

NMOSD and Romantic Relationships

You can watch the video of this podcast at: youtu.be/p_O-Am_dJOU

[00:00:02] **Announcer 1:** "ABCs of NMOSD" is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder, or NMOSD, a rare neuroimmune disorder that preferentially causes inflammation in the optic nerves and spinal cord. "ABCs of NMOSD" is hosted by SRNA, the Siegel Rare Neuroimmune Association. SRNA is a non-profit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our web site at wearesrna.org.

[00:00:55] **Announcer 2:** In this episode, Landy Thomas was joined by Doug Newby, Heather Dawn Newby, and Caitlyn Flickinger. Doug Newby has worked in criminal justice and security. He became symptomatic more than ten years ago with NMOSD, transverse myelitis (TM), and optic neuritis (ON). Doug is newly married to Heather Dawn Newby, and they live in Pennsylvania. Heather has a background in environmental science, sustainable agriculture, and sustainable fisheries. She first became symptomatic with NMOSD around 2004.

[00:01:35] Caitlyn Flickinger is a care partner to Landy Thomas, her fiancée, who has been diagnosed with NMOSD. Caitlyn, a prolific writer, is pursuing her bachelor's degree in political science, with minors in sociology and business. You can view the guests' full bios in the podcast description. This episode is made possible in part by the generous support of Amgen; Alexion AstraZeneca Rare Disease; Genentech; and UCB.

[00:02:07] **Landy Thomas:** Hello and welcome to "ABC's of NMOSD." My name is Landy Thomas, and I moderated this episode, "NMOSD and Romantic Relationships." For this episode, we are pleased to be joined by Doug and Heather Newby, who both have NMOSD and Caitlyn Flickinger, my fiancée and care partner. You can view their full bios in the podcast description. Let's just begin. Can you guys introduce yourselves? Who are you? Everything.

[00:02:33] **Heather Newby:** You first.

[00:02:34] **Doug Newby:** I'm Doug Newby. I live in Pennsylvania now, was from Colorado.

[00:02:43] **Landy Thomas:** What did you do for--what do you do for work, Doug?

[00:02:46] **Doug Newby:** I'm on disability for my NMO.

[00:02:51] **Landy Thomas:** No, that's totally fair. What do you like to do for fun? Tell us about who you are as a person. How do you spend your days?

[00:02:59] **Doug Newby:** I like to go fishing and I like to go, if I have the money, I like to go to the casino every now and then. And just have fun or watch TV and together we'll watch TV together. Even at night when we go to sleep, we'll turn TV on and watch something. She'll be asleep before I will.

[00:03:24] **Landy Thomas:** It's really, it sounds really peaceful. I think that's important.

[00:03:27] **Doug Newby:** It's peaceful. And we got, we got our puppy wherever she's at.

[00:03:30] **Landy Thomas:** Cute. You guys got a cute little dog together. That's awesome.

[00:03:35] **Doug Newby:** Then we got...

[00:03:38] **Heather Newby:** Two crazy cats.

[00:03:39] **Doug Newby:** ...a cat on the laundry right now.

[00:03:42] **Landy Thomas:** Good. Ok. Lots of pets, lots of life in the home. That's important. Heather, how have you been doing? I've caught up with you in a couple different episodes. Anything new. What are you into now?

[00:03:54] **Heather Newby:** I've been doing really well. We got married in July and then we did some traveling. We did our honeymoon in Jamaica, which was amazing. Amazingly, I felt really good there, so I would love to go back. I'd like to live there. Minus the lack of really good medicine. Other than that, I can move there easily. We went to Colorado and since then we've just been working in the house.

[00:04:22] We're putting in a pellet stove. So just little things. And of course, I'm pretty much the same as I've been, working in advocacy for the Guthy Jackson Charitable Foundation and just helping patients in general. One of my passions. Other than that, we just play with our dog, Bailey, and just enjoy life.

[00:04:45] **Doug Newby:** Yep. And she's been doing a lot of canning.

[00:04:48] **Heather Newby:** Oh, I have been. That is my new hobby. I've been canning anything I can get my hands on.

[00:04:52] **Landy Thomas:** I think that's a great. You're getting to have the real, you're taking on a lot of the nice wife roles, the fun ones. It's not, it's not all the cooking and cleaning, but it's all the good, like the canning, the homemaking. You're making a space that's good for you and your husband to really live, have a really good time, good life.

[00:05:10] **Heather Newby:** Exactly.

[00:05:15] **Doug Newby:** Got kind of travel logged, but we're starting back up next month.

[00:05:20] **Heather Newby:** We're going to Tennessee.

[00:05:22] **Doug Newby:** Tennessee for the regional.

[00:05:24] **Landy Thomas:** Yes. I'll see you there. Hey, I finally get, I'll get to meet you in person.

[00:05:25] **Doug Newby:** There you go.

[00:05:30] **Landy Thomas:** I got to vet you out myself.

[00:05:33] **Doug Newby:** Then we have to go to DC on the 7th? No, 1st of November. My son's going to have...

[00:05:44] **Heather Newby:** He's having surgery, so we're going to go down and be with him.

[00:05:50] **Doug Newby:** He's trans and he wants to have the surgery, so...

[00:05:54] **Heather Newby:** We're gonna support him.

[00:05:55] **Doug Newby:** So, we're gonna go there to support him because his husband won't be there.

[00:06:00] **Heather Newby:** The whole time.

[00:06:01] **Doug Newby:** The whole time. He has to come back to go back to Colorado. So, we're gonna be there to stay in a hotel with him.

[00:06:07] **Landy Thomas:** That's really cool.

[00:06:08] **Doug Newby:** While he's resting, we're gonna go sightseeing.

[00:06:11] **Landy Thomas:** Ok. No, that's so great.

[00:06:14] **Doug Newby:** But we are going back to Jamaica though.

[00:06:17] **Landy Thomas:** Yes. You'll have to. You've fallen in love with the place you got to go back.

[00:06:21] **Heather Newby:** Exactly.

[00:06:22] **Landy Thomas:** This episode's gonna be really specific on relationships. I think, like you, it's important to get to know me as the podcast host a little too.

[00:06:32] I think things have been going really well. I'm in school. I'm getting married in February, which is nice. We're getting married. I'm super excited about that. Everything's just really coming together. I've been really enjoying my life. I'm living in a college town now, but we're hoping to move somewhere a little bit more rural next year, which will be nice.

[00:06:53] I like the quiet a bit more. I like the ability to go into a town, but I don't like the bustle necessarily. The city living is you are hearing a police siren outside every couple weeks. And it's, "No." I like the campus, it's great for now, but I wanna be able to have a very peaceful life. It sounds like you guys are living my dream in a little and hopefully we'll be able to have that same thing.

[00:07:18] **Doug Newby:** It's quiet. It's quiet here.

[00:07:21] **Landy Thomas:** You can focus on you and your life, and your home. Which is important.

[00:07:26] **Landy Thomas:** And then Cait, would you introduce yourself?

[00:07:28] **Caitlyn Flickinger:** Okay. Hi, I'm Cait, Caitlyn. A little bit about me? Obviously, I am in college. That's

where I'm met this one, but that's a different question for later. I'm primarily a writer. That's my big thing. I write in my free time. I really want to write professionally. I love to go traveling with Landy, obviously.

[00:07:56] **Landy Thomas:** We've been to some crazy places.

[00:07:57] **Caitlyn Flickinger:** Lots of road trips.

[00:08:00] **Landy Thomas:** Lots of road trips. We're trying to, ok, we're moving out of Florida. Florida's beautiful. It's a beautiful place to live, but we know we're going to move. We've been trying to see every single tourist attraction in all of Florida in under a year, which is an intimidating goal.

[00:08:15] We took a couple days just to drive around, go across the coast all the way down to the south. We went all the way down to the Florida Keys and back, and then up through Everglades. All the things. We're trying to just hit it all. Just that we can get the full experience. We also went to Yellowstone recently.

[00:08:33] **Caitlyn Flickinger:** Yes. Yellowstone's the best.

[00:08:35] **Doug Newby:** Well, I took Colorado because that's my original home.

[00:08:39] **Heather Newby:** Yeah, so where he grew up, he took me there. And then we went to some places in Arizona. It's called Four Corners. So, four states at once. So, I was sitting there and had my feet on every spot. And it's hot. My butt was very hot, but it was worth it.

[00:08:58] **Doug Newby:** And I took her into the Navajo Nation where they do a lot of filming.

[00:09:02] **Heather Newby:** That was really cool.

[00:09:03] **Doug Newby:** John Wayne movies and other western movies in the Monument Valley.

[00:09:07] **Landy Thomas:** That's amazing. Honestly, the country's so big and there's so many different things.

[00:09:12] **Doug Newby:** Oh, there's so many places.

[00:09:13] **Landy Thomas:** We're just, we're so excited to just be able to have that ability to just go places and do things. That's the point of living is getting to see stuff, getting to love the things you're doing. Really excited about that. Everything's going really well, and we're just excited about life now. All right, well, I guess let's just start with the next question, which is a fun one. Could you tell us your love story? Could you tell us how you met, how you knew they were the one, that kind of thing.

[00:09:45] **Doug Newby:** You wanna start off? Go ahead. Go ahead.

[00:09:49] **Heather Newby:** So, we met through the Patient Day. So, we met at Patient Day 14 years ago. Is it 14 or going on 15? 15 years ago now. So, we met 15 years ago at one of the Guthy Jackson Patient Days. And at the time it was just like another patient that I was meeting. I didn't know that one day he would be my other half.

[00:10:14] So we were friends. At the end of Patient Day, we exchange numbers and stayed in contact. And from that it, it literally went from friends to best friends to I really like him. Eventually he kissed me the first time. At that point it was, I think I really like him. And we just bounced back and forth forever. I wanna be with him.

[00:10:41] **Doug Newby:** We did.

[00:10:41] **Heather Newby:** And then he would go and get cold feet and then I would be sad for a little bit, but we always came back to each other. And then eventually it was just...

[00:10:52] **Doug Newby:** And then the last Patient Day, they had the full international one. I was sitting next to her the whole time.

[00:10:59] **Heather Newby:** He was.

[00:11:00] **Doug Newby:** We were together, we went everywhere. And then after we parted our ways, it was hard for me to get back on the plane because my feelings for her were pretty strong. When we got home, she says, "I hope you don't have COVID because everybody has COVID." I go, "Oh no." So, but I did end up with it. But anyway, I told her how I felt and my reasoning and how I felt, and we stayed in touch every day up until the day I flew out here to ask her to marry me at an Italian restaurant.

[00:11:52] I came out a week early and we would talk to each other by Skype or FaceTime, and we wouldn't go to sleep. We would go to sleep together. I'd have my phone next to me on the end stand, and...

[00:12:13] **Heather Newby:** I'd have him in my bedroom with me, and I would wake up with him there.

[00:12:18] **Doug Newby:** She didn't hear me. She yelled at me.

[00:12:21] **Heather Newby:** Yeah, I did. So, he, when he had COVID, and I couldn't hear him breathing. And I was yelling through the phone like "Doug, you're not breathing." And he was, I just couldn't hear him.

[00:12:34] **Doug Newby:** But anyways, I came out and asked her to marry me and she, we flew back. I had everything in the U-Haul, and we moved everything in a U-Haul, loaded it up. because my house was on for sale at the time. And we came here, came back through, and she don't like Kansas by the way.

[00:12:57] **Heather Newby:** Too flat. Too flat.

[00:12:59] **Doug Newby:** Anyway, we, drove all the way back. It took three days, four days, something like that. And came back here. We set a date. And it was on July 5th.

[00:13:11] **Heather Newby:** And we got married.

[00:13:12] **Doug Newby:** We got married.

[00:13:14] **Landy Thomas:** That's so nice.

[00:13:15] **Doug Newby:** She did everything herself. If you haven't seen any pictures.

[00:13:18] **Landy Thomas:** Well, she's a hard worker, I think. I think that she'd have to put it all together herself. You know what you want. You're ambitious.

[00:13:24] **Doug Newby:** She did most of her flowers herself.

[00:13:28] **Heather Newby:** DIY'd everything.

[00:13:38] **Landy Thomas:** Which is great. You could have complete control.

[00:13:48] **Heather Newby:** Hobby Lobby is the best. If you need stuff. It's the cheapest. Quality's good.

[00:13:58] **Landy Thomas:** Good. Ok. Thank you. That's good advice.

[00:13:42] **Doug Newby:** As far as her and I know it's probably one of your questions, but I know how she feels as far as NMO. I know, some of the signs. Vice versa. She does me too.

[00:14:02] **Heather Newby:** We get each other so well.

[00:14:05] **Doug Newby:** And knowing each other so well with NMO and how to live it together is a big step. And we learn together with it. And we know each other, what NMO can do and what it does. So that's how we, that's how our biggest second goes. But as far as being in love, we work at that, and we know what's going on.

[00:14:32] **Heather Newby:** I was listening to you talk. I like your version.

[00:14:37] **Landy Thomas:** I think it's a nice way to get it across. What about you? Do you wanna jointly tell our whole story or do you wanna take the stage?

[00:14:46] **Caitlyn Flickinger:** We can jointly because I feel...

[00:14:48] **Landy Thomas:** Are we talking about the Reddit?

[00:14:50] **Caitlyn Flickinger:** Sure.

[00:14:52] **Landy Thomas:** We also met online, which is, I think, important. And I think it's a very pivotal part of a lot of modern love stories, which is the online component. Basically, I was living in the Panhandle. I didn't have any friends, especially, because it's a very, it's a very small town.

[00:15:11] We get a lot of visitors that are from, they wanna go on spring break, but they don't really want to, you're not really meeting people to be friends with them very often. Yeah, a lot of military families too up there, so they're in and out. You really don't get to have a lot of friends that stick around for very long, which is hard.

[00:15:29] So I was lonely, and I had been looking at this subreddit for UCF. So, all the UCF students used that to talk to each other. And I saw a post one day that said, "Hey, does anyone want to play Minecraft with me?" And Minecraft is a video game where you get to build buildings, you hang out with each other, just like you can do anything that you want and hang out in a, in that kind of a visual playing medium.

[00:15:57] And I was, oh gosh, this person sounds like they, they're kind of a little lonely like me, but...

[00:16:07] **Caitlyn Flickinger:** Desperate. [Laughter]

[00:16:08] **Landy Thomas:** A little desperate, but not a bad way, "Hey, I'm lonely. I'm desperate to start up a friend group or have a group of people that really wanna go hang out, do stuff with each other."

[00:16:18] I have fun. I was raised on it. So, we were like, ok. And I commented and I said, "Yeah, I'd be willing, I'd wanna do it." So, then we started the group, and it was not just us, it was us and then six or seven other people. And we played every single day. Tuesdays and Thursdays from 5 pm to midnight.

[00:16:41] I think for, at least, it was 10 months. 10 months. And we realized all of a sudden. Me I, was really not, I didn't have a lot of friends my age. I had a lot of NMO friends, but yeah, when you're young and you have it, it's just weird because everyone's a lot older than you.

[00:17:00] Generally. Average age of onset is 41. Getting it at six is a weird sort of thing. So, getting to have friends that were my age and you talking to them, it was so important to me. And it wasn't long before we were hanging out. I would be on more than anybody else just because I was like, I wanna be here, I wanna hang out with people.

[00:17:23] This is finally it for me. I'd love to have a really good group of friends. And since you owned the server and started the group, you would be on.

[00:17:31] **Caitlyn Flickinger:** I was pretty consistently on, of course. And then whenever the actual game stuff ended, we'd end up on a call pretty much all night. And eventually that became every night. So, I was laughing a little earlier when you were talking about going to sleep with the phone on, because that was pretty much

[00:17:50] **Landy Thomas:** Yeah, it turned out every day we were just talking and really connecting. And think the moment that I was ok, this definitely is the one.

[00:18:02] Definitely it was, it comes in small moments, but since I do my IgG subcutaneous treatment once a week and I've been treated really poorly about it by a lot of different people. I know this is so weird, but people in real life, I would go to, I'd go get dinner with somebody or we'd have a visitor in town or something and we'd have to go get dinner with them.

[00:18:27] And I had to infuse that day. And it was that, that's the only time that would work for me. And people would be like "Do you have to do that now?" Or, treat it like it was gross or something. And I always felt really bad about it.

[00:18:41] Plus I have a little symptom from it where I'm just a little sleepy. I'm not out. I can't--it's not like that I can't talk. It's just I'm a little out of it, compared to how I normally would be. But then I was hanging out with her and being, yeah, do you want to, you wanna be on call with me?

[00:18:59] Do you wanna hang out with me? Throughout my entire treatment? And she would just take the opportunity to be, yeah, let's just watch a movie together. Let's hang out. Let's do it. Oh, you're doing it this night? Yep. I'll be there with you the whole time. I was like, what? You're, you wanna be there?

[00:19:13] You wanna, even though I'm a little, out of it. I'm a little less. I very much pride myself on being able to construct a sentence, but all of a sudden when I'm a little sleepy, it's just weird.

[00:19:27] **Caitlyn Flickinger:** It's super cute.

[00:19:28] **Landy Thomas:** It's very. But anyway, to have a person that's, yeah, I see you, that you're dealing with this. I see that it's hard for you or you're a little off, but it's not a burden on me. I'm good to go. Let's do it. If anything, you probably need me to hang out with you more when you're doing it.

[00:19:47] **Landy Thomas:** Cool. Because nobody else had ever been like that for me. Everyone else that I talked to about IgG were always just they're so focused on how gross it is that the needles are going in my...

[00:19:59] **Doug Newby:** Ours is together.

[00:20:02] **Heather Newby:** We do ours together at home, so we joke that it's date night. Our nurse comes and we hang out all. We have dinner, because she's coming later. So, we'll have dinner, we'll hang out on the couch, watch movies. It's date night.

[00:20:16] **Landy Thomas:** I think it's a good time. It's date night. It's a moment where you're like, ok, I'm not gonna be able to go run a marathon right now. It's a day to, it's a nice day to stay in and we hang out. We cuddle. We watch a movie. It does force you to set aside a good amount of time to just breathe.

[00:20:34] **Landy Thomas:** So, there is benefits. Obviously, it's, nobody wants to have to do these kinds of things.

[00:20:39] **Doug Newby:** No.

[00:20:39] **Landy Thomas:** It was nice to have a person that wanted to do it alongside me and wanted to walk that path with me. Even if you can't fully, you're never gonna be poached by it, but you understand that I need extra care in those moments.

[00:20:51] **Doug Newby:** It's just us. We do the same thing, and I'll say sometimes she'll have a day after or something like that. She'll get real...

[00:21:03] **Heather Newby:** Tired

[00:21:04] **Doug Newby:** and blah.

[00:21:05] **Heather Newby:** I call it my blah.

[00:21:06] **Doug Newby:** Mine is my legs hurt right after.

[00:21:10] **Doug Newby:** And, but different, we know each other's feelings about it, and we know it's not gross for us. Of course, it's at home, not have to go to infusion center, to have Jess come here and do it for us. It helps. And the neurologist I used to see in Denver was Dr. Bennett and he put me on Rituxan too long where I was, it killed my system, my immune system. So, but when I got here to her doctor, he said we're gonna...

[00:21:43] **Heather Newby:** We're changing this.

[00:21:44] **Doug Newby:** We're changing this. So, my immune system isn't to par where it should be.

[00:21:51] **Heather Newby:** We're working on it.

[00:21:53] **Doug Newby:** We're working on it. He went ahead and instead of having an IV in my arm and stuff, we both have ports, so...

[00:22:04] **Landy Thomas:** Not to pivot too hard, but I wanted to ask you as well what was your moment?

[00:22:11] **Caitlyn Flickinger:** What was my moment? There are lots of moments, but if I had to choose one this was not too long after you finally moved down here. We were on a sort of impromptu date to an ice cream shop by campus. Because the place we've been intending to go was closed.

[00:22:30] So we ended up at a different place, and I don't know, we were sitting outside because there was no seating inside. It was dark and muggy because it's Florida, but I was looking at you, watching you eat your

ice cream, and I thought I want this all the time, forever. This sort of miserable day outside after our plans have fallen through. I'm this, this is what I want, this is what I'm here for. So...

[00:22:55] **Landy Thomas:** Just eating your ice cream. I don't know. It's good. The domestic. I don't know. I feel every day I get to just hang out with my best friend and do all the stuff that I wanted to do. Yeah, it's nice. The companionship is so important, and I think a lot of people have to miss out on. It's frustrating.

[00:23:15] **Doug Newby:** We try to go work out together.

[00:23:18] **Heather Newby:** Yeah, we did work together, a lot of things, little things.

[00:23:22] **Doug Newby:** She did everything for the pellet stove. Wouldn't let me...

[00:23:27] **Heather Newby:** I had fun.

[00:23:28] **Doug Newby:** ...but she had fun because she liked spraying, spreading mortar...

[00:23:34] **Heather Newby:** Painting stuff.

[00:23:37] **Landy Thomas:** A natural homemaker, which is important. Which is fun. I wanna to be able to personalize whatever space we get to move into now, because we're in apartment now. Once we get a house and we're really sure we're gonna get a house. We've been trying to save up as much as we can.

[00:23:53] Put all our scholarships away, all that stuff. Once we get a house, I really wanna make it a unique and fun space. Just a place that we can really go home and look at and be really proud of, which is, yeah, that's...

[00:24:03] **Doug Newby:** what we do here...

[00:24:06] **Heather Newby:** the little things.

[00:24:07] **Doug Newby:** We did a lot of other things, remodeled. The house belongs to her mom, and, but we're just staying here and renting it as long as we want. So, we remodeled the kitchen and little things. She painted all the cupboards, and we did the floors and got new appliances.

[00:24:31] **Heather Newby:** So, it's nice.

[00:24:32] **Doug Newby:** It's nice.

[00:24:34] **Landy Thomas:** Good.

[00:24:34] **Doug Newby:** I, and she likes it because I do the laundry.

[00:24:39] **Landy Thomas:** Put him to work. That's what I'm saying.

Heather Newby: Stairs are my downfall. going down the basement stairs, I'd probably fall. So, he does that.

[00:24:53] **Doug Newby:** Of course, we I, ended up investing in a washer dryer combo.

[00:24:57] **Heather Newby:** Which was nice.

[00:24:58] **Doug Newby:** Which was nice.

[00:24:59] **Heather Newby:** It's so cool because you don't have to spend all the time changing things around, just one device.

[00:25:05] **Landy Thomas:** Wow. That's actually really cool.

[00:25:09] **Doug Newby:** It helps, and it saves energy too, and it's all connected to her phone.

[00:25:15] **Landy Thomas:** Oh, wow.

[00:25:17] **Doug Newby:** And the refrigerator and the stove are too.

[00:25:20] **Heather Newby:** It's fun.

[00:25:21] **Doug Newby:** And as soon as we get the pellet stove going, that's also wi-fi.

[00:25:28] **Doug Newby:** So, she likes that part.

[00:25:31] **Doug Newby:** Refrigerator door opens.

[00:25:33] **Landy Thomas:** You're modernizing. It's great.

[00:25:34] **Doug Newby:** And her phone, it comes right on her phone, "Ding ding, the door is open" and I don't mind that much.

[00:25:44] **Landy Thomas:** But yeah, we'll go. Well, if you're cool with that, I wanted to ask the next question. Yeah, just to say having NMO and navigating a romantic relationship can be really difficult.

[00:25:55] It really is. Whether you've been in a relationship and have just been diagnosed or you're entering a new relationship, it's hard to find a person that's really willing to put in the effort, put in the time to. What's oftentimes a hard path. I've seen a lot of sad stories within our community of people that they get, they've gotten married, but then that person didn't expect a diagnosis like that and, those relationships can fizzle out or struggle at the very least.

[00:26:29] **Landy Thomas:** It's stuff like that. So, what do you think the commitment to walk through that hard path alongside one another, like what does it look like?

[00:26:38] **Doug Newby:** It's a strong commitment to do, because my last marriage is when I was diagnosed with NMO and she was actually a nurse.

[00:26:52] But she just couldn't handle the portion of me being going on disability and staying home. And she just basically couldn't handle being sick because she went to the first, our first, my very first Patient Day. She was with me. I went to that therefore after I went by myself.

[00:27:15] But yeah, it was hard, and she just didn't really live out being together. And when I found Heather, it's totally different story because knowing she has the same thing. We can work through his path and work together until we're gone. It is pleasing and it's inspiring together. So how about you?

[00:27:54] **Heather Newby:** I feel similarly. I obviously, I was not married before this, but I had a relationship in college. Before I had really got sick, and he went home a couple times with me when I had optic neuritis. Then that first summer he is like, "I can't do this. You're, too sick, you're in the hospital too much."

[00:28:17] And he broke up with me and it's well, if you don't wanna stand by me, then good riddance. I bawled. Don't get me wrong, I was so upset and devastated because I thought he was there for me, but he wasn't. So, for the longest time, I like relegated myself to being the single girl. I'm gonna have my friends, I'm gonna enjoy my family.

[00:28:41] And if I ever find someone, then I count myself lucky, I did find someone, and it might have started off as a friendship. And I think that what, that's what makes it so strong is we spend so much time together getting to know each other and being friends, that the relationship part was easy. It was the easiest part.

[00:29:04] But understanding what each other go through definitely helps. There are times when one or either of us doesn't feel great. I'm having an NMO day and intrinsically we know exactly what they're talking about because we feel it for the other person. We understand it. And that really makes a huge difference.

[00:29:27] It does. I give a lot of our people credit. Even you, finding someone in this world. I mean, it's hard. So, I get it. It's a pain in the bum and finding someone is amazing. It really is.

[00:29:45] **Landy Thomas:** What about you? Me being the person that has NMO and you not having NMO means that I understand what the hard path is going to look like for somebody else, but I don't understand how the hard path looks like to you right away.

[00:30:00] **Caitlyn Flickinger:** I think really the biggest thing for me has been that I, when you first explained it to me, it was daunting, of course. But yeah, I think that at a certain point I really realized that I had to make a commitment to learning, to adapting myself and everything that I'm doing because if here's a person who I really love.

[00:30:25] And if I really mean that, when I say that, then I'm going to learn, I'm going to do what I have to do because there's no one like you. So, I've committed myself to that. I've committed myself to, getting involved in the community, volunteering, following you to...going with you, not follow, following you is not the correct phrasing, but going with you to events, conferences, that sort of thing because this is your life and this is our life now.

[00:30:55] **Landy Thomas:** It's so easy to understand how scary it is to an outsider looking in. We've all had to explain what NMO is to other people so many times and what it can do in its worst cases. Of course, people look aghast quite a lot, so I just inverse when trying to explain what it was to Cait.

[00:31:18] I really tried to guide her in like, "Hey, this is what it can do, but this is where I'm at." Where I'm like, I've been doing really well for myself now. But it wasn't always like bad things were bad. I took the time to show photos of childhood stuff and all the, when it was at its worst because I think if you are trying to get somebody to be like, "Hey, I'm gonna commit to you." I think it's only fair that they know everything that is possible.

[00:31:49] **Landy Thomas:** It's hard because it's like, it can definitely get a person to be like, "Ok, no, I'm, I can't do this." And that's happened before for me where it's like you can't really, if somebody is not willing to commit to it and they can't look what is a nightmare to a lot of people in the face, then that's not the person.

[00:32:09] And you have to keep searching and you really have to look. There's a lot of good people in the community and I'm really, really glad that you guys found each other. But in the world, it's really hard to find a person that's willing to take on something like this.

[00:32:22] **Landy Thomas:** That's just a fact of life and I've tried to navigate that the best I could. And I got really lucky to find somebody this early on who has seen what it can't do and has heard my story, but also the stories of other people in the community, right? And saying, "Hey, I'm gonna walk it with you if it gets that bad and I'm not gonna love you any less, and I'm never gonna see you as a burden."

[00:32:47] Right now we've been dealing with this is just part of life, but hospital bills, that kind of stuff. Right now, we're trying to figure out our financials. We're trying to figure out all that stuff. To a lot of people, I think that a big bill coming in can be terrifying, especially when, you know what I'm saying, it's like this is a not a, this is not a little thing. Gonna be able to, it's not unmanageable, if we can't find financial assistance. We're applying to everything.

[00:33:17] I'm applying to every financial assistance program in the universe. And I'm hoping and praying, but at the same time, there's a chance that this couldn't go well. There's a chance that I could have to pay some of these bigger bills. And I've been upset, and I've been worried, to myself of, am I burdening another person?

[00:33:35] Am I holding Cait back? Is she going to be with me? And we're always gonna be in some sort of debt because this is a disease that creates debt, a lot of debt really quick. But throughout this entire process, I've been really pleased to say that Cait assured me that's not gonna be a problem, that she's never going to come to like I don't know, the worst fear is that somebody would come to resent me.

[00:33:59] If it gets worse and what if a big bill comes in. And I don't know, it's hard because I've been living with this and I know my whole life has been a series of big hospital bills. Throughout my childhood,

[00:34:11] we were going through a lot. And my family actually had to go bankrupt, and we lost a house, we lost a car, we lost everything. Which was such a, which was such a blow to our family, but also a blow to me because I was a child and I really didn't understand. All I understood was that it was my fault.

[00:34:28] So I've always had a huge fear of the financial side of things. I felt like a huge burden to my family. And now I'm trying to figure out a situation in that I don't feel a burden to my future person, my future partner. And throughout every step of the way, Cait has assured me that she's going walk with me when it may be the financial side of things and the other parts of the disease that people don't talk about as readily. So, I think that's important too, is finding a person that's willing to contend with the reality of it, right?

[00:35:06] As for the next question I would like to just talk more at length about that, the differences between dating inside the community and outside the community. Because I think there's a lot of merit for both. Obviously, the community is, like you can find a lot of good people that understand right away. But it is limited. The dating pool is smaller than you'd think, right? But outside the community, the world's wide, but not everyone knows how to care.

[00:35:36] So honestly Doug and Heather, have you ever tried dating people outside the community? Heather you, you've briefly touched on the that person. Was there anybody else that you tried to date or was it just him and then you "Oh, I need to be single for a bit. This is terrible?"

[00:35:50] **Heather Newby:** It was kind of him. I had high school boyfriends before I got sick, but he was the one while I was sick. Then after that, I needed a break. I needed to just not even think about relationships, think

about getting healthy or not healthy, but getting a grasp on the NMO and focus on what was going on and focus on my family. I always had book boyfriends. You can escape into a book and then you have a boyfriend.

[00:36:25] **Doug Newby:** Really?

[00:36:25] **Heather Newby:** So, yes, it was, it's nice to be able to escape like that. But then, I met him. I fell hard for him. I did. He dated around and it made me sad.

[00:36:44] **Doug Newby:** I did, and I had dated a few and then one of them didn't or couldn't understand what I had. She figured, oh, I'm gonna have to take care of him financially and blah. And it was, it's like, "Goodbye." I did. I said goodbye because she just couldn't understand.

[00:37:07] Financially I know how to take care of myself. As far as that goes. There was that, and I just said, "OK." Every now and then I'd go out, and I explained I'm on this or that, and that was it. We never touch base again. It is hard sometimes because you feel like, oh my gosh, am I a bad person? I have this disease.

[00:37:42] **Heather Newby:** Nobody wants me.

[00:37:42] **Doug Newby:** Nobody. Nobody wants me. But I got her, so I don't have to worry about that. And I feel that with NMO to your, to myself, be who you are. Go out and do what you want, exercise, go out in the public. Who cares, who cares if I have that in my neck. I don't care.

[00:38:11] If I wanna wear a t-shirt or a tank top or something like that. I don't care who sees it. If somebody asks why you have it, it's like when you have a port, you think, oh my gosh, it's cancer. And if somebody asks, I say, "Nope." And I'll explain to them, "This is what I have. This is how to deal with it." Just be yourself. Life will get bigger and stronger.

[00:38:39] **Landy Thomas:** I think that's important is just being able to say like, "Hey I'm here. I exist." There's a lot of shame that comes with the disease and trying to start relationships with them.

[00:38:51] It's like, "No, this is what I'm dealing with. If you wanna come partner with me and live your life with me, I'm really cool. If not, your loss." Because it's so, you have to guard yourself. You can do a lot of pitying, and you can do a lot of, "Oh, I'm just gonna, I'll do anything. I'll beg and plead with people to give me a chance."

[00:39:16] But in the end a lot of people, if you have to beg and plead for them to give you a chance, then they're not your person. You have to be like, ok, you have to have, find the person that's gonna be good to go with that. You're worth it. Like seeing a person past the disease. The disease is so, part of us, but it doesn't mean that it's us. Exactly. And, I think that completely saying I'm not my disease and I'm my own person. It's fair, but it's also your life is going to be tied up with it.

[00:39:50] You're going to walk alongside the disease, but you just need somebody to walk alongside you who's walking alongside the disease. It's still part of you and still part of your life. It's not you, but you got to find a person that's willing to contend with both.

[00:40:04] **Heather Newby:** Definitely.

[00:40:06] **Landy Thomas:** Cait, so being pulled into my circle of things, my community, my life, my health issues. It must have been daunting. Do you think that those initial feelings, obviously daunting at first, but how have they shifted over time? As you've learned about the community, what's happened?

[00:40:25] **Caitlyn Flickinger:** Well. To be honest, in the very beginning, I don't think that I fully understood what has happened a couple times and started to explain things to me. But once it clicked, I was nervous.

[00:40:39] I was a little anxious about it, but ultimately, I thought to myself, "Well, I'm young. This person cares about me. I care about this person. I might as well try to ride it out, see what happens. And if the relationship works on other merits, then I'll find a way for this to work too." So obviously there, there are still, there's always gonna be little moments of anxiety or fear with anything of any sort of health thing.

[00:41:04] But ultimately, it really just has been this learning to walk beside it as you described, to learn what I can both in the purely factual realm and also in the community realm. I've met so many people because of you. I've seen so many people's life stories, stuff that I would've never interacted with or considered. It's really expanded my view as a person. And I think that is valuable and it's worth it. All of it.

[00:41:39] **Landy Thomas:** So, I think I mean, that's a good, good answer and an answer that brings me a lot of hope and peace about it. Because it's hard, it's very hard to invite somebody to follow that path, especially when they don't...when they're not walking the same path necessarily.

[00:41:53] I think that's Cait and my relationship has only ever strengthened the more that we are with each one another. We're really committed. And I think that's really important and somebody that's willing to contend with my issues and all that.

[00:42:10] But also, I think that we complete each other in really important ways, right? My aspirations and her aspirations are linked. My preferences, the things that we would like to watch, the things that we think about, the things that we do together. We have a lot of commonalities that kind of supersedes any of the pain of the illness, all the nonsense that comes with it.

[00:42:35] That's what I think that's important. For me, I think I was really hesitant to start dating. It's hard, especially when you're 16 and you're like, oh gosh I have this thing, I should be in the prime of my life. I should be dating boys. And all the, all the TV and the movies, they tell me that I should be in the world and people should like me and I should be liking people.

[00:42:57] I was scared and I just stuck with things that I trusted and things that could be like a crutch for me. I was definitely a big reader too, because I think that helps especially. It's not the same as a real relationship.

[00:43:13] And it's not the same as real, not just romantic, but friendships too. But it's a crutch. It's something that you can survive with until you find a real person. And it's still fond of to read those romance books now. But at the same time, I'm getting to live my own romance novel, so it's helped me survive.

[00:43:31] Until that point, the people in the books did help. And I got to here and I got to have her, and I've just been good. I mean regarding that slow insight to date. My first kiss was at 21. I think that's it's early for some, but late for others. Some people are like they're dating in high school and all that stuff, and I never had that.

[00:43:55] I didn't date I didn't even date in college. I was graduated my, bachelor's, by the point I had my first kiss. Ultimately, I was thinking about the one time that I did go on a date with somebody was when I was 18 and the guy was like, "Hey, oh you have this thing?"

[00:44:13] And I tried to explain it to him and the first thing he said was that he didn't expect me to live very long. It was a huge blow to me. Because I tried my best. I told him about how well I was doing and how I hadn't had a flare in a decade. And I was doing really well.

[00:44:34] And the first thing that he thinks to himself is, oh gosh, you are going to, not you're gonna be a liability for me. Or, so you're not gonna live very long. It killed me. I didn't want to date anybody else. I didn't wanna try again and I got more reclusive with that kind of thing.

[00:44:52] And I just thought to myself, ok it was maybe they, maybe one day somebody was gonna just stumble into my life and that'll be the person. But right now, I'm rejection sensitive. I can't do it. I don't want to be a burden on somebody else.

[00:45:10] I don't want somebody to see me as a person that's so sick that I'm just going to die at any given moment, even though I've cushioned it with as many facts and figures and the flat fact that I'm doing really well. I'm on a good treatment. I'm surviving. I haven't had an issue, but still, but when they hear the, what it can do, they think that's what it'll do every time, which is hard even.

[00:45:35] Even when I told Cait about it, she never reacted outwardly, even if she had some doubts. She never reacted outwardly like that. She never just was like, "So you're gonna die soon," or started asking me weird questions about whether or not I'm going to be able to have kids or all that stuff,

[00:45:52] really personal and hard. But I understood that she might have not understood right away, but I knew that I was gonna continue to give her more information as our relationship evolved. And that was just gonna be how it was. But generally, I think that Cait's been really good for, as a partner for me.

[00:46:14] She volunteers at like SRNA camp and goes to those conferences with me. I need a person to accompany me to some things because I do get tired, still have a lot of fatigue type symptoms and I need that companion...

[00:46:28] Which is such a benefit for me. Well, that's just, that's really just my stance on the dating thing. I think you definitely do have to, you have to look for a person, but you have to wait too. It's okay to be a little patient and just hope that you find that person, especially when you're dating outside the circle, right? Because there are a lot of beautiful people out there who will take you on, but there are a lot of people out there that won't, and you have to fight for it and have to really pursue it.

[00:47:00] Generally, I'd like to ask the next question, which is what would your advice be for people with NMO who want to start dating but don't know how, or are worried that they're bringing baggage into a relationship?

[00:47:13] **Heather Newby:** Sometimes I think that the best way to approach it, even if it's even if it's an older person, not even a younger person. If you're going to wanna get into that dating field, maybe don't tell them right away. Make them see you instead of you with the disease or you and the treatment.

[00:47:35] Let them get to know the fun part of you before they are faced with something daunting. Because maybe if they know that instead of, "Oh yeah, I'm Heather, I have NMO" right away, maybe they'll see me for more than just the disease. And that's what I tell a lot of teens, because they're one of the biggest groups that come to you about the relationship aspect.

[00:48:01] I wanna date, but people don't want me. And one of my teens a couple years ago was so excited that they went on a date, all right, with this amazing guy and she had bowel incontinent issues. So, she had an accident and that sweet guy took his coat off and wrapped it around her. I was like, he's a Prince Charming.

[00:48:28] He didn't think there was anything bad or crazy about it. He just wanted to make sure she was ok. That really hit me. You need to find that Prince Charming, not the one that will go buy you all this stuff.

You need someone that's gonna stand by your side when it's abrupt and sometimes, I don't wanna say you have to lie to someone.

[00:48:55] But hold some stuff back and make yourself comfortable in that relationship before you head headfirst into, "Oh my God, I have this disease."

[00:49:07] **Landy Thomas:** I think that's important. I think I waited three weeks until I started telling Cait anything, and then I just really trickled it in, I talked about what my current symptoms are, what my current things are, and then I started talking about, as our relationship progressed, then I started talking about what can happen, which is, that's the scary part.

[00:49:27] Like where I'm at now, pretty good. If you're on a good treatment and you're in a stable spot, you're pretty stable. But there, there's always the fear of what could happen, that the reality of what could happen that they also need to be aware of at some time.

[00:49:45] Definitely trickling in, starting trying with more friendship type things helps too. We were friends first before we even started dating. Which helped a lot because as a friend you understood what was going on and then you were like, yeah, I'm good to go with the romantic side of things. Even though I know about it because I've told you about it as a friend first, which helped.

[00:50:11] Anything from you, Doug? What would be your advice for people that wanna start dating but don't wanna feel like they have baggage into the relationship?

[00:50:17] **Doug Newby:** More of the same. I wouldn't directly tell them, "Hey, I got this autoimmune disease, it does this or does that." I wouldn't do that. I would just ask, go out, have fun. Have fun, be yourself and have fun, and not even say anything. And maybe a couple dates later or whatever or say, "Hey, I'm..." or you get sick or something. Just let them know.

[00:50:46] Then just ease into it and if they're that type of person that will be sympathetic to your needs, then that's the right person to be with. If not, then, "See you."

[00:51:02] **Heather Newby:** "See you."

[00:51:04] **Landy Thomas:** That's how it has to be. So, I don't think that's unfair to say. It's like they're not the person. Then I know this isn't typical of our experiences just because we're, we're both in this specific condition. But for people that were in a relationship. Maybe Doug, you're gonna be more of a person for this. But people that were in a relationship when their symptoms first arrived, is there any advice we'd have for them? People that are in that relationship and are having those big feelings? It's hard to be that person. It's hard to be the partner where a lot of life has been reframed by the diagnosis.

[00:51:47] **Doug Newby:** Not sure how to answer that.

[00:51:48] **Heather Newby:** I might have an idea of...

[00:51:49] **Doug Newby:** You might, go ahead.

[00:51:52] **Heather Newby:** So, if you're in a relationship with someone that has the disease or is symptomatic of the disease and coming into it, I would say don't run right away.

[00:52:08] **Doug Newby:** Don't run.

[00:52:08] **Heather Newby:** Educate yourself and...

[00:52:12] **Doug Newby:** Kind of like you, Cait, how you educated yourself on it.

[00:52:14] **Heather Newby:** Exactly. Educate yourself. Give yourself time to learn about the disease. If you have to take a step back and take a breath, that's ok, but come back to your partner, your loved one, because they're going to need you. On the same hand, if you know you can't handle it, if you're not emotionally equipped to handle it, if you're terrified, talk to them and be honest about it because maybe that person is also terrified...

[00:52:49] I can see in the community you can see a lot of people who have had loved ones that have walked away. And maybe sometimes it's for the best. Maybe they weren't meant to be your forever. Maybe they were meant to be your beginning, but just because someone's a beginning doesn't mean it's the end.

[00:53:14] So I think that's important for some people to know. That if it's bad, you don't have to stay in that relationship either. You're always free to walk away if you feel you have to, if you're not safe. If you don't feel safe with your loved one, it's ok. I know there were quite a few relationships that fizzled out over the years because people started to resent their loved ones for being sick, and that's a hard one.

[00:53:46] But then there were also some where it became abusive and we don't want that either. So, you really just have to go day by day and find your new normal with your partner because it's hard. Us together, we're lucky because we both experience it. So, we know intrinsically what the other's feeling.

[00:54:14] I can look at him in the morning, and I know if he's having a good day or if he's having a bad day. And it's like, "Well, what can I do to help?" And sometimes he probably gets annoyed. I'm like, "What do you need to help?" And then sometimes he has the cold, and he is having the pseudo symptoms, and it's like, "Well, we need to let it go and see if it lasts 24 to 48 hours and then we'll go get tests," just because of pseudo relapses and all that.

[00:54:43] And it's whole new thing. And, luckily, we know each other, and we know the disease in and out, so that helps. But when someone is on the outside looking in, it's hard for them and that's ok. I want people to give themselves grace because it is hard and that is Ok.

[00:55:08] **Landy Thomas:** It is really hard.

[00:55:10] **Doug Newby:** I won't kick you out of the door, honey.

[00:55:12] **Heather Newby:** Good.

[00:55:14] **Landy Thomas:** Very good. Very good. Ok, well this is pretty much it. I would like to ask if there's any final thoughts any of you would like to share that you didn't get to the chance. Anything that you would think that you wish that somebody who was either trying to get into a romantic relationship or is in one should know. Any tips or tricks? Any thoughts about at all that you wanna share?

[00:55:40] **Heather Newby:** I just wanna tell people to love themselves...

[00:55:42] **Doug Newby:** and be themselves...

[00:55:42] **Heather Newby:** Because if you love yourself first, then someone out there is gonna love you. Right? So, love yourself.

[00:55:53] **Doug Newby:** That's pretty much it.

[00:55:56] **Caitlyn Flickinger:** I got one.

[00:55:57] **Landy Thomas:** You got one?

[00:55:57] **Caitlyn Flickinger:** Yes. I think really the big thing is to remember that you are a person. You have inherent value in that, no matter what the other considerations that there may be. There's always going to be things that have to be considered. Everyone has something going on with them that people are going to think certain thoughts about, positive or negative. And ultimately this doesn't define you in any absolute sense. There's still that inherent value and there are people out there who will appreciate that. You just have to find them.

[00:56:34] **Landy Thomas:** Ok. Well, I think that's about it. Thank you, guys, so much.

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