

# Men and NMOSD

You can watch the video of this podcast at: [youtu.be/0YCMekjAb6c](https://youtu.be/0YCMekjAb6c)

[00:00:02] **Announcer:** "ABCs of NMOSD" is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder or NMOSD, a rare relapsing autoimmune disorder that preferentially causes inflammation in the optic nerves and spinal cord. "ABCs of NMOSD" is hosted by SRNA, the Siegel Rare Neuroimmune Association, and in collaboration with the Sumaira Foundation and Guthy-Jackson Charitable Foundation.

[00:00:38] SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at [wearesrna.org](https://wearesrna.org). This series is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease; and UCB.

[00:01:01] **Landy Thomas:** This is a podcast about men's experience with NMOSD. We're here on "ABCs of NMOSD." I would just like to talk to you about your experiences as someone that has NMOSD and is male. You guys are in the minority group. So, I'd love to hear just a little bit of your story. Can you guys each begin by briefly introducing yourselves?

[00:01:29] **Doug Kirby:** Yeah, I'll go first. My name is Doug Kirby. I live in Herriman, Utah, which is a little bedroom community just Southwest of Salt Lake. I'm married for a little over 40 years now to my wife Holly and we just celebrated our 40th wedding anniversary here a couple of months ago. We have five kids and eight grandchildren, and several of them are here visiting. So, if you hear some small voices in the background, that's what you're hearing, it's obviously the grandkids. I was diagnosed with NMO 7.5 years ago.

[00:02:06] And so I still work, I'm partially paralyzed and I can walk a little bit, but for long trips, I take a wheelchair that's powered, that I can get around in. But I work from home, which is awesome to be able to do that. So, I get a little bit more time to sleep in the morning and whatnot. So, we can talk some more about that in a minute.

[00:02:32] **Landy Thomas:** How about you, Andrew? Who are you? What's your introduction?

[00:02:37] **Andrew Jopson:** So, my name is Andrew and I'm originally from Northern California, but I currently live in Baltimore, Maryland where I'm a graduate student studying health policy and public health at Johns Hopkins University. I was diagnosed with NMOSD in May of 2022 following my first and only attack and it was around the same time that I was also diagnosed with other autoimmune conditions including lupus and Graves' disease.

[00:03:14] **Landy Thomas:** And just in case the viewer is curious, I also have NMO. I've had it since I was six, so I've had it for 16 years. I've been in it for a bit. But again, I'm just so pleased to be able to be here and talk to two people that are like me and two people that I feel their stories can really connect to our community.

Now if it's okay, can we talk about the diagnosis? What was your diagnosis story? How did it first start out? Whoever wants to take the question first?

[00:03:45] **Doug Kirby:** Andrew, why don't you go first?

[00:03:47] **Andrew Jopson:** Well, I don't know that I've always had thought as much about how all of this happened, because it happened so quickly. I think I fell very ill in early May of 2022. And I was actually admitted to the hospital with a neutropenic fever initially. And my fever would stabilize and then it would come back, and this happened for 4-5 days, and my doctors really weren't sure what was going on with me. Initially, they thought I had some infectious disease and after about again, 4-5 days at the hospital, I started vomiting and then I had a lot of the other symptoms that we associate with NMO and they all just began to snowball, I experienced bladder retention, lower extremity, weakness, paralysis, double vision, and I had persistent hiccups. And so, I'd already been admitted.

[00:04:52] So I was already in the hospital when a lot of these symptoms really manifested in a pretty severe way. And so, I was diagnosed fairly quickly really within a matter of days also, just because of the hospital where I was at and I took some blood work and we realized weeks later, once it came back that I was seronegative for both the aquaporin-4 and MOG antibodies. But my clinical presentation was just so in line with NMOSD, I was diagnosed ultimately after that episode with double seronegative NMOSD in the setting of lupus. And I had already been diagnosed with Graves' disease about a month before my initial hospitalization. So, it was really rapid, and I went to inpatient rehab and really relearned how to walk. And was in physical therapy for a few months.

[00:05:57] But I've regained most of my functional status and I try to stay active. I like to swim and run occasionally and play pickleball. But I was fortunate enough to be able to regain a lot of my functional status.

[00:06:18] **Landy Thomas:** That's wonderful. It does take a lot. It's a lot to bounce back from all that. How about you, Doug, what about your story? I've heard it before. It's a beautiful story.

[00:06:29] **Doug Kirby:** Yeah, I'll try and do that. I'll give you the short version. So, in 2016, I started having symptoms, some of the ones that Andrew mentioned, I started having nausea and vomiting and intractable hiccups. That's a new word I learned intractable, and I went to the ER three times with two or more of those symptoms and they treated the symptoms, but they didn't know what to do with me and no one had any idea what was going on, send me home, send me to specialist other folks to take a look.

[00:07:03] The one thing that, I think it's different about men that I've heard about women as they believed me, and sometimes women, I've heard from other women that have this disease that they're not always treated as well honestly, as men are, I don't know why that's the case and it's unfortunate, but I was believed. And so, I appreciated that. Just around Christmas time, I started feeling tingling in my hands and feet in other places. And one day at work I pulled a bottle of chocolate milk out of the refrigerator, and it was warm. So, I put in the other hand and put it back and it was cold, so I was having problems sensing temperature as well.

[00:07:43] I once saw my primary care physician who started me on a therapy and then referred me to a neurologist, took me about three weeks to get into the neurologist. And when I finally got there, we had a good visit, and other than the tingling and some of the other symptoms, I was in pretty good shape. I have a brother and sister that both have MS, and I assume this was probably just my turn. About a week later after that visit - during the visit, she was going to have an MRI and a poke in the back. What do we call that?

[00:08:22] **Landy Thomas:** Spinal tap?

[00:08:22] **Doug Kirby:** Yeah, one of those. And she was going to schedule those. And about a week after that, I guess it was on a Monday, I started to feel weak and by Saturday I couldn't walk and by Sunday I was bedridden. Essentially, I had some people come over and help me get out of bed and MRI, and the lumbar puncture happened on the next Tuesday. I had to have help getting into the car and out of the car. And I was pretty paralyzed. I didn't know where anything on my left side of my body was. While we were going through that process, one of the bigger hospitals called my wife and said, "We have a room for your husband on our neural floor." I got there and the neurologist that was there sat me down on the bed and said, "Well, you'll be here for a few weeks while we get to better, and then you'll have several weeks of inpatient therapy and then outpatient therapy and so forth and so on."

[00:09:18] And I assumed I had MS and so I thought she was talking crazy to me and as soon as they would start the high dose of steroids the feelings would start to come back, and I would be fine because that's what my brother went through with MS. That didn't happen with me. The steroids didn't help at all. And it wasn't until they did PLEX or apheresis where they essentially replaced the plasma in your blood that I started to get some feeling and sensation back. I was in the neuro floor and it's a little more complicated than this, but for about four weeks getting better and I went through the plasmapheresis five times twice. I had to do that two times and then I was six weeks in inpatient therapy. When I got home, I could walk if somebody was holding me, but I still didn't know where my left foot was and it took about 2, 3 months to find my feet. This arm is especially the fingers are still a mystery to me. I don't know where they're always at.

[00:10:21] This hand works like that. Clothing that you walk into a big superstore and there's that thing where if you're lucky you can grab a plush toy and pull it back out, that's how this hand works. I think that's the best way to describe that. So, I had a lot of the same symptoms Andrew that you had, but nobody knew what to do with me. I wasn't in the hospital, and it took a long time, and I think because it took a long time for me to get diagnosed. I still have several deficits that don't let me do the things that I would like to do.

[00:10:58] **Landy Thomas:** I know that can be frustrating. I'm sorry.

[00:11:03] **Doug Kirby:** Well, we all have those. So, I don't complain about them.

[00:11:08] **Landy Thomas:** I mean, you have every right to complain about them, but people look to you as a real pillar of our community. So, we appreciate it.

[00:11:18] **Doug Kirby:** That's very kind. I was reading in social media yesterday or the day before through a bunch of people in our community and one person made a comment, "I can't wait for them to find a cure so that I could have my old life back." And I thought, you know what - I didn't respond, because I wasn't quite sure how to say this, but your old life is gone and if you're going to find happiness and joy in what you're doing, you got to understand your new life and you have to find it there. So that's not true. Just for people in our community. I think people all around the globe have experiences like that where they think they're going or where they think they're going to get somebody puts up a roadblock in the way and you got to take a new path.

[00:12:04] **Landy Thomas:** I firmly agree with that. It's a better philosophy to have. It's something that it takes time to really grasp. I know for me, I always told myself, "Oh, I'll go do all those things once I'm better." But then I started putting my whole life on hold. So, I definitely understand where you're coming from, but leading into this, what are your emotions like going through the beginning of your disease that the disease journey

up until like now? How are you feeling then? And how are you feeling now? That question goes to both of you, whoever wants to answer first.

[00:12:40] **Doug Kirby:** Go ahead, Andrew.

[00:12:41] **Andrew Jopson:** During the initial hospitalization, I think really so different than - my experience was so different than Doug's in that the diagnoses happened so quickly, and I was given treatment immediately. I mean, I remember that time period, those few weeks when I was in the hospital, I think initially, I felt a lot of disbelief and denial that my body was actually falling apart. Doug, it's so interesting to me to hear that you had siblings who had MS and so in some ways, you had some anchor to try to imagine maybe what was going on with your body. And I felt like my body was in so much shock and I really was so delayed in being able to process everything that was going on with me.

[00:13:32] I mean, I remember feeling like in similar ways to you, I was just going to wake up the next day and be totally fine, even though, I couldn't even get out of bed by myself. And I had a Foley catheter in me. I mean, just really illustrate where I was emotionally. My older brother was getting married a couple of weeks after I was actually hospitalized. And so, the symptoms were getting worse and I kept asking nurses and doctors, "Hey, do you think I'm going to be able to get on that flight next week?" That's where I was, even though I couldn't even get out of bed. But I was trying to figure out, "Oh, should I just move my flight back, so I can attend my brother's wedding?" And everyone said, "We'll see."

[00:14:20] And I think that just really illustrates the state of denial that you're in and not really understanding the circumstances of what it actually what was going on with me. And I feel like that it wasn't really - when I realized I wasn't going to make that wedding, I think that was, I think the first time I started really getting a sense of grief or that loss that you go through the first time I had experienced what had changed. Doug like what you just said, things are not going to be the same anymore really settling in what this diagnosis means. And I think initially planted the seed, which is where I hung out in for a long time was that I just wouldn't be able to do anything, any of the things that I wanted to do or that I'd done before. And I think I was in that headspace for so long that I was like, "Everything is different. I'm never going to be the same again." But really took a really cynical or a grieving perspective.

[00:15:31] And I held on to that for a long time, I would say. I wish that I had moved through that more quickly and it actually came back six months later when I had a follow-up MRI, I gained all my functional abilities again. But getting that MRI being back in that environment back in the hospital just really set me into really spiraling for a while. And so, I would say that my initial emotions were disbelief and denial and then went into just deep sadness and anger that how could this happen? And I think now I'm really probably the last year - maybe the last six months have really been - two years since I've really been able to move a little bit more toward acceptance or seeing this and being able to find glimpses of how to live with this disease again. So, it took a lot longer than I would have wanted.

[00:16:38] **Doug Kirby:** I'm far enough down this road, I'm going to maybe start by talking about grief. And you have to grieve, you have to go through a process. It's just like you would if you'd lost your favorite pet or a friend or something like that. And for me, I think that process was a little different, but I think it was a good year before I was moving more forward. But you have to go through it.

[00:17:09] **Landy Thomas:** Me too.

[00:17:10] **Doug Kirby:** And the people that don't want to or deny that, you're going to get stuck and so you have to get used to that. So, I use a couple of different approaches, and Andrew you of set this up. So, I'm going

to go down this road. And a part of this conversation Ireland is, how is this for man? How is this different? And one of the things that I learned very early on is I had to turn in my man card. I had to just say there's stuff that I can't do on my own. Now, I was fortunate that my wife was with me pretty much 24/7. And so, I was able to have her help me take a shower and do some of those other things.

[00:17:50] But I'll give you two experiences. And one is, I had just gone to the bathroom and there was my wife there and then an aide was there helping me to do what you need to do after you've been to the bathroom and I turned to the aide and I apologized to her and said, "I'm sorry that you have to do this." And she was so kind, and she said, "This is what I do. This is what I'm here for." And she made me feel so comfortable, in spite of the fact that I was not in a very comfortable space.

[00:18:18] And then maybe a second experience. But let me back that up with two thoughts real quickly. First of all, Andrew, you've heard this story, I think. But I'm not going to show the whole thing other than to say when I was a teenager, I had an experience that led me to believe that later in life, I would have some difficulties, health-wise. And so, when this came to me, even though it took a while to get diagnosed, it was not a shock, it was something that I was expecting. And so, I handled this a little differently and one of the things that I tried to do was to make sure that everybody that came in to help me was having a good day because I was doing the best I can.

[00:19:03] And when I was in inpatient therapy, the catheter had gone out. I didn't have that anymore, but I still couldn't go to the bathroom on my own. And if you've been there and if you know what that means, that means a nurse is going to come in with a straight cath, a catheter and insert that thing and drain you and then make sure you're empty and they come in every four hours and with an ultrasound to see how full you are. And on that particular four, their aides were allowed to do that once they were trained.

[00:19:40] And I remember this brand-new aide and she said, "Can I do this?" And you think about this experience. You got the regular nurse there and this aide who's in her early 20s and she's so excited. And so, I said yes, because that was my goal is to make her day happy. And she did a great job and a couple of weeks later she saw me in the hallway, and she screamed, "You're the one that let me do that thing." And she described it. I don't remember what she said. But you just have to - like I say, I don't know what the right metaphor is. But I turned in my man card. I had to get help from people, and I had to appreciate that help. Some people reject that, and they see that as not doing the best they can or they're embarrassed. There's a lot of reasons that you could be that way. But you just have to let it go.

[00:20:36] And Andrew and I are in a rare group of a rare group. Andrew, even though you're seronegative based on some of your symptoms, I suspect that you have the same disease that I have, aquaporin-4. And first of all, it's a rare disease, and Andrew for every one or two of us, there's 8-16 women. So, men having this disease is exceptional and there are an exceptional group of men that have this. Andrew, you're one of them we haven't met, but I just get that sense from what you said already. And in our conference that we had a couple of weeks ago in LA, there were 10 men amongst the other 85 women or whatever were there. So, it's different for men and we have a good man's group, and we talk about things and we're open about things and I've gone through that grieving period and now I look at things that I wish I could do, and I don't feel terribly bad about that. Maybe that's the medication. I don't know. But you get beyond that at some point. I'm rambling.

[00:21:51] **Andrew Jopson:** I just wanted to respond a little bit to what Doug was saying. I mean, I think this man card that you're talking about Doug so resonant with me in the ways that even just growing up obviously in sports, it's like people will have to be like, "Man up, be tough." And I think that was definitely a lot of the ways that was definitely the environment that I was raised in. And I think what I realized - so I'm not

married, I'm in my mid-30s still in school trying to figure out what I'm going to be. And when I got sick when I was hospitalized - my family lives on the other side of the country and they were not able to be there even though I'm unmarried. My mom is still my emergency contact, but my family wasn't able to fly out and be with me during that time.

[00:22:57] Obviously, my brother was getting married, but my younger brother is disabled, and my mom's been a full-time caregiver for him. And so, I think even growing up in that an environment I knew, given just how much care that my parents provide to my younger brother on a regular basis that I needed to be independent, I needed to take care of things and be on my own. And now I was for sure, put in a situation where I had to rely on others. And I think, especially as you go into adulthood, there's this idea that we should become less dependent on others, financially, emotionally, and to be stronger.

[00:23:48] And during my entire hospitalization, I had to rely on my friends and my cohort of other PhD students who were here in Baltimore to really advocate for me when I wasn't in a position to advocate for myself. Even though we studied health services, research, and policy, when you're interacting with the healthcare system for the first time, I've been pretty healthy for most of my life. And so, learning how to talk and understand what's going on when it's really complicated and there's so many different doctors coming in and out of the room. I t

[00:24:28] Hearing you talk about turning in the man card, I think what really came for me was just not so much the man card that I lost it in some way. I think it was just forced to be in a position to reframe that for myself and reframe that identity that was already pretty broken already. This idea that as we get older, we must rely less on others. And I think for those in the NMOSD community, I've personally have never felt treated differently, because we are rare. I mean, people keep saying. I'm aware of that and I haven't been as much - maybe that's more apparent when you're in these more patient advocacy spaces and you look around the room.

[00:25:27] But the other thought that came to mind too and I thought about this beforehand is because men are expected to be strong and mature, especially by a certain age. I think one thing that I've learned is that to not rush to finding meaning, I think we are often resilience and that's a way of reclaiming this strength again or power that many of us want to have. But I think when you're diagnosed with these conditions, you do have to give up a little - you have to give up power to this because there's so much unknown that we live with on a regular basis.

[00:26:14] **Doug Kirby:** That's right. You triggered a thought and that as we're diagnosed with the disease, and we're left with some degree of disability. If you dwell on the question of, why do I have this disease or why did this happen to me, and whether you're faith-based or however, whatever. If you dwell on that question, you're going to get stuck. The way that I like to look at this is I'm in a new space. What is there for me to learn in this space? What can I learn while I'm here?

[00:26:50] And I've learned so much about - I mentioned I'm from a small community here in Utah and quite frankly, my breadth of friends was not very wide, and I have got to know so many people that I would never have met that I did not have this disease. I've been able to identify some of my biases that I've been able to correct because I have met real people instead of caricatures of people that I had in my mind and that would have never happened. And so, the fact that I have this disease is an opportunity for me to learn things to grow in ways that - there's just no other way to happen to do. I've learned that probably 70% of the people that we meet, even though they won't say anything are going through something equally as difficult as what you and I go through, and we should treat them accordingly. We should be nice; we should care for one another. So, I'm a different person.

[00:27:55] I talked about this a few weeks ago in a work meeting and a couple of the people then said flatly that - one that I've worked with for probably 15 years now. And he said, "You're a different person than you were seven years ago." And if I hadn't had this opportunity - it's a bad way to say it, I suppose. But if I hadn't gone through this experience, I'd be the same person I was seven years ago and that wouldn't be the right thing. I would not have grown. And again, I don't wish diseases upon anybody. I don't wish them upon myself. But if we take what we're dealing with as an opportunity to figure out who we are and what we can become even in this awkward weird state, good things can happen.

[00:28:43] And by the way, I did get my man card back mostly. Every once in a while, I have to turn it in. But I'll just be honest with you, there were at least two times that I could think about when I was alone in the hospital having a bad experience that I cried. I cheered up and asked for some help and got that and got some comfort. So, we men are like to think we're macho and we are, but we don't have to be, and we don't have to be always. And it's a difficult - well, let me say that differently. It's an opportunity to learn about who you can be and what you can be. So, I'm sorry, I'm rambling. I keep doing that. But this is a -

[00:29:43] **Landy Thomas:** No, it's wonderful.

[00:29:43] **Doug Kirby:** And I hope I don't sound too pollyannaish, but I'm pretty happy and I have a good life. I can't do a lot of the things that I used to do. I used to love to go out and weed and the temperature of the heat when we sat to about an hour, sometimes when I'm out eating, I find myself on the ground and I can't get back up. We had to call the neighbors once to come, help me get up off the ground. So, you have to not be embarrassed at those things. So, anyway.

[00:30:15] **Landy Thomas:** No, I think it's fair. I think that if you don't try and find the positive, even in the darkness, it kills you, kills your light, you have to cope somehow. Nobody can ever look down upon you for that. I think that you are an amazing person.

[00:30:33] **Doug Kirby:** And I think it's important to recognize that there will be times. Even seven years later, there are days.

[00:30:41] **Landy Thomas:** There are dark days.

[00:30:41] **Doug Kirby:** And we get through those, but, but I try to limit those and try not to have too many, and sometimes those happen when I get real comfortable just sitting and I don't feel any buzzing. I don't feel anything. And then I stand up and then I remember, "Oh, yeah, I have NMO, and I have to deal with that." But they go away quickly. Now, I don't really have very many bad days, but I want to be careful that people don't think that life is 100% wonderful all of the time, because there are going to be some bad days.

[00:31:15] **Landy Thomas:** People understand that that's how you get through it. I think it's a fair way of getting through it. We're journeying together through this. So, I did hear, I mean, Andrew, you said you might not feel it as much, but NMO tends to affect more women than men. Do you feel really isolated ever being the minority of the minority? Or do you still have the connections?

[00:31:42] **Andrew Jopson:** I think one of the benefits I think, or I was really fortunate that when I was in the hospital and still recovering and then my providers were already looped into all of the amazing organizations that support patients with NMOSD that exist out there. Whether that's obviously SRNA, the Guthy-Jackson Foundation, and the Sumaira Foundation and my provider wrote these organizations on the whiteboard in my hospital. So, I knew that they existed. So, I knew that there were, I wasn't in a position to start reaching out, but I felt like I reached out really early on in my recovery.

[00:32:28] So as soon as I was out of inpatient rehab and still doing outpatient physical therapy, I decided to reach out and I actually think that I found the men's NMO group really quickly, I actually met Doug. Probably the last time we've ever chatted, we've seen each other at different events online and I've come across your name and different videos, Doug. But I think I attended that support group within a couple of months after I had been diagnosed and was still recovering.

[00:33:09] And so I found I think in that way, Ireland, that's where it was hard for me to realize how few of us there are because I found so many and I saw that the conversation was vibrant, and the people had been done this before. And at that first meeting, I remember that it was, I think Doug and probably, Craig Klein, who the first thing that they said to me because I showed up really freaking out. I was expecting to relapse. I was in that waiting period where I just waiting for my treatment to fail and waiting to be back in the hospital. I thought this is going to going to be the rhythm of my life.

[00:33:52] And I remember, I think it was Doug Craig and whoever of the other guys that were in that group they stopped, and they said, "You are not going - this is not going to happen, you'll live a life. Again, you will live a life that you want to live again. And you will find new things on how to live that life." And so, I think I feel like I've been in a fortunate position to have that level of support so quickly and early, and part of that was I was motivated to seek that out. Part of it was that my providers knew that it existed and told me to go for it.

[00:34:30] And shortly after I attended another support group for younger folks in 20s and 30s with SRNA and I think through that, I've just been able to feel less alone. I'm realizing how rare we are and unique, I guess we are Doug. But I think I've never felt alone in this disease process or just in coming to terms with this condition, because of the group of people who are actively reaching out to each other.

[00:35:06] **Doug Kirby:** Yeah, I agree with that. It took me a little longer to find the groups and our first Guthy-Jackson that we went to, we got in late and had to leave early. And so, we really didn't connect with anybody, but it was helpful to know that that there were others out there. A lot of people are hesitant to join a support group, I think because it feels it's like therapy or whatever. It shows a weakness of some kind, but the support group and the men's support group in particular because is what I'm mostly familiar with and it's just about a bunch of people that have something in common and boosting each other up and how is it going and how did your last treatment go and it's just a place to chat, and it's a really good experience.

[00:35:56] My wife and I also do a general support group with SRNA, and I love it, because I can be having a bad day and when I get together with my friends, men or women that have this disease, they lift me and that's always so helpful. So, yeah, there's a lot to be said for SRNA and for Guthy-Jackson and the other foundations. It's a strong community. It really is. Once you figure it out and get into, it's because it can be a lonely disease.

[00:36:33] **Landy Thomas:** It can be. Jumping off from that, I think that you both have very different experiences, because one of you has been a part of a family, one of you might want to start a family someday. I do want to ask. So as men, you have certain social expectations about being the head of your household and the provider of the household, the breadwinner. Do you think that having a rare neuro disorder and having that expectation levied on you comes into conflict? How do you feel about that? How do you manage that as someone who's in that state right now, who already has a family who already has a wife to care for, and someone who might want to have those things someday, household?

[00:37:20] **Doug Kirby:** Andrew, what do you think about that?

[00:37:25] **Andrew Jopson:** Well, I definitely struggled initially right after being diagnosed with feeling desirable, desirable whether that's in a romantic partnership or even in a career, I think I was really wondering, and I still



actually wonder that I know I'm still in school. I'm hoping to finish, and I still ask those questions of myself like what does work look like to me going forward just given ongoing symptoms, like fatigue? I think in terms of being the breadwinner of a household that's still ingrained in me. So, I'm actually queer and so my current partner is male. And so, I guess those dynamics can still exist in queer relationships. But I think in some ways, maybe I feel a little bit freer of that. I'm trying to figure out what that might mean for me.

[00:38:33] I think regardless, there's still this pressure to at least, for me being in a degree program that it is, I've done all this education. I must turn this into something useful. I put that on myself and I'm still at a stage of trying to figure out, what career would look like for me, let alone just what family formation will look like. What I do want to be is I still want to be present to my family. I think a role that has always been clear in my own family is, because growing up, my younger brother is disabled, I've always imagined my role as being a care provider at some point, he will live a long life and we want him to outlive my parents and that he will because he's cared for well. I think I've only ever imagined my role as being a care provider myself as I get older.

[00:39:37] **Landy Thomas:** Not the one that's cared for?

[00:39:39] **Andrew Jopson:** And this diagnosis like totally flew that or just totally changed how I think about my own role and being able to do that going forward. And I'm still navigating that. I'm still trying to figure out what that means for me and I'm still trying to understand how I can still be there for my family or how that role might change given my circumstances.

[00:40:07] **Landy Thomas:** I mean, you are just at the beginning of your journey. I think it's totally valid to say that you're in between stage because I mean, Doug and I have been in it a little bit longer, but it's not great. It does take a lot of time to cope and stuff with that, especially the way that a relationship dynamic change over the course of having it. So don't worry about not knowing quite yet, but we barely know we've been in it. So, I'm happy that you're so honest about your experiences, especially as a peer person. Especially someone that's navigating a situation that's even niche it's an important perspective. So, thank you. Dough, do you have any thought on that?

[00:41:01] **Doug Kirby:** I'm on the far end of the journey. Andrew and Ireland, if you put your ages together, I'm still older than both of you. First of all, I was really lucky. Well, actually we're just blessed that my employer had awesome insurance. I was out of - I didn't go to work for five months and never missed a paycheck and it all worked out really well for me. And so, I didn't have to worry about money while I was there and I was able to come back, half a day and then we started adding time to that until I went back full time.

[00:41:36] Initially, I was going into work every day and then when the COVID hit, we all came home, and we continued to work from home most of the time. So that's great for me, because Andrew, you touched on fatigue and I tire easily and I think if I had to do all of the things by myself and I do my own laundry, I had to figure out my meds. I had to cook. I had to do all that, I couldn't do it. And so, I can be - how do I say this? I can be who I am, because I have a good partner. I have a good wife takes such good care of me. And in spite of having issues, even if I get a little bit sick, get a little bit of a fever, then my bowel and bladder control goes out the window, she takes care of me and so she's really helpful that way and I really appreciate that, because I don't know that I could deal with that.

[00:42:38] So I am able to do what I can do because of my care partner because of Holly and Andrew, perhaps you'll have somebody at that point when you need somebody at that point. It doesn't sound to me like you quite need that. If you have somebody with that amount of care, you're in pretty good shape. But when that happens and when you get there, you'll have somebody that will be able to take care of your needs. Pretty confident of that.

[00:43:11] **Andrew Jopson:** Yeah, I'll just have to make sure to let them take of that.

[00:43:16] **Landy Thomas:** Yeah, that's a big deal.

[00:43:17] **Doug Kirby:** That's hard because my wife's younger than I am, but not much. And she has probably more aches and pains than I do. And so, I tried to cut back on the things that I asked her to do.

[00:43:30] **Landy Thomas:** But Holly is a sweetheart, a good woman. She is. I think everyone that's in this situation when we have to pick the people that we spend the rest of our lives with you do have to find somebody that's like that. You have to find somebody that just love so endlessly that care comes almost easy too. So, I appreciate Holly. Every time I talk to her, I'm always so happy to see her, happy to talk.

[00:44:01] **Doug Kirby:** And you know what, I'm glad you said that, because she's such an important part of my story.

[00:44:07] **Landy Thomas:** She is. You couldn't do without her.

[00:44:08] **Doug Kirby:** That's right.

[00:44:12] **Landy Thomas:** Do you think that there's any aspect of chronic illness that you worry will affect your relationship? How has it affected you over time as people that are in relationships with other people, whether that's your care partner, whether that's your friends? Do you think that it's changed now that you're not adhering to that strong masculine, never cries persona anymore now that you're vulnerable?

[00:44:45] **Doug Kirby:** Yeah, I think it changes. We find different aspects of each other and who we are. Again, I don't know how quite to say this, but nothing works the way it used to and so our life has changed as a result of that. But that's good. It gives opportunities to grow and to develop and to be who we are. So, I'm a person of faith and I get one of the things that I really rely on is the belief that there will come a time when I can do the things that I can't do now. I used to play the guitar, the piano, neither one of them very well by the way. But well enough that I could sit down, and I could enjoy doing that.

[00:45:43] And one of the things that keeps me going is my knowledge, my belief that there will come a day when this hand will work and this leg will work and not likely in this life, but in the next or another. And again, I share that, because that's an important part of who I am. And I know that keeps a lot of people going. I don't know if I didn't have that how well I would be doing.

[00:46:12] **Landy Thomas:** Andrew, any thoughts on how your relationships have changed now that you no longer are invulnerable, the way that some masculine men have to be? As someone, especially because you've been in the care relationship side of things. Now you're being more in the needing to be cared for at times.

[00:46:36] **Andrew Jopson:** I think continue to - I've been fortunate that my treatment has worked well and so I haven't relapsed, and I think sometimes I worry that many of my friends or family still don't understand what the day-to-day looks like for me. And I often find myself trying to over-explain that I'm in this or having to defend. It's a position that I have to defend that I am still a chronically ill person because I've recovered so well.

[00:47:17] I think I do worry about what it means for work relationships or being in a grad program, being able to communicate my own needs, especially when it's a high production environment and those are the expectations. And so being able to - I worry that having this chronic illness people view me differently, maybe

they might be more hesitant to put too much work on me because of that. And I might want that. I might want to work more, or I might want a more flexible deadline, or I wish that I was getting more things done. But I do worry. I worry how that might affect people's perceptions of my worth, which is at the core of it.

[00:48:06] And so I think again, as I said earlier, it comes back to a word is just desirability. We live in such a city where having a chronic illness is seen as a liability. We're costly, we're expensive. And I think I still wrestle with those themes of like, "Am I a liability to my family now if I get sick? Are my parents caring for two kids? Am I a liability for my older brother and my sister-in-law who would be the next in line?" And so, I think I do worry about that, but again, as Doug could probably attest to this, and my therapist works with me constantly on is either those are not real present things right now. I am I could worry and think up so many more scenarios now. I've just become so much more creative after being hospitalized about what could happen to me for better, for worse. So, anything can happen, I guess.

[00:49:23] **Landy Thomas:** Do either of you feel there's any misconceptions about this disorder in relation to men that you'd like to address? Anything that people think about men with this disorder that you're like, "Can someone just please clarify this, I'm tired of hearing this question?"

[00:49:41] **Doug Kirby:** Not so much. In fact, I think the thing that I worry about sometimes is that - well, there's two thoughts. One is people don't like to be around sick people or disabled people. And now let me explain that. So, about the same time that I went back to work, one of the guys that I worked with had a bad skiing accident and shattered his leg. And after about six months or a year, he was back to normal. He got it up with the exception of some still that they had to put in his body. I was having a conversation with him, and it was clear from the conversation that he had an expectation that at some point, I would be back to normal that I would be walking fine and that I would be okay.

[00:50:32] And people want that people want you to be okay. I get that. And that's great. I'll never be that way again. I have to accept that. And so do they. But what I've also found is that because I do walk and when I go to church I walk and use a cane, but people probably don't appreciate my degree of disability, because they look at me and they're very positive about what they see. And so, it's not so much a question that I get Ireland, maybe there's a disconnect between what people see and how I'm really feeling. And every once in a while, I wish I could take my finger and touch people and so that they could feel how I'm feeling for just a second.

[00:51:23] The problem with that is that I would probably get the reciprocal. I would feel what you're feeling, and I wouldn't like that either. So that's why we don't do that. But I guess every once in a while, I thought it can be a little bit lonely still, because it's really difficult for others to appreciate how you're feeling.

[00:51:45] **Landy Thomas:** The whole expectation of you're sick, aren't you going to get better, it can be frustrating. I've written extensively about it. People want me to package up my story and tie it up in a little red ribbon so it's finished and done with but chronic illness is a journey. It likely will end within our lifetimes. It's probably going to be like this. We just make the most of it. We just do our best. It's OK if our narrative isn't pretty, it's ours, it's our life. It's totally valid to feel that way. Andrew, do you have misconceptions or questions you're tired of hearing or anything about being a man with this disorder? Anything you'd like to say.

[00:52:39] **Andrew Jopson:** I think one thought that came to mind when I was really trying to think about how this could be different is I've been fortunate enough to build a really good relationship with my team of providers. And I think I've been fortunate enough that the folks that saw me impatient continue to - for the most part, see me outpatient. And so, they have that really important memory of what, where I was, and where I am in front of them, and they haven't forgotten that.

[00:53:08] But I think that - and this is just for myself learning, I was more reluctant to share my full symptoms with providers or to express my needs to other people. And I've really had to learn how to do that again. I've had to really learn how to say like feel when something feels off in my body. And to be more aware of that, I also think that - and this comes up Doug and I haven't really like said it explicitly or maybe I did a little bit. But I think really, when you have this disease being really mindful of anxiety, stress, and depression and that is such a difficult thing that maybe men may not seek out as easily on their own. I think everybody has to struggle with it. But in particular that.

[00:54:00] And I think that I had folks in - I had wished that when I was initially hospitalized that someone had told me not just getting some support, but really getting some help, managing anxiety and depression that are going to come with this and to know that that's really normal, but also to really get the care that you need for that too. I was up walking and running within a few months and swimming back again and then feeling down came later. My mind showed up later and that was a longer recovery for me to navigate and I still go through it. But I think just building up that strength too is something that I think is really important for men to be able to share openly that it's like, "Yeah, I am feeling depressed or I'm really anxious about what can happen. I'm really nervous about going and getting this blood work or getting this MRI."

[00:55:15] Or when I went back to the hospital, if I smell the soap, I just feel a certain way in my body and becoming more aware of that. And being able to share that with others too is a really important thing that I think men might struggle with a little bit more and providers should be aware of that.

[00:55:42] **Landy Thomas:** I think that's totally fair. I think, especially mental health and then there's huge stigma on actually going to therapy and going to go see the psychiatrist and/or even receive mental health medication, antidepressants, anti-anxieties. So definitely, I think that people should focus on that and do whatever they can to support their mental wellbeing as well as their physical. Do you guys feel as though there's anything healthcare providers could be doing to provide more gender-sensitive care? Has there ever been any moments where you were? I really wish that they understood health care for me as a man with sort?

[00:56:27] **Doug Kirby:** You know what, I really haven't. I've had awesome much - like Andrew said, I've got really great health people providers. I've got a good team, and they allow me to participate in the decision-making. And Andrew talked about the anxiety of having some procedures that - I don't know. Andrew if you had PLEX or apheresis, but when the second time I had to have that, I was nervous, because they cut your jugular, put a tube in and they were good enough to give me a little Xanax before that happened and it was fine and then I slept for 12 hours straight. But it's about admitting that I told him, I said, "The last time wasn't very much fun. I'm not looking forward to it this time." And they were able to approach that, but I've never felt any gender bias in any way towards me and asking questions and answering questions. My neurologist is a woman, and we have good conversations.

[00:57:35] **Landy Thomas:** That's good. Andrew, did you experience that?

[00:57:40] **Andrew Jopson:** I think the one thing that was maybe more difficult for - not difficult, but I think was harder to bring about was - and you see this often in the men's forums as sexual health and sexual dysfunction and how you navigate that or how do you ask or bring that up? And actually, I had to initiate that conversation with my providers. And oftentimes, I might feel more comfortable talking with my neurologist about that, but they might not be the right person to talk to. I might want to go talk to a urologist or anything with bladder or incontinence, and I may not need to go see a urologist regularly or have regular scheduled follow-ups, because I don't have those issues as often.

[00:58:31] I do think that sometimes with providers like sexual health is a huge part of that. There's an interplay with anxiety and depression and all of that comes together. I think that and that's not just for men. I think that's for all. I do think that in particular men might be more or really concerned about bringing that up to their providers as a key component to living a healthy life again. We're trying to work on that with a group of people.

[00:59:12] **Landy Thomas:** I mean, honestly, they send you from doctor to doctor to doctor. I've got so many referrals, urologists, physical therapist. It's hard to find the right person.

[00:59:21] **Doug Kirby:** It is and particularly for sexual health as Andrew was talking about when you have a significant case of NMO, as I mentioned earlier, everything is affected, everything is impacted. To Andrew's point, I've said this before, I collect urologist. So, I have a urologist that I go to for those kinds of issues. I have a pulmonologist for my lungs and part of this navigating this disease I think is finding the right person, the right urologist to help you with the specific questions that you have, and you build a team, and I have an immunologist that I see regularly as well. So, it's good when you go to the doctor and the doctor knows who you are. They remember you from the last visit and that's the team that you need to build.

[01:00:19] **Landy Thomas:** Just offhand mention, I'm a big proponent for physical therapy for sexual dysfunction. It does help. I've tried doing a couple of different medications to help me, that stuff, but it wasn't until I stumbled upon PT or the physical therapy that I actually had any results. So, anybody listening, I would definitely recommend trying to get a referral to a physical therapist for any sexual dysfunction or weakness of bladder control, all that. It did help, but it took a while, but it did help. We're close to wrapping up. What advice would you give to men who have been recently diagnosed with this disorder?

[01:01:03] **Doug Kirby:** I would go back to what Andrew said earlier. I think you find out you get connected with other men that have this disease and got the Jackson has a men's group. I'm not aware of any others that are specifically for that. But I would get connected with that group and I would get connected with the SRNA groups as well. It's not just a man thing. Men and women get this disease and there are things that I learned from men and women all of the time that help me navigate this. So, get connected.

[00:01:44] **Landy Thomas:** There's also peer-to-peer connections too. So, if anybody needs to just be on one on one, we also offer that at SRNA if you want to like look it up, you can look up peer to peer and they can immediately just connect you with someone who has your same disorder or similar disorder. Be able to have one on one conversations. Although the support groups are really taking off. I really think that it's a great option to receive support after diagnosis. Andrew, did you have any advice to men who have been recently diagnosed?

[01:02:20] **Andrew Jopson:** I think patience, it is really important. I think I said this a little bit earlier, but we often want to move on as quickly as possible just to show our strength and resilience and/or we dive deep into learning. So, learning about this condition just as much as our doctors. And part of that's just because we have to, to advocate for ourselves and in medical appointments. But I think that sometimes there's this pressure to master your condition or master your body. To take autonomy back is to master and know how this disease works. But also recognizing ways that, "No, there's researchers still doing that." We are still trying to understand how this works and to also leave room to just the unknown, to being able to hold the unknown with a lot of curiosity and patience and I think that it forces you then just to become more interdependent.

[01:03:32] So I would just really recognize too that your body is something that's really scary, especially when you're right after feeling diagnosed, you're scared of it. You're afraid that it's going to hurt you. Why is

this attacking myself? But I think what comes from that is really trying to figure out how to reclaim some autonomy over yourself. That doesn't mean becoming the full-on expert but leaving room to hold some of that unknown a little bit better. So that's what I would say. It's easier said than done.

[01:04:14] I would say spend - if I were to go back and tell myself, spend months wallowing if it's okay to wallow. And that is part of this, and you don't need to wrap it up any time after that. There's a lot to grieve and that's totally okay.

[01:04:36] **Landy Thomas:** Well, is there anything else that either of you would like to have the chance to say before we wrap things up?

[01:04:44] **Doug Kirby:** I would say that the view looking forward is always better than looking backwards. You can check your rearview mirror a little bit, but there's a reason it's a lot smaller than the windshield, is because that's where our focus should be is what's ahead of us.

[01:05:01] **Landy Thomas:** What about you, Andrew?

[01:05:06] **Andrew Jopson:** I don't have too much more to share; other I totally agree with what Doug said. I think I spent a lot of time looking in the review mirror to try to make sense of it, but now I'm more toward the future even though still is unclear, I could still have relapse, but it won't look like what it did before, because I'll know what's happening.

[01:05:38] **Landy Thomas:** The future is still bright.

[01:05:41] **Andrew Jopson:** I think so in some aspects of our world.

[01:05:46] **Landy Thomas:** Just takes time.

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