationships can be, ours was just... We were too involved and we had a lot of growing up to do, but we both remember my dad telling us that... Or telling Amy, just need to let them

go. If it's meant to be, it'll be.

Amy Shinneman: We really held onto that.

Jamie Shinneman: That's what happened. And Amy had an aunt too that, she really believed that

we were meant for each other. And she's passed now, but we believe that she

was right as well.

Mindy Henderson: Yeah. That's so great. It's wonderful that you had families looking out for you

and that you had the wisdom to take their advice. Because when you're kids, when you're teenagers, you don't know what you don't know yet, and yet you

think you know everything.

Amy Shinneman: That's right. That's exactly right.

Mindy Henderson: Right, exactly. I love that. Well, John, Krystle, which one of you would like to

take us through your journey?

John Kerr: I can start. Yeah, definitely.

John Kerr: Krystle and I met on a camping trip through some mutual friends. She came up

there with some friends of mine and we met, and I saw her at lunch one day, walking across with her lunch, reading a book and I just... She caught my eye and I was like, wow, she's really cute. And so that afternoon we're sitting by the pool and I went up to her, and she was sunbathing and I was in my chair. I sort of bumped her with my toes on her shoulder and said, "Hey, would you like to

take me into the pool?" And she said, "Yeah, sure."

Mindy Henderson: Wow.

John Kerr: And then I'll let her tell the rest of the story.

Mindy Henderson: But you guys didn't know each other at this point. Right?

John Kerr: Well, maybe for a day or two, we had met on that trip. So it was during that trip,

yeah.

Mindy Henderson: Okay. Gotcha.

Krystle Englehart: Yeah. We had chatted a couple times before he came up to ask me to take him

in the pool. And I was just like, I was smitten instantly the first time I talked to him, he was just so funny, like a wicked sense of humor and so attractive. And I was just like, man, this guy is awesome, so I was so excited when he asked me to take him in the pool. And then he really like sealed the deal on stealing my heart when I had him in the pool because he looks up at me and he's like, "Are you okay? Are you okay?" Like checking to make sure my arms weren't getting tired because I was holding him, kind of like floating him around. And I was like, "Yeah, yeah, I'm good." But then he said, "Because my life is literally in your hands," and he said it in like just the funniest way, just his sense of humor is so

amazing.

Mindy Henderson: Wow. That's fantastic. And then how long after that did you guys get married?

Krystle Englehart: It was a few years. We were actually friends for like a year, kind of casually

dating each other before we started dating more seriously. And then once we jumped into like serious, exclusive dating, we jumped all in. We got engaged my last semester of college, I didn't want to super long engagement and I didn't

want to get married while I was still in school. So yeah.

Mindy Henderson: Okay, yeah you kind of answered my question. I was going to ask, what stage in

your lives you guys were in. Were you in college? Were you working? John,

were you also in school or were you working by then?

John Kerr: I was working. I'm much older than her, I'm an old man. And I tell her that she

keeps me young. But yeah, we wanted to wait until she graduated college. So I actually proposed to her on my 40th birthday, and we got married about a year

and a half later. Yeah, seven and a half years ago, time flies.

Mindy Henderson: I love it. I love these stories. They're making me so happy. So let's go

back to you, Amy and John, when did you know that this was your person? Like when did you, without a doubt, I know you had the break in the middle, but

when were you just positive?

Amy Shinneman: I mean, I felt like it was just something we always knew, but since we were so

young it caused some doubt. People would just say that people could see that we were very in love, but we'd get a lot of comments like, "You're too young," or, "There's other people out there." I think we always felt it, but I think it's when I went and visited him in Memphis again, saw him again, even though we were friends, we didn't see each other much. We just talked on the phone.

Amy Shinneman: But when I saw him again for me, I just felt just sure that he was the one.

Mindy Henderson: Mm that's so great. Was it the same for you, Jamie?

Jamie Shinneman: Amy and I were talking about this earlier today that I agree, that we just felt like

it was it in high school, but yeah, we were so young. Yeah, it didn't take much to rekindle the spark again there after the college year. So, I just think we always knew. I know we'll get into more about her disability and stuff like that, and why

I felt like I wanted to be that person for her. I just felt like I was called to be that

caregiver for her.

Mindy Henderson: Oh my gosh, that gave me goosebumps. That's amazing. Oh, so nice. So Krystle, I

know that you said you had a moment in the swimming pool where he kind of stole your heart, but was there a specific moment for you when you just knew

that it was John for the rest of your life?

Krystle Englehart: Yeah, it actually was that moment in the pool.

Mindy Henderson: Really?

Krystle Englehart: Yeah, like that moment. And I didn't tell anyone because I knew I would sound

like very crazy. Like I knew I would sound very unwell to be like, I am in love with this person I met three days ago, but in my heart I just knew it. Yeah, it was

instant for me.

Mindy Henderson: Wow. John, what about you? What was your moment?

John Kerr: For me, when I first met Krystle, we had so much in common, we laughed at

everything the same and we spent a lot of time together as friends, and I wasn't

really in a mental place when I met her to sort of allow myself to be in a vulnerable place that you have to be in order to let love happen naturally. And

so, it took a little time for me to spend time with her and get to know her. And finally I slapped myself on the side of the head and said, "Hey, wake up. You're going to lose an amazing girl here that just absolutely loves you." And I let myself sort of drop all my shields I had around my soul and my heart, and just

let her in. And I couldn't be happier that I did.

Mindy Henderson: Oh my gosh. I just want to hug all of you, your stories are so sweet. Amy and

John, let me talk to you guys for just a minute. I'm curious, Amy, if you want to go first, how did your disability, how did it, or didn't it, impact your dating

journey before you got married?

Amy Shinneman: Yeah I mean, I think it definitely did. For me, the one thing that stuck out when I

came across this question was... And just honestly speaking, I was very, very insecure just living with a disability and I didn't know anyone else that was like me. And so I was constantly comparing myself against other, non-disabled girls. And I think I would almost just self sabotage in my relationships of just letting those insecure feelings win out, and ultimately that was a lot of the problem in many of my other relationships and in my dating. But at the same time, I do feel like I tried to be honest about my disability and what my needs were. And I had a lot of fun times with some other people, but it just never felt the same as it

felt with Jamie.

Mindy Henderson: Yeah. Okay and John, how about you?

John Kerr: Yeah, very similar to Amy's experiences. Growing up I had a lot of friends,

female friends, and I'm a straight male, so I found myself sort of always being

placed in the friend zone. I had a very busy social life, I didn't lack for having fun and going out and doing fun things, but when it came time for intimacy or closer relationships, I didn't really experience that until like my college years. And even at that point, it wasn't to the point where I was completely allowing myself to be open a hundred percent. So I just hadn't really met the right person, but I definitely put myself out there and it did pay off because I built up enough confidence to finally love myself for who I am, which in turn allowed someone else to love me as well.

Mindy Henderson:

Nice. So I'm curious, how did you share about your disabilities? And what you needed, what kind of assistance maybe you needed, what kind of assistance you didn't need? How did you approach that in dating? I know you said that maybe there were some walls up, did I kind of hear that right?

John Kerr:

Well, as far as the disability factor and my needs go, I've always had care providers do my care. So when I was looking for a partner, or dating, or just hang out with friends, I didn't really need to fully rely on them to do my care. I was fortunate enough to have care providers that do all my care. And I really like to keep that line drawn between care provider and life partner. Krystle does help me out with some things, but in the earlier stages of my life, where I was just dating casually and, and being young and dumb, I didn't really rely on the person that I was with to do any of my care. So I didn't really have to explain my needs or anything like that. But there were occasions where somebody would have to need to drive my van, because I don't drive, or cut up some food for me, small things like that.

Mindy Henderson:

Yeah. Okay. And Amy, what about you? Was your disability part of the conversation much when you were dating, let's say other people besides Jamie?

Amy Shinneman:

Yeah. It definitely was. I mean, it kind of had to be. My experience with Bethlem myopathy is, I was undiagnosed until I was 44 years old, but I was disabled, but I didn't know. So for me, it was kind of hard explaining this unidentified neuromuscular disease too, when I didn't really know what it was called. That was a real struggle for me growing up, I kind of felt silly that people would ask me... The way they usually worded it was, "What's wrong with you?" Which isn't great, but that's what people usually say. And so, I think I did struggle with explaining all of that, but there would be times... I had a big surgery during high school and I had started dating a guy that had been a really good friend of mine.

Amy Shinneman:

And so he didn't really skip a beat. I was in a wheelchair for several months after that, and he would pick me up at my house and load the wheelchair in the truck for me, and drive us to school, some people are just naturals at stuff like that. And I think as far as me, when I was not like having a surgery or something and I was walking, like stairs were really hard for me and just getting to class without falling or getting knocked down in the hallways. And there would be times when I would fall and the person and I was dating they would explain, I couldn't get up on my own, so they would help me up. So I think it was things like that, that I needed help with and I think I was pretty good about communicating that.

Mindy Henderson: Yeah. And were people's responses usually pretty favorable? Did you have

mostly good experiences?

Amy Shinneman: I did. I think for me, I was bullied a little bit in elementary school, but I really was

fortunate that during high school I had a pretty good group of friends and some boyfriends that were able to... That they were just really kind about it. So I feel

like I was very fortunate.

Mindy Henderson: Great. I'm going to jump back over to the spouses. So Jamie, before you

started dating Amy, I know you guys were really young, so I don't know if this applies or not, but had you ever dated somebody with a disability before?

Jamie Shinneman: No, I hadn't. Really Amy and I were kind of our first loves and stuff, so it was all

new to me. I hadn't dated anybody really before, so didn't have anything to

measure against.

Mindy Henderson: Okay. What about you Krystle?

Krystle Englehart: No, I hadn't dated anyone with a disability prior to dating John.

Mindy Henderson: Okay. Okay, and what sort of challenges Krystle, did you experience then when

you first got together? And what were some of the victories?

Krystle Englehart: As far as challenges go, I have to say just really honestly, like the ableism of

society was annoying for us. Like we would be out on dates and we were very affectionate, like not gross, but like we would hold hands and we kissed, and people would assume that I was his like relative, which was disgusting, or like his caregiver. Or people thinking, like literal strangers, thinking it was like appropriate on any level to ask really personal questions about our sex life, like just out of the blue, like at a party I remember that happening. And just being

like, what? You wouldn't ask that to any other person at this room.

Mindy Henderson: Wow. No, you're right, they probably wouldn't.

Krystle Englehart: Yeah, it was a societal attitude toward disability and sexuality, and disability and

love and dating that really was a challenge, just because it made me see another

side of humanity that I hadn't seen before.

Mindy Henderson: Interesting.

Krystle Englehart: And I don't understand the victories. Could you expand on that a little? Like I

was curious the way you saw that.

Mindy Henderson: Yeah. Anything that maybe you, I don't know, thought might be challenging

going into it, but then it turned out to be a non-issue, let's say.

Krystle Englehart: I didn't think of any disability-related challenges going into it. I just knew that he

was a really amazing special, like hilarious, smart, fun, sexy person. And that's

really all I cared about.

Mindy Henderson: Awesome, that's fantastic. So Jamie, when you met Amy, did you have any

preconceived notions about her disability and any challenges that you might

have in your relationship? And how did that play out for you?

Jamie Shinneman: Yeah, I was trying to remember, going back being 15 and seeing her that first

time. And I think she said it was a common class we had, and we hadn't been introduced yet, but I noticed her. She got up to leave the class and I noticed that she walked differently as she left, but I still remember thinking that she was cute, but I wondered what the disability was about. And I must have learned it a little bit later, in high school you hear rumors, things like that, are they true or not? And somehow we got introduced by friends and we had our first date. And I guess challenges back then were, you had to find people to drive you around

that had licenses and stuff like that.

Jamie Shinneman: But it was just getting to know her. I mean she was just, I mean, just like me.

The worries or whatever that I might have had about what are people going to think and that kind of stuff, she was just, so, again, like me, it just kind of melted away. And I know that I need to see the disabilities and not let it just not be there because it is, but that's just how it kind of has been for me and her. And it's not that I don't see it, but I just, I see her, she's so, again, just like me, I

wasn't worried about anything after that first date.

Mindy Henderson: That's really great. What about when you were thinking longer term? When you

were thinking about... I'm assuming you proposed to Amy? Or did Amy propose

to you?

Jamie Shinneman: I proposed to her, yeah.

Mindy Henderson: Okay, because that can happen, we're progressive people here. So when you

were thinking longterm about proposing and spending your your life together,

were there any considerations there? Or again, was it all just Amy?

Jamie Shinneman: Just her. I mean, she had been my best friend from, she was 14 and I was 15 and

her disability, at least back then, it wasn't as progressive. With age and stuff, it's getting harder, but she still was getting around pretty well. She was able to walk without assistive devices and things like that, unless she had a surgery. So she was pretty independent and really always has been. I wasn't as concerned, again, she was just so independent I knew that maybe there eventually that I might need to help more. And again, I felt called to be that person for Amy.

Mindy Henderson: That's really great. Did you guys have discussions, did you talk to Amy, or did

you have things to think through on your end about how your relationship

would be impacted as Amy's needs or mobility or function changed?

Jamie Shinneman: I don't know that we had many discussions. They were really more of, as Amy

touched on, kind of frustrations because we didn't know what her disability was. We weren't sure how it was going to manifest itself, all we knew was that it wasn't real progressive, it affected her how she walked and sometimes she would overdo it. We just knew that if she did have those days where she

overdid it, she needed the rest and take it easy, get her strength back. So it was just kind of day by day, but really frustrating more for her, but still tough to plan ahead.

Mindy Henderson:

Yes. Okay. Okay, and Krystle, what about you? John already mentioned that he proposed to you. So when you were thinking about again, longterm spending the rest of your lives together, was there anything related to his disability that you really needed to consider or that you talked about? Or things that you discussed as John's condition progressed potentially, that you would need to factor in?

Krystle Englehart:

No to be honest, that wasn't a part of my decision making just because, I mean, every person changes all of our needs, regardless of disability, all of our needs change over time. Like we, as people change over time, so to me I never saw it as being different than that. Like my needs as a person have changed over time, and so I knew that we could learn together and grow together and adapt together to both of our changing lives over the course of a lifetime. So, that was my consideration.

Mindy Henderson:

That's amazing. John, she's kind of amazing. I have to tell you.

John Kerr:

I'm a very lucky man. Yes, I agree.

Mindy Henderson:

Krystle sounds pretty wonderful. Amy, you are also a very lucky person to have Jamie. Jamie, to what extent do you own the caregiver role? And how do you balance the role of caregiver and spouse?

Jamie Shinneman:

Well, I feel that I do own this. I want to be the first person that she thinks of and leans on when she needs help, but again, she's very independent and always has been from how her parents raised her. She cares for us quite a bit as well, for me and our two boys. But again, I've talked a little bit about where she will overdo it and we just need to convince her she needs to take some time and rest, and she doesn't need to do all of these things that she thinks she needs to do.

Jamie Shinneman:

I'm here for her. We haven't touched a little bit on some of the stuff we do with MDA, but I'm a runner and so are our boys, and you might think that's strange for someone with Amy's condition, but she's always told us to use our gifts, that if she had those abilities to get out there and run and jog, she'd be doing it. So some people might think that we're rubbing it in her face or something when we're out there running, but we do that and now we've made it part of our family by including her in races. We've got an adaptive chair that we use and Amy's done two marathons now with us. We try to do whatever we can to include her in all of our family events.

Mindy Henderson:

I love that. I love that. You guys just finished the New York City Marathon, right?

Jamie Shinneman:

Yeah.

Amy Shinneman: With our older son, Luke.

Mindy Henderson: Wow. So, I mean, you guys are serious, you do some serious marathons.

Jamie Shinneman: Crazy.

Mindy Henderson: That is wonderful. That's wonderful. So inevitably Amy, the conversation when

you are getting married and all of that, I think inevitably the conversation of expanding your family, having children comes up. And I know that your situation may have even been a little more complicated because you didn't have a firm diagnosis yet, but was your disability or your condition a factor in your decision

making about growing your family?

Amy Shinneman: Absolutely, it was. And I think for years would just say I was okay not having

kids, and that was that and I was pretty solid on that. But I think that was fear.

Amy Shinneman: And I think that was the unknown of not knowing if my body would be able to

handle a pregnancy, or if I would be safe or would my kids have my same disability? I didn't know what it was. And I think it took me a while to... The only way I can explain it is, something in me just switched. And I decided... And Jamie, just to say, was always very open that he did want children. And I knew that. And I think that I just came around to trusting that since I was having these strong feelings that I did want to become a mother. And I didn't know if that would look like me having children myself, or if we would adopt a child or how it would happen, but it turns out I was able to handle two pregnancies and those

were born by C-section.

Amy Shinneman: And both pregnancies did take, I would say a permanent toll, obviously totally

worth it. But I feel like those times were the most that my disability progressed.

Mindy Henderson: Yeah. Were your doctors good about advising you and helping you kind of

through that decision making process also? Or was it really up to you and

Jamie?

Amy Shinneman: They were very good about... My doctors basically told me even as having an

unidentified neuromuscular disease, that there would be a 50/50 chance that

our children could inherit my disease. But we both talked and I'd had a

wonderful life, and we knew that we would help our kids if they did in fact have the same disability, they could have a great life too. And we just decided that really was the right thing and had doctors around us giving me really good care

and monitoring me very, very closely, so I felt safe.

Mindy Henderson: That's great. And spoiler alert, both your boys are okay, right?

Amy Shinneman: They are. Yes. Like Jamie said, they're both runners, which is absolutely makes

my heart soar to see that, it's just really special.

Mindy Henderson: That's wonderful. And I also happen to know that your kids also have worn

some of that caregiver hat and they help you, I've read some other things about

you and you've talked some about that. It sounds like they're good hearted kids with you and Jamie's hearts.

Yes. I mean, definitely. I think Jamie is a very good example of what it looks like Amy Shinneman:

> to... I think as a caregiver it can be, you don't want to over caregive, I guess if that's a way to put it, you want to give that person as much independence as

they would like to have.

Amy Shinneman: And I think my kids... It's kind of like a dance that you learn with the people that

you live with and it's kind of an unspoken language that my kids have learned as

well, just through watching their dad and how he engages with me.

Mindy Henderson: Yeah. It's kind of amazing. I think the listeners probably know that I have SMA as

> well, and I have a daughter, we chose to adopt. And it was interesting as she was growing up because I would notice her just sort of naturally reach for things, or do things for me, I think just out of observing other people, and it's kind of heartwarming to see that they're becoming those kinds of people who

observe and just kind of know to help out.

Amy Shinneman: We agree. It's a beautiful thing.

Mindy Henderson: It is. It really is. John, what about you? How much of a conversation was it

around your disability and expanding or not expanding your family?

John Kerr: Well I mean, the disability is a part of who I am for sure. Obviously I do have a

> significant disability and so it was something to consider, but for me and Krystle it's just sort of in the back of our list of considerations. I mean, we always sort of make do with whatever situation we're in, we just make it work. So I know that

we both know that if we were to have kids, that we would make it work

somehow, but for us, it's not very high on the list of concerns or considerations. We're more concerned with things like climate change, and overpopulation, and bringing kids into a pandemic and things like that, that are happening in the world right now that sort of make us stop and have a little more consideration

on those factors.

Mindy Henderson: That makes sense. So this is another question that I want to just throw out to

whoever wants to catch it. But I think that in any married relationship there can be a dance that you do around just household responsibilities and ensuring that not too much responsibility falls to any one person. And I know that that can be a hot topic in conversations with some couples, but how do you all manage

household responsibilities and keeping things sort of evenly balanced? I guess.

Amy Shinneman: For me, it is a tough balance. Like Jamie had said, my parents really raised me to

be... My mom will say I was just naturally an independent person and I just kind of took off and did things in a way that worked for me. And I feel like I do try and maybe overdo it a lot with the household responsibilities because I feel like sometimes I don't want to be, this is for me personally speaking, sometimes I struggle with, I don't want to feel like a burden and I want to pull my weight.

Amy Shinneman: I struggle with those feelings of needing I guess, to prove myself. And not that

that's anything that Jamie's putting on me at all, that's just kind of maybe a fault of mine, but I think communication really is the key with the household staff and just being open about if I need help with something, and obviously he does the heavy lifting as far as those little chores. And it is, it's just like you said, a dance that you got to figure out and still after 23 years, we're kind of fine tuning

that still, it changes.

Mindy Henderson: I think it's kind of an ongoing conversation. At least it is in my household. And

things kind of ebb and flow, and one person will pick up one thing along the way and another personal will pick up another thing. Jamie, I know that you've already said that Amy does too much. But do you pretty much agree with what

she said? Do you have anything to add?

Jamie Shinneman: No, I agree with everything that she just said. I'm not sure that I can add much

there.

Mindy Henderson: It's okay. Okay John and Krystle, how about you guys? How do you balance, do

you have assigned things that each of you do, this is Krystle's, this is Johns? Or is

it just sort of a natural, "Hey, I'm going to do this today."

Krystle Englehart: Yeah. We actually just kind of more so like take it day by day, and share the load

depending on... We both have very, at times like stressful, busy jobs, so it's kind of like maybe if I'm having a less intense work day, maybe I'll pick up more and vice versa. We try as much as we can to share the load, but I am like such a clean freak. Like I make the Monica Geller character look like a slob, so like I really enjoy taking on the cleaning myself, so that John will have to like fight me for to help out with because that's just something that I love to do, that's

cathartic for me.

Krystle Englehart: But yeah, I feel like one of the things I was really attracted to with John, besides

everything else, is his communication skills. He's made me such a better communicator, so we just really keep an open line of communication as far as expressing our needs. As far as you know, I can't do this today, can you take this on? Or whatever. So that's something that I appreciate about our marriage.

Mindy Henderson: Nice. John, anything you want to add to that?

John Kerr: Of course not, she's in charge.

Mindy Henderson: Smart man. There were never wiser words spoken. I love it, I love it. So I'm going

to do a quick round robin here, and John I they think I'm going to start with you.

What is your favorite thing about Krystle?

John Kerr: I just love how smart she is, and she is completely obsessed with social justice

and just making sure that everybody in society has a fair shot at succeeding. And that was what really attracted me to her. Just everybody who has any sort of, not the standard set by society, she fights super hard for their rights. And she's

incredibly smart and obviously very adorable and sexy. And I can't pick one thing, how do you ask me to pick one thing? I can't do that. Oh, no.

Mindy Henderson: Well, you know, it sounds like she's probably too wonderful to choose. Krystle,

what about you? What's your favorite thing about John? Or your favorite 50

things.

Krystle Englehart: Oh my gosh. I will try and narrow my list, although it's very hard because there's

so much to love about my incredible husband. But honestly, I think one of the things that like really just keeps me so magnetized to him is his energy as a human being. Like he is the calm in any storm. I could be having the most stressful day at work or with activism things I do, and I could just be having a hard time and he always knows how to center me and calm me. And just, he has this incredible energy that is just, it's soft and safe and consistent. And I love that so, so much, but it's hard because then he's also hilarious and he's pretty quiet, so he'll like slide in jokes while we're at like a party that only I can hear, and I love that. And he's very sexy and charming and yeah, but I think that that energy and that calming force he brings to my life is pretty high up on that list.

Mindy Henderson: Nice. This is so, so nice. Amy, what about you? What's your favorite thing about

Jamie?

Amy Shinneman: Oh gosh. Well like they said, it's hard to pick just one thing. I mean, a few of my

favorite things are just, super hardworking for taking care of our family and I really admire that. But really I'd have to say probably my favorite thing is, having a disability at times can feel very heavy or if you suffer a fall, he always makes me laugh, and he just finds a way to get underneath my sadness at times and just makes me laugh. And all the little inside jokes that we have, and it's not hard for us to start belly laughing at just things that we say. So, he's my biggest cheerleader and I couldn't love him more. He's the absolute best person for me.

Mindy Henderson: Aw. Well Jamie, after hearing those three answers, I feel like there might be a

little bit of pressure on you.

Jamie Shinneman: Yeah, I have stage fright.

Mindy Henderson: Yeah. But what's your favorite thing about Amy?

Jamie Shinneman: One of the top things for me is her faith in God, for both of us, that's a big thing

for us that we center a lot of everything that we do in our lives around that. It's just so important for us as a family, as a couple, as parents. So that, and like she mentioned too, her sense of humor has always been off the charts, sarcastic person that she can be. And again, the inside jokes that we have with each other, the funny voices and things, I love just, for as long as I can remember, just sitting on the couch and just watching TV and stuff together, just being around each other is what I look forward to every night, coming home and just being in

her presence.

Jamie Shinneman: And it's just something about her. Obviously, beautiful, hasn't changed, aged a

bit since she was in high school, and so many people tell her that she really hasn't. She's so kind as well, she wants equality and same things, everyone should be able to have the same things, so I love her fight for that and I try to

get behind it and support her in any way that I can.

Mindy Henderson: That's so good. Oh my gosh. So I want to ask one more question, and then I'm

going to wrap it up with kind of parting advice. Amy, I want to start with you. Being young and being a teenager can be so hard when you first start dating. And when you have a disability, there are additional insecurities and things that

can, don't have to, but can come along with that.

Mindy Henderson: If we've got any young people listening, any teenagers who are maybe about to

get out there and put themselves out there for the first time in the dating world,

what advice would you give them?

Amy Shinneman: Yeah, I would say, I mean I agree, it can be very difficult, but I think what it really

comes down to is just honesty and being yourself, don't try to change yourself to be something that you're not, and just be upfront. A lot of people, especially at a young age, haven't even ever had contact with a person with a disability. So just kind of explaining it as it is, and kind of maybe educating almost, and kind of helping them to understand that people with disabilities are just like them, they

want relationships, they want love.

Amy Shinneman: And I think that's just the bottom for me really is to be honest and be patient,

don't rush into a relationship that maybe isn't healthy, just to say that you're in one, you want to be patient and take your time. And overall, I would just say, don't change yourself so that someone will like you, just be yourself and the

right person will come along.

Mindy Henderson: I love that. I love that you said all of those things, because I've seen people fall

into traps of changing themselves or like you said, being with the wrong person just to be with somebody, and it's so not worth it. Number one, it makes you unavailable when the right person comes along. So yeah, I couldn't agree with you more. John what about you, any advice for first time young daters out

there?

John Kerr: Absolutely. Well, first I really agree with what Amy said about not wanting to

have to rush into something so serious right off the bat. For me, I would advise that younger adults get involved in as as many activities as possible in their community, whether it be at school, or at church, or sports or whatever, and just meet people, and make friends, and learn good social skills and take care of yourself. Love yourself first, have good hygiene, and develop your friendships

and see where those go.

John Kerr: And then you can learn how to start dating just on basically forming good

relationships that are platonic at first, and then hopefully you'll start meeting people that you want to develop a further relationship with. And then take it nice and slow, don't rush into anything and put yourself out there as much as

possible. My parents used to tell me, my dad especially would say, ask a hundred girls for a date and one or two might say yes, and that one or two just might be the perfect one. So don't give up, and just keep putting yourself out there and be confident, and it'll happen

Mindy Henderson: Very well said, very well said. And John, am I remembering right, that you also

put on seminars or conferences around relationships and that sort of thing?

John Kerr: I do. I have a nonprofit and we have a life development retreat every summer

up in Yosemite, in central California at a campground up there. And it's for young adults with disabilities, specifically muscular dystrophy, where they can come and stay for four days and learn about jobs, and college and benefits, how to manage your healthcare. And then of course, we do have a session on dating and relationships that Krystle helps me teach that. So yeah, it's very rewarding and I love being able to share knowledge with these young adults who are

getting ready to enter into independence.

Mindy Henderson: Oh, that's so good. And everything you said is knowledge that's so needed by

young people. So we'll definitely make sure and put your information in the show notes so that people can maybe find you, I can't think of two better people to teach those courses. Except, maybe Amy and Jamie should join you

and teach [crosstalk 00:51:22].

Amy Shinneman: That would be great.

John Kerr: That would be great.

Mindy Henderson: So last question, and I know that this is a big question, but it's I think the one

that everybody maybe wants the answer to in their own relationships. So I'm just going to go around one more time. Amy, what do you think is the best piece

of advice you've got for making a marriage successful?

Amy Shinneman: I think the best piece of advice I could give is, to communicate often and laugh

even more.

Mindy Henderson: Oh, that's beautiful. I love that. Jamie, what about you?

Jamie Shinneman: For me again, it's having that faith in God and just putting that like at the center

of the wheel, and it just affects every spoke, affects every part of your life, whether it's your marriage or your work or your kids, sports. That's so important

to us, it's the center of everything.

Mindy Henderson: Nice. Krystle, what's your best advice for making a marriage successful?

Krystle Englehart: Honestly, I think it's something that I learned from John really early in dating,

and that is to always treat your partner and speak with your partner from a place of love. Like even if you're frustrated or having an argument about something, always come to that encounter with vulnerability and understanding and that softness of love, because it's like, no matter what struggle or problem

you're going through, the core is how much you love your partner. And I think if you can center that in your life. I mean, honestly that's advice that's helped me in all of my relationships, not just my marriage, it's just no matter what is happening in the world or in our present circumstance, coming from a place of love.

Mindy Henderson:

That's wonderful. That's absolutely beautiful. And John, I'm going to give you the last word, although Krystle said that she got her best piece of advice from you.

John Kerr:

Well, she flatters me. I don't know if I'm that good. But I do agree with Amy though, I think honesty and openness is just the most ideal key to a successful relationship. And then something, I know it's super cliche that people say to you at your wedding, but don't ever go to bed mad or upset with your partner. Me and Krystle, we're lucky enough that we don't get mad at each other very often, we usually resolve things pretty quickly, but when we do, we make sure that we resolve it and don't let it linger or stew on it for too long and let those negative vibes build up. Just be honest and open and resolve a situation as soon as you can.

Mindy Henderson:

Perfect. I love that. Well guys, I can't thank you all enough for spending this time with me and for sharing your journeys, and just yourselves and all of your advice with all of the listeners, so a very big thank you from me. And I hope that we can get you to come back sometime.

Krystle Englehart:

Thank you so much for having us.

Amy Shinneman:

Sounds great, it's been Awesome.

Jamie Shinneman:

Yeah, thank you.

John Kerr:

Thank you for having us.

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.