

Lily Newton: Welcome to Everything You Know About Disability is Wrong.

Erin Hawley: A podcast by disabled people for disabled people.

Lily Newton: But if you're not disabled, stick around. You might learn something new.

Jennifer Msumba: Oh my goodness. You are such an inspiration.

Jennifer Msumba: Wow, you really are.

Jennifer Msumba: You're so strong.

Jennifer Msumba: Can I pet your service dog? (singing).

Erin Hawley: In today's episode, we're chatting with Jennifer Msumba who's an artist, musician, and fantastic advocate.

Lily Newton: We are huge fans of Jennifer's work here at Everything You Know, so much so that when we made this podcast, we knew that she had to make the theme song. So let's get into it. Hi, Jennifer. Thanks for coming on our podcast.

Jennifer Msumba: You're welcome.

Lily Newton: So just to get us started, one, I'm so nervous. I'm so nervous.

Erin Hawley: Yeah, me too.

Lily Newton: I think partially the nerves come in because when you're making any kind of art about an underrepresented group, then it seems like you're responsible for then representing the entire group. No, that's not what we're doing here. We're just chatting.

Jennifer Msumba: We're just chatting about our experiences, yeah.

Lily Newton: Absolutely. So we knew we had to have you on this podcast because for our listeners, Jennifer wrote the amazing theme song that you just heard. When we heard that theme song, we immediately, immediately knew she has to be a guest because she so clearly understands what we're trying to do with this podcast. Thank you for that. If you want to talk about making that song, what you felt the vision for it was, I'd love to hear about that.

Jennifer Msumba: Yeah, so, okay, I wanted to make a song that made a statement. I didn't want to be generic about it. I wanted it to be memorable and something that really said something in a short amount of time. Plus you gave me the task of fitting everything you know about disability is wrong in a song, and that was a challenge because it just doesn't fit in a song too easily. Okay, I'm up for this. So

I started thinking about things people say to me. The first thing and most common thing I get told is, "You're such an inspiration." I appreciate the sentiment, but oh my goodness. They say you're an inspiration. If you said I was an inspiration because of my music ability or something, that's different. But just because I have autism doesn't make me an inspiration, just because I'm living in breathing. So I really wanted to include that and a little bit of humor with acting out how it gets said. I don't know, I fit it all together in this little rock and roll song and there you go.

Erin Hawley: Speaking of relationships in general, in my previous relationships, I felt like I couldn't really be myself. I had to be this a person that was not ... didn't have feelings that aligned with being disabled, even though my other partners were disabled too. I still felt like they had expectations of me that didn't fit who I really am.

Jennifer Msumba: That's a good point. I think especially when it comes to romantic relationships, it's so nerve-wracking as it is for any people meeting each other. Sometimes we find ourselves changing to try to feel comfortable or make them feel comfortable and not show our true colors.

Lily Newton: I know that masking often gets talked about in terms of just autism, but I think masking affects everyone with disabilities because there is this level of feeling like you need to be what people expect of you rather than who you actually are. First off, I have a confession and that confession is that I have always dated while autistic, but didn't know up until recently that I was dating while autistic. Because I've been autistic my whole life, but I didn't figure it out until in my 20s. It's something when I look back on many of my dating experiences, I'll think like, wow, that person literally knew a version of myself that I had crafted just for them. So in your experience, Erin or Jennifer, of dating, have you mostly dated other people with disabilities?

Erin Hawley: I have, yes.

Jennifer Msumba: I don't have very, very, very long dating resume at all. I've been mostly just to myself. I'm just more comfortable that way. Now, list of crushes, very long, but list of actual dates or the other person knowing my feelings, very short. I think when I was 15, there was this boy. I was in a psychiatric hospital on the adolescent unit. There was this kid. He was a little younger than me and he was shorter than me, but he was just in love with me. Yeah, so when my mom came to visit, he put on his best shirt and everything. He used to write me poems and it was so sweet. That was my first kiss as well, was him. We snuck around the corner and kissed. So I got that out of the way. After that, really that was probably my most experience dating somebody and we weren't really dating. We were just two kids stuck in a psychiatric hospital together.

Lily Newton: That is such a coming of age in the mental health world story. If you had sold me that movie as a teenager, I would've watched it and probably re-watched and re-watched and re-watched.

Jennifer Msumba: After I got released from the hospital, I went to a group home residential school. My roommate had a picture of the boy on her cork board. I'm like, "What are you doing with that picture?" She's like, "That's my boyfriend."

Erin Hawley: Oh my God.

Jennifer Msumba: I'm like, "That's my boyfriend." Yeah,

Lily Newton: No way.

Jennifer Msumba: That's serious. That was pretty funny.

Erin Hawley: That's rare.

Lily Newton: Oh my goodness.

Jennifer Msumba: So apparently he was quite the charmer. He got around the facilities a lot.

Lily Newton: I feel kind of cut off from the world sometimes. So it makes dating pools smaller. Most of my dating experiences early on were before I identified as disabled. Oh, I think that so much of the problems in them were just because I was with people who did not understand my brain.

Jennifer Msumba: I felt like that boy understood me because we were both in the same situation. Now that I'm grown, I have a crush currently and they know about it, but I always try to mask when I'm around them because I feel like they're not going to like me if I do tics or stims or something. I feel like it makes me look like a child or they'll think of me as immature or it is not pretty because of those things. So I worry about that when I'm around someone that I like, whether they know I like them or not. I definitely still mask and that's a problem because if I ever did pursue a relationship, at what point do I let myself be myself? But then again, I'm thinking about human relationships with neurotypicals. When can I stim around you?

Lily Newton: That is such a good point. Also I feel like that's the best way to explain to neurotypicals what it's like to have that second train of thought running of, hey, you know when you're early in a relationship and you have to fart? That's what it's like, where your body is giving you signals and you need to do something, but you just ignore the signals. I had a lot of tics growing up. I'm doing it now. I move my neck a lot when I get anxious. That was something that, oh my gosh, the second someone would point it out, it was like, "I can't talk to you anymore. I can't." So then I'd be so focused on not moving in a weird way that it's, well,

now I have no social skills because I'm only thinking about this, so I can't possibly be thinking about what you're talking about.

Jennifer Msumba: Yes, that is spot on. Oh, Erin, what were you going to say?

Erin Hawley: Yeah, I was going to say about the farting thing, going back to that, my current relationship, we've been together for eight years, so know how each other smells. We just have that comfort of having been in a relationship for so long is just the best. I would never do those things in my other relationships.

Jennifer Msumba: Well, that's good. I'm glad you have that, Erin, hashtag couples goals.

Erin Hawley: Yeah.

Lily Newton: Seriously. Yeah, my experience with my current relationship is kind of interesting because we dated and then I moved to Los Angeles for a few years. Then, we didn't want to do long distance, so we broke up. Then when I came back to Chicago, we got back together. In that time that we were broken up, I found out I was autistic, and so such a different relationship. It felt like starting again where the best example I can think of is there was a fight that we had gotten into in our first go at a relationship that in our second go at a relationship, that fight got brought up. I realized. I was like, "To be completely honest, we were in the car and the music was too loud and I was overstimulated." Now I can look back and see, oh, I was just super overstimulated and was on the verge of a meltdown. So then I just took it out on my partner. So now it's interesting to see him kind of learning. Is this about me or is there something else going on?

Jennifer Msumba: I have a friend. He's not my boyfriend. It's not romantic, but we're really close friends now. But when we first met, he's autistic as well, and we were talking all the time, but he had his set of issues with past hurts because of his autism, people taking advantage of him. I had my own issues and they were clashing because my things were triggering him and his were triggering me. We ended up in this huge fight and blocked each other and everything. Then a few months later, he emailed me and was talking about how our friendship was good when it was good. Anyways, long story short, now we're like best, best friends. Because of that fight where we learned each other's ways and what triggered us and what overstimulated us or confused us, we learned we can't have conversations and make decisions over text message. We have to FaceTime so we understand the other's intentions and we can explain it. So definitely, that has played a role with other people and my relationships, the fact that certain things are happening that autism is affecting why I'm acting that way.

Lily Newton: Yes, you've just unlocked something for me that I'm realizing that in all of my closest relationships that have withstood me figuring out my own brain, figuring out my place in the world, almost all of my closest relationships have had some

kind of, at one point, large falling out where we've gotten into it about something and there's been a big fight. Now hearing you say that, it makes so much sense why that would be the case though. Because if my brain doesn't function on the neurotypical level, it's not the same. It's not doing what is expected.

Then sometimes the only way to really understand how a friendship needs to function is to let it blow up and then realize from there, okay, what led to that? Because the love I felt for people who I've had those kind of fights with, the love is still there. But then there's the ... Yeah, that's so interesting. You totally unlocked that for me. I think that that's just a good indicator and a realization that sometimes when have a first couple fights with someone, it doesn't necessarily mean count this person out. It might mean you're overcoming some kind of barrier.

Jennifer Msumba: And I feel like that fight is what made our friendship what it is now, because now automatically I already know. One of his things was he felt like I didn't text him back right away, but then he'll see me post on Instagram. So I'm like, "Okay, always text this friend back as soon as possible because that makes him worry." Am I mad? He doesn't understand that. Then once we had the fight and we're like, "Well, you're this and you do this and I do this," and we just yelled it all out and then we separated, we each processed the situation. When we came back together, we're tighter than ever because we already know what the other is going to ... how they're going to feel about these certain things. So there is something to be said about having a good old-fashioned fight with your partner. Sometimes it'll bring you closer.

Lily Newton: Yeah, and I wonder if part of that is because of the weight of the pressure to mask and behave neurotypically, that once you're in a fight, that pressure's gone. I'm not worried about that. I'm just fighting now.

Jennifer Msumba: And the truth comes out, which sometimes needs to come out, but your true feelings and what's behind your actual actions, because there's feelings behind your actions.

Lily Newton: Yeah, absolutely. So speaking of feelings and deciding things, one of the topics that Erin and I have discussed in deciding to make this season about love and relationships is the understanding of when someone likes you, knowing what flirting is, and knowing how to tell if someone likes you or not. Erin, I know you kind of brought this idea up.

Erin Hawley: I have a hard time discerning between are they flirting with me, or are they being nice to me because I'm disabled? Because there's that default feeling that I have is they're just being nice to me, which is true a lot of the times. But when I was in high school, there was this kid who I felt was really nice to me because he liked my caretaker. Then I find out he liked me, and I was so awkward about

it. I was like, "Oh, hey, thanks." One day he came over and put his arm around me. I was like, "No, leave." It was this big drama.

Lily Newton: That makes sense.

Erin Hawley: It doesn't really matter now because I'm in a relationship. Now I know obviously that he likes me. I hope so.

Lily Newton: Right, but that makes sense why you would build walls and why you would push people away if you have that experience. It kind of goes back to where we started talking about, oh, you're such an inspiration. If somebody were to come up and tell me, "You're such an inspiration," completely separate from a conversation about disability at all, I might take that as, oh, they think I'm an inspiration. They think I'm a great person. They must really like me. But once you incorrectly assume that and then you realize, oh, they meant I'm an inspiration because I'm autistic, then how could you not build up walls and push people away assuming?

Jennifer Msumba: That's true. I feel like dating and disability is the last frontier for disability. If we can just show people that we have feelings and all the feelings, sometimes for me, I don't really want to act on them, but I still have the feelings. But then if the chance were to present itself, I would probably just run away. Because I had a crush on this waiter at the Sugar Factory in Orlando, and he was so nice to me, brought me extra ice cream and stuff and was talking to me. I'm convinced. This guy, he's really gorgeous. I'm like, "Oh, that's my crush." I used to go back there and ask for his table. He found out and so my support person was like, "Oh, she wants to take a picture with you." He's like, "Sure."

We took all these pictures and in my mind I'm like, maybe he does like me, but then I'm like, no, I think he realizes that there's something different about me, and I couldn't figure it out. So I see what you're saying about that and the caregiver thing too, because I've had really pretty caregivers. Then all of a sudden the guys that live around in the place where I live are like, "Oh, is your staff there today? Who's your staff?" I'm like, "Thanks a lot. Thanks a lot. You could have at least said hi or something. At least pretend to be interested in me for 30 seconds."

Lily Newton: Well, this seems like a good space we can segue. We need to take a quick break, but we will be right back.

Erin Hawley: This podcast is brought to you by Easterseals.

Lily Newton: We work for Easterseals, but maybe our listeners don't know what that is.

Erin Hawley: Easterseals is leading the way to full access, equity, and inclusion for disabled people and their families.

Lily Newton: And we've been doing this for more than a century.

Erin Hawley: This includes helping disabled people find meaningful employment and addressing healthcare needs for all ages.

Lily Newton: We're proud to serve communities across the country and ready for the next 100 years. For more, check us out at [Easterseals.com](http://Easterseals.com). And we're back. So speaking of pushing people away because of your expectations and what you think of, I know when we were working on making the music, Jennifer, you had told us a story about your expectations of what you thought dating would be like versus your first experience or your recent experience with dating. Could you just tell us a bit about that?

Jennifer Msumba: So I just thought, because I guess I watch a lot of movies and I thought it would be like the movies, I don't know, call me naive. But that's all I really had to go on, was what I see on the TV or something. I just thought it was going to be so romantic, but it's the most ... I don't know, just going out with someone is awkward. It's just all awkward. All of it is. It's just awkward and it's not ... I don't know, it's not romantic to me. I don't know if I would ... Maybe I'm done exploring romance. I feel like it's just too awkward and it's too much for me. At least I know that I tried, that I didn't just assume I couldn't do something, but I tried and I think that's good enough for me to know.

Because as I got older, I'll make myself try things because I don't want to miss out. I missed out on so much of my life because of my disability, because I was in placement after placement. You just don't get any normal life. So now that I'm able to live a normal life, I am like, "Okay, I'm going to try out for America's Got Talent. I'm going to do this and do this." I just want to do all the things. Now I'm happy that I gave romance a try. Maybe it's not so much for me, but I know that I gave it an effort.

Lily Newton: I love that. I think that you're so right, that anytime you try to manufacture romance or try to really make a romantic thing happen, then that's when it's awkward. I'm awkward all the time, so romance is just even more awkward. I think because we don't talk about disability-

Erin Hawley: Yeah, I feel like-

Lily Newton: So awkward.

Erin Hawley: When I was dating, I would be on regular dating sites, not disability dating sites, but still the only people who responded to me were disabled because I feel like, I don't know, I just never really talked to or had a date with somebody who was not disabled, even though I wasn't necessarily looking for a disabled person. We just kind of find each other.

- Lily Newton: Yeah, I think that makes sense. I think that there's something about what the point of this podcast is and having authentic conversations is that because disability is so not talked about ever, if you're with non-disabled people, it feels like there's so much ground to cover before you can even start talking about anything else. So there's so much explaining of, this is who I am. This is how I function. This is what my needs are. There's so much of that before, hey, how was your day today?
- Jennifer Msumba: Yeah, and also I feel like with dating and romance, I really need my space every day. I don't mind talking to someone for an hour, but then after that, I just want to come back to my little house with my dog and have absolute silence and just be there. I don't think I could be married or in a long-term, for me, because I really need a lot of downtime, a lot of quiet time where I'm not having to make sure the other person's emotions are taken care of or their feelings are not getting hurt because I don't want to look at that TikTok that's so funny. That burns me out.
- Lily Newton: So many things that are seen as red flags or bad in dating that are actually just accommodations. Even you just saying that, well, I don't really want to watch that TikTok right now, I could so easily see people being like, "Oh, if your partner doesn't want to watch the things you want to watch, that means they don't care about you." No, that's not the case. It's just exactly what you said. I get burned out really easily. I think social battery is such an important conversation. My battery is gone. Or I love the metaphor, I think it's a metaphor, of having enough spoons for the day. When I'm out of spoons, I'm out.
- Jennifer Msumba: Oh, and you'll know it too. I'll let you know, because one of my people that helps me out, she was like, "Hey, you want to see a picture of my daughter?" I was like, "No." She was like, "Oh, okay." I'm like, "Okay, maybe that was harsh." I was like, "I'm just really worn out right now," but I can see how that can affect somebody else.
- Lily Newton: I wish people knew, on the topic of Everything You Know About Disability is Wrong, I wish people knew, especially for us being autistic, that feeling that I can't look at something or watch something or take something in in a brain that's not mine. My brain processes intensely. Looking at a picture of someone, I'm not able to just look at it and then move on. It might fire something else in my brain that might make me think about something else. My brain fires thoughts so quickly that I don't think people realize when I say no to looking at something else, it's because I can't let my brain fire off any more thoughts right now.
- Jennifer Msumba: It's like I hyperfocus, so when I'm focused on something, I don't want anything to try to break that because I'm so locked into something. That's usually when I'll just cut people, no, no, no, no, no. But I do have feelings and empathy. A lot of people think people with autism don't have empathy because of responses



like that. But really I do feel bad when I realize, oh, I think maybe I hurt their feelings and I'll go back and say, "Sorry, I was just worn out at that moment."

Lily Newton: I think that that also goes back to why it's so nice to have disabled partners, friends, et cetera, because it seems like those are the kind of relationships where you get to have that deep understanding of, hey, I'm done for today. Nothing personal, but that's it. Going back to what I was saying on breaking neurotypical standards, my boyfriend and I live together. We have our own rooms. People think that's wild. I'll be like, "Oh, I'm in my room. I'm in his room." People think it's so weird. No, I need that because sometimes he needs to go into his cave. I need to go into my cave. It helps us be closer because we allow ourselves to be apart.

Jennifer Msumba: That's a great accommodation. I never considered that. See, I could maybe do that. I might open myself back up to romance. So if you're out there, I'm here.

Erin Hawley: Yes, I'm not autistic, but I absolutely have to have my own room and my own space because I have anxiety. For me, the most common thing is to be alone in my room with a book. I just have to be away from people for a while. So if I was ever to live with somebody, I'd have to have my own room, absolutely. A lot of people think that's weird, but I think a lot of people now are doing it more.

Lily Newton: There are so many right things you're supposed to do if you're in a relationship. You're supposed to share a room. You're supposed to want to be together all the time. You're supposed to, and I was definitely where you were at, Jennifer, of, I'm done. I'm not dating again. I'm going to be alone. I like to be alone. I'm not doing this because I felt like dating was this landscape of shoulds. I can't function in a world of how I should behave because then I just start masking. People don't know this, but masking is really bad for your health. It can really hurt you. It's very stressful to have to completely hide who you are at all times. I think so much of dating culture encourages masking even from neurotypicals, which go back to the fart.

Erin Hawley: The fart.

Lily Newton: Back to the fart, that's it. There is that level of you're supposed to mask who you are.

Jennifer Msumba: I just want to find somebody that's super awkward too, and so that it counteracts. It's like when you put two elements together or something and they counteract and it becomes something beautiful.

Lily Newton: Jennifer, maybe that person who is the perfect amount of awkwardness that will fit into your awkwardness is listening to the pod. So if you're listening and you're looking for your perfect awkward partner, I want someone-

Jennifer Msumba: I want his shoes to always be untied. That's cute to me. I just want all the awkward.

Lily Newton: I think that anyone, regardless of if you have a disability or not, can understand that feeling of, I want to show up, no makeup, sweatpants, and have you pick me every time. Well, yeah, and my version of that is I want to say way too many words and talk in long sentences that don't quite get to the point until they get there and I need you to accept that about me. I think love is out there for all of us, and this has been such a wonderful conversation. Any other points on dating we want to get to?

Jennifer Msumba: Just that I want the people to know that people with disabilities have feelings, all the feelings that people without disabilities have. You might not express it in the same way, or you might think, oh, we're not capable of that, but we are. I would love to see it represented more in film, in television, in books. I just want to see two disabled people together, a disabled and non-disabled person together. I just want to see that represented so that people understand we're not these ... What's a word for not a prude, but we're not non-feeling beings. We have the same feelings and the same ones. My biggest fear is I don't want to die alone. That's my fear, that I'm going to be alone. That's the one reason why I want to find a husband, because I just wanted somebody that was always there. I don't know, it's just feelings.

Lily Newton: Thank you for sharing that. That's got to be one of the most intrinsic parts of humanity, needing others. So much of disabled representation is people who are isolated and alone. I think that also, husband isn't always the answer. There's beautiful friends too. I've learned that disabled friendships can be-

Jennifer Msumba: Amazing.

Lily Newton: Intimate and beautiful and deeper than a lot of what people expect from friendship because we do see each other as real.

Jennifer Msumba: That's true. You're right, you're right. I have great friends too, so I won't complain.

Lily Newton: Well, it's okay. You can complain a little, but yeah, there's no right answer in love and dating. So thank you so much for sharing your perspective.

Jennifer Msumba: You're welcome.

Lily Newton: Erin, I don't know if there's any last closing thoughts you want to say.

Erin Hawley: Just thank you, Jennifer. This was great, and I think everybody should find somebody that they can fart with.

Lily Newton: I completely agree.

Jennifer Msumba: So that's the best summary. Oh my gosh, is that a T-shirt yet? Because Erin, you just made a meme right now.

Lily Newton: When everyone listens to Everything You Know About Disability is Wrong and we are the number one podcast and everyone wants merch, because that's going to happen, manifesting all of this to happen, someday we'll make shirts that say-

Jennifer Msumba: To fart with.

Lily Newton: Find someone you can fart with.

Jennifer Msumba: I love it. Erin, that is perfect, perfect ending.

Lily Newton: Welcome to Ask Us Anything where we answer anything that's been asked of us. Erin, today's question from the Ask Us Anything is, should I disclose my disability on dating apps?

Erin Hawley: I believe that you should, because if you want to have a real relationship with somebody, they're going to know that you're disabled at some point in the relationship. If you say it from the beginning, it weeds out all the ableist people. I've had that in my experience when I haven't shared a disability, and it's always ended badly. So I firmly believe that people should share it as much as you feel comfortable. You don't have to share everything. I think it's better to start off with that knowledge of your partner is disabled or you're disabled.

Lily Newton: Yeah, I think that's a really smart answer. I think that I'm still in the area of understanding what disability pride is and understanding how I want to hold being autistic and the role that plays in my life. I think that your answer is definitely an answer that I needed to hear, because sometimes I think it can be easy to want to hide things and to want to try to be a person on dating apps that you're not. It's so easy. You're making a profile, so it could be so easy to not disclose things and to make what you think the perfect profile is. But you're right. Weed out the ableists. If nothing else, our answer is, yeah, disclose so that you can weed out the ableists. Because anyone that would not want to date you just because you're disabled is someone that you don't want to date.

Erin Hawley: Exactly, and it's not good to start a relationship hiding something that's so intrinsic to who you are as a person.

Lily Newton: I completely agree, and that's the Ask Us Anything. If you want to be part of the asking us anything that we answer, you can email us at [EverythingYouKnow@Easterseals.com](mailto:EverythingYouKnow@Easterseals.com). Ask us anything. We'll answer.

Erin Hawley: Thanks for listening to our podcast.

Lily Newton: If you liked what you heard, be sure to write a review, like, and subscribe wherever you get your podcasts.

Erin Hawley: Join us next time when we discuss more reasons why everything you know about disability is wrong.

Jennifer Msumba: (singing).