Women at Warp Episode 251: Chronic Pain in Star Trek

[Women at Warp theme]

Aliza: Hi and welcome to Women at Warp, a *Star Trek* podcast. Join us on our 10-year mission to explore intersectional diversity infinite combinations. My name is Aliza. Thank you for tuning in. With me today are Sue.

Sue: Hello.

Aliza: And our guest, Heather Rae Barker.

Heather: Hello. So happy to be here.

Aliza: We're so glad to have you here, Heather. What an honor.

Heather: The honor is all mine.

Aliza: It’s been a while.

Heather: Yes, the honor is all mine. It is all mine. It is always a privilege to be here. I am always so flattered and excited when asked to be here. So, deeply thank you from the bottom of my heart.

Aliza: Oh, thank you.

[laughter]

Okay, well, before we get into our topic, we have some housekeeping. Our show is made possible by our patrons on Patreon. If you'd like to become a patron, you can do so for as little as $1 per month and get awesome rewards from thanks on social media to silly watch-along commentaries. Visit *www.patreon.com/womenatwarp*.

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With that done, let's get into it. First of all, Heather, can you tell our listeners a bit about yourself, your history with Trek and anything-- Yeah, if you have like-- Your history with chronic pain that you'd like to share.

Heather: Okay, so I will try to make this as short as this CliffsNotes version of my *Star Trek* life. I will just say I did not grow up watching *Star Trek*. I found it in early adulthood. My partner at the time, his wonderful mother, OG Trekkie, raised him on *Star Trek*. And so, I actually truly found *Star Trek* through watching it with him. And in 2009, we went to the Star Trek Las Vegas convention and that convention changed my life. I found a community there. I mean, I saw that there was a community, and I wanted to be a part of it. But I really, truly found a family through that convention and through all the people associated with it through podcasting. I've been podcasting since, gosh, 2000 something, I don't-- I've lost track.

And now, I am with Roddenberry Podcast. I'm on Mission Log Live, their *Star Trek Strange New Worlds* live show. And I am with the Team TREKtivism, as we call it, and one of the hosts of the TREKtivism podcast. And we interview people and organizations out there doing the work to get us to *Star Trek*. So, lots of nonprofits, activists, all sorts of really amazing, wonderful and inspiring people. And I just finished up running Trek the Votes this last election season. So, we were encouraging people to get involved with election protection, learning how to be a poll monitor, doing phone banking, letter writing, and that was really rewarding.

Aliza: Amazing.

Heather: Yeah, I've been really lucky. I've gotten to live a pretty cool *Star Trek* inspired life, as I say, even though I found *Star Trek* later in life. But I have had chronic pain throughout my life. And the sad thing is that even though as a child I had pain that was dismissed as growing pains, it took almost 30 years for me to get a diagnosis of fibromyalgia, and it was great to have answer. I still struggle today knowing if it's fibromyalgia or if it's other things. I get chronic migraines as well. And then in 2020, I suffered an injury that left me with extensive nerve damage in my left arm and hand. And so, I have a collection of diagnoses, and they are-- The pain, some of them, it's daily pain. Some of it, it’s intermittent pain, but there's pain throughout my life and it's-- Unlike Captain Kirk, I don't need my pain, but I have to live with my pain and it informs my life and how I function. So, I'm not excited to talk about it, but I-- This is a meaningful conversation and so I'm happy to be here to share my personal experience.

Aliza: Yeah, and thank you for it. Yeah, it's not an easy topic to talk about. And I'm sure our listeners who also have chronic pain, chronic illness, disability, can particularly resonate with what you said about having a collection of [laughter] things that seem to happen. Once you have one, you realize that it's not just one, there's multiple things going on. So, thank you for sharing that and for being here with us to talk about this. Sue, did you want to share anything about your relationship with chronic pain?

Sue: Sure. I guess the most, I don't know, pertinent to the conversation is that I have some back issues. I have two herniated discs, one of which also causes sciatica. So, it's a good ‘ole fun time. And I very much identify with spoon theory, and how some days you have more spoons than others. It's something that started with me later in life. It's been maybe a decade since I started dealing with chronic pain from those back issues. And it is fascinating in kind of a terrifying way of how much it also affects you mentally.

Aliza: Oh, yeah.

Sue: And that's something that I didn't hear a lot of people talking about as I was getting used to it. As you are learning what your body can and can't do anymore, beyond normal aging, or maybe typical aging. I don't like the word “normal.”

Aliza: Right.

Heather: Yeah, there's-- I think a lot of people with chronic pain also live with anxiety and depression, whether, whether diagnosed before or because of-- Again, they're very comorbid. And it definitely changes. Again, it changes the way we interact with the world, especially when it comes later in life. And those are hard adjustments to make.

Sue: And it comes from the outside as well. I'm sure this will come into the conversation more later because you start to think a lot more about people's perceptions of you. Like, if it's a rough day and I decide that, you know what, I want to wait for this elevator to go up these stairs instead of walking up a flight of stairs, you get side eye, or people think you're being lazy and you're just trying to avoid having more pain. And it starts to affect you in all kinds of ways.

Aliza: Absolutely. Well, my relationship with chronic pain is also a very twisty long one, similar to you, Heather. It took me 30 something years to get diagnosed with fibromyalgia. And recently, also this year, got diagnosed with both ADHD and autism. And realizing how now that I'm getting to treat the ADHD and get support for the autism, my fibromyalgia is a little bit more manageable, which is pretty incredible to see and experience. But of course, still having to limit myself and live like a paced lifestyle. I, in particular, really want to encourage people to advocate for themselves because once I got my fibromyalgia diagnosis in 2018, after being sick, very sick for like three-ish years, they were like, "Okay, that's it. Bye. There you go." And I was like, "I think there's still other stuff going on. I don't think it's just my brain responding to pain out of whack. I agree." I was like, "Yeah, this sounds like what I have, but what about these symptoms? What about this other thing that happens?" They're like, "Oh, it's all fibromyalgia."

And so, I would say don't stop looking for answers if you feel like you're not getting the treatment and support you need. And I'm glad I didn't stop because that's what brought me finally to understanding that I'm autistic and that I have ADHD, and I needed to be on medication for that. So, don't stop looking for answers even when people tell you, you should stop looking for answers because some doctors actually did kind of say that to me.

Heather: Yeah. I would say in this day and age with our medical system in the United States, that no matter who you are, you need to be an advocate for yourself.

Aliza: Yes.

Heather: And that it's hard because I think a lot of us feel like, "Well, they're the experts and they're going to lead us in the right direction. We're overwhelmed with information and may not know where to start or what kind of doctor to see." But I have learned very much so that I must advocate for myself. And in the last year, I lost my health insurance post divorce and relocation. I have not been able to afford it. And so that leaves me in a place where it's kind of on me to do my own research and even self-diagnose. So along those lines, I have also self-diagnosed with ADHD and autism. I am not--

Again, I'm not a medical professional, but in the last several years, especially with all that we've been learning about how ADHD presents and people assigned female at birth and autism as well, I don't know that the doctors have quite caught up. I know that diagnosis for both have multiplied. I'm not going to quote specifically how high it's gotten because I don't have the document in front of me, but they have multiplied over the last few years and so many of us are left without the ability to go in and spend 1500, 3000 or more to get that evaluation and diagnosis. A, yes, I just doubled down on learning how to become your own advocate and fighting for yourself. And, B, I think it's important to go learn as much as you can about what you think is going on so that when you're able to see someone, you've got that with you because that helps with that advocacy.

Aliza: Absolutely. And self-diagnosis is 1000% valid, especially in regard to autism, as you said, for all the reasons you said, how expensive it is and how under diagnosed it has been basically in marginalized communities, in women, in gender queer people, transpeople, a lot of it has gone just undiagnosed for our entire lives. So, self-diagnosis is absolutely valid. Also, I will say too, my fibromyalgia, I didn't know I had it, but it was a rheumatoid arthritis friend who was like "Hey, our similar are--

Heather: Yeah.

Aliza: You know what I'm saying? "Our symptoms are kind of similar. You should see a rheumatologist." I had never even heard of a rheumatologist. I didn't know what that was.

Heather: Same. Same.

Aliza: And my doctor just didn't even refer me out. I told them I'm in so much pain all the time and I don't know why, and they were like, “Well, hope it goes away,” literally. Literally, a doctor said that to me. And this friend was the one who got me on the right path. I got myself the referral thanks to that friend's advice. And from there, I got diagnosed with fibro and then I self-diagnosed endometriosis and then got an official diagnosis when I had the surgery. So, it all-- Yeah, this self-advocacy is valid and it's so important and necessary. I might even look up some resources if people need help with that, with self-advocacy or with navigating health insurance. I'll look for some notes to put in our episode notes so that people can maybe have some resources if they need.

Sue: I should probably qualify this with, this is not medical advice. When I started using the phrase, “Please record on my chart that you are declining to order further tests.”

Aliza: Oh, yes.

Sue: I started getting my further tests.

Aliza: Yo, I've heard that works.

Sue: Yeah.

Heather: Yeah.

Aliza: Amazing. Again, a lot of stuff we're talking about today could be its own episode.

Sue: I also feel like I should mention we've got an ADHD trifecta going on.

[laughter]

Aliza: The heavenly trio of ADHD.

Sue: It's a miracle we're even recording.

[laughter]

Aliza: We made it. Well, that said-- So yeah, moving us into the meat of this episode, chronic pain in Trek. I just want to start us off with a couple of little, smaller quick topics for us to dip into.

Sue: If I can, Aliza?

Aliza: Oh yes, please, please.

Sue: Just jump in really quickly to give our normal caveats here.

Aliza: Yes, thank you.

Sue: This will not be a comprehensive list. There will certainly be things that we leave out. There's only so much time in the day, and we can only speak from our own experiences, so we're going to do our best. But obviously, the chronic pain experience is not a monolith. Everybody will experience it in their own ways.

Aliza: Thank you for that and absolutely. So, yeah, when I was doing research for this topic, every time I searched chronic pain and *Star Trek* or in *Star Trek*, I saw kind of the same links coming up and the same questions people ask. So, this first thing I saw is by a physical therapist. I have thoughts about physical therapy. I'm sure we all do. Good and bad thoughts, to be honest. But I respect physical therapists, and this is like a blog post on their website. I will put the link in show notes, but the blog post is called Nociception and Star Trek. And it's a very short post.

This physical therapist, his name is Michael Mullen, and he makes this metaphor that he gives to his patients about chronic pain, as if your body and brain are a starship. And you're on the bridge. Your brain is the view screen so the things that you can see and are immediately dealing with that are in front of you are what populate on your brain. And then, there's all these other little buttons and dials and smaller screens and things that are pulling your focus away. And some of them take over the main screen, the main big view screen. And you can't focus on the other things that maybe you were intending to focus on, like if you're in class or if you're taking care of a relative or taking care of things in your life. Your pain is like that, it pushes itself onto the main screen and can take a lot of your mental focus. So, I thought that was a cool metaphor. I think he explains it better than I just did, but yeah. Any thoughts about that? Do y'all resonate with that metaphor?

Heather My ship is on red alert.

Aliza: Oh, baby.

[laughter]

Heather: Yeah. No, I think it's great. I had never seen this before. We mentioned the spoon theory earlier. So, I'm very familiar with that and kind of comparing how much ability I have on a certain day to how many spoons I have. But I had not come across this one. And yeah, it-- Especially when it comes to doing tasks, there are times when my pain is so disabling and I do a scale. So, it's 1 to 10 scale. And I would say when my pain is at like a 7 to 10, I'm disabled and I can't even, excuse me, hold a book. If the pain is in my arm, I am unable to hold a book and read a book and focus on that. It's like everything in my mind is just red alert, red alert. And I can't do all the things that I normally would do because either I'm disabled by the pain, or I'm just constantly brought back to the pain. Especially if the pain is a throbbing pain or a sharp pain, something that's ever present, you can't just turn it off. There's no off switch. So, it's overwhelming.

Aliza: Yeah, absolutely. Sue, do you have any-- Do you feel like you relate to this metaphor or is there a different one that you--?

Sue: I feel like, for me anyway, I'm not sure about the pain always being on the main view screen because I think sometimes when there are-- If we use the scale right, if you're used to a daily 3 or 4, it's almost like your scale shifts and that becomes your 0. So, you learn to function, if you will, at those levels. And the way that people without chronic pain may react to a 3 or 4 is not going to be the same way that I react to a three or a four.

Aliza: See, I would say the same for me. Literally, this past week, I had a followup with one of my specialists and she was like, “Yeah, what have been your pain levels this week generally?” And I was like, “Wait, hold on, hold on. We need to-- What exactly do you need to know?”

Sue: We need to set our scale here.

Aliza: Yeah, like, “Where are we starting the scale? Do you mean what debilitates me or what I deal with every day or like on the best day, on the worst day?” Yeah, it's not so straightforward, that 1 to 10 pain scale.

Sue: I think this analogy might make for like a more acute injury.

Aliza: I agree with that. And I think that's kind of my gripe a little bit with physical therapy to be honest. I haven't found it to be really effective for my fibromyalgia or even my endometriosis, not yet. Although I am starting dance therapy and we're focusing on my feet.

Heather: Ooh.

Aliza: And I think this actually might stick. I think this is what I need. But other ones that have been like general overall body physical therapy, it's almost better for me to just like work out and go to the gym if I can because physical therapy just flares me up. I have so many thoughts about this. I don't want to take up too much time.

[laughter]

Heather: Yeah, it's tough and it’s same for me that exercise—So, I joined a gym called Orangetheory. And I love it because it's like my healthcare right now. It's my mental healthcare. And I could put it on my credit card each month. But what I love about it, I don't have to plan a workout. I go in and they tell me what to do and I get like a full body workout. And there's no one there that judges me on how hard I'm working.

Aliza: Good.

Sue: Mm-hmm.

Heather: So, if I am having like a low pain day, sometimes going in-- And this is the difficult thing, sometimes I can go and the exercise will help me feel better. Sometimes I will go in, I will feel worse. Sometimes I go in, I feel great. I have an awesome workout. The next day, I'm disabled by pain. It is so unpredictable. But I will say that for me, and this is just-- It is for me, I have to say it because for some people, exercise does not help.

Aliza: Yes.

Sue: I laugh because we're all doing that.

Heather: Okay.

Sue: [crosstalk]

Aliza: That's what's amusing to me.

[laughter]

Heather: Okay. I have found that maintaining some sort of ongoing exercise routine, whether it's walking or going to this gym or just moving my body does generally help with the amount of pain flares that I have. I don't do medications for it because medications in general, I have all sorts of weird side effects. So, that's been a struggle throughout my life. I don't take Lyrica or whatever the drug is for fibro. I manage it through exercise, through some diet, like they say, an anti-inflammatory diet, because with fibromyalgia, your body is fighting inflammation. But it's a catch-22. There's no cure, there's no fix-it-all. There's no medication I can take. There are only preventatives that I can do to try to help, and exercise is one of those things. And I think that for many people, it is very beneficial, but it's certainly not for everyone, especially if you're at a point where you can't, like you cannot get there. You can't move your body in those ways, which is very real.

Aliza: Yeah. I'm also similarly in a place where doing regular movement and exercise is beneficial for me. But exactly, everything you said, Heather, absolutely applies to me. I've been doing Pilates for the past few years, and I love it. I'm obsessed. But yeah, sometimes I leave the class and I'm feeling good for like the two days after, just a little bit of soreness, like a normal amount of soreness. And then, sometimes I-- Like, literally the class before last week, was a great class. I thought I had paced myself, did enough rest between sets. And over the next week, I had gnarly shoulder nerve pain that flared up because I don't know why it happened, but something got irritated and then kicked off my nerve pain. So, yeah, it changes. It's very dynamic.

Heather: I know that we've got a lot of points to hit. We have something in the notes talking about invisible versus visible conditions. And I can say for me, I have the “you don't look disabled” because for the most part, I don't need to use any aids. There are some times when I do, but aside from the nerve damage and scarring on my arm, you cannot see anything that's going on with me. So, in some ways, that can be a privilege of how I am perceived. In other ways, it's very frustrating because it doesn't mean that I'm any less disabled than I am when I'm lying in bed, not able to move. I'm not less disabled. But I do just want to point out that for me, that's the space where I'm coming from versus people that do use aids. And again, where I'm trying to advocate for exercise, not everyone out there I know with chronic pain is able to exercise. I just want to emphasize that we want to include everybody and that we are mindful of that.

Aliza: Yeah. I also will say I was also on that side of things too. Like, when I first got diagnosed in 2018, I only got diagnosed finally because the pain became so present and unbearable. I couldn't just ignore it and think, “Oh, everyone has like low-level pain every day, right?” [laughter] It became really, truly up that scale. And during that time, of course, I had doctors telling me, “Well, you need to work out. You need to get better sleep. You need to eat better,” blah, blah, blah, all that shit.

Sue: You need to do everything and be everything and be perfect and sleep eight hours and make your own meals and go to work.

Aliza: And lose weight, like all this bullshit. When it's like, “Can you please just diagnose me and then I can do all that stuff?” because I couldn't work out. It was too painful. I couldn't move my body in certain ways. And they kept telling me, “You need to work out, fibromyalgia. You need to get light exercise.” I was like, “How am I supposed to exercise if every time I do squats, my hip turns into nerve radiation the next week and a half or four weeks? Are you kidding me?” So, it wasn't until I got on medication that actually has helped manage my pain that I have been able to work out again. So yeah, it's different for everyone.

Okay, yes, moving us along. The other quick topic I wanted to just touch on is-- A question that I saw come up in particular on a Reddit thread was about the Borg and pain. This is from five years ago. It's the Daystrom Institute subreddit and I don't know their username, but they posted, “Are Borg in constant pain?” And they wrote this post. I will link it in the show notes. Just kind of like laying out their theory about why they think that Borg do experience chronic pain or constant pain. And some specific examples, Seven of Nine has brought up and how they say Seven and other ex-Borg are all given painkillers as a matter of course, perhaps rejiggering their nanobots as part of their therapy. The pain is just one of the horrors of the Collective.

And I think that's really astute. I thought that was like really a true thing. I've really, in my own like TTRPG, *Star Trek* writing and DM'ing, I've explored ex-Borg for this exact reason. I feel like they have a disability that is multilayered and complex. They also have trauma. They were tortured. Like what they received was torture, obviously, and forced labor. They have a lot of interesting and really difficult things that they deal with. And I like to look at them through that lens a lot of the time. And chronic pain is one of those layers for me. Do y'all ever think about the Borg in that light?

Sue: I don't think that it ever super sunk in because we also see once fully assimilated, it's like you don't feel anything.

Aliza: Right. Yeah, probably.

Sue: So, I think I always perceived that the assimilation itself was painful. And being de-assimilated and then needing therapy after the fact was when they got the painkillers. But that while a drone, it just was blank, which is a different kind of horror in its own way.

Aliza: Yeah, yeah. For me, that's still also-- I totally agree with that, Sue. And that's kind of how I-- Once I started thinking about it through that lens, I also thought that too. Like, once they're in it, they're not really perceiving pain per se. And I think that also really does correlate with trauma. I'm learning a lot about CPTSD. Oh, hey, I also got that diagnosis. So, if any listeners are not familiar, it's complex PTSD, and it works pretty differently from the PTSD that we are probably more familiar with. That's from-- I guess you could consider it like acute PTSD or from an acute thing that happened, and then you continue to feel and experience that trauma. But complex PTSD is from layers of trauma that you've experienced over time.

And honestly, I think the Borg being in the Collective, I think is like experiencing the CPTSD because you-- Yeah, you basically become numb to your pain, and you paper over it, you cover it, you mask it. You find ways to live and survive, but you're hurting, and you're covering up that trauma, not realizing how deeply hurt and traumatized you are. And then once you're out, all of that trauma becomes apparent. And the physical pain, the psychological pain and stress, you have to deal with it. So yeah, that's kind of how I've been viewing it lately.

Sue: In the Collective, there isn't even a you to cover it up. It's just you're like subsumed by the Collective, and your thoughts and your feelings are almost replaced by that of the hive.

Aliza: Yeah. That's a mask, right? Am I crazy? It's like masking. [laughs]

Heather: Because they don't have that individual sense of self or relation truly to their body, I wouldn't see the perception there. It's hard to believe that somewhere in that Collective consciousness, there wouldn't be some semblance of, A, the pain that their bodies experience. But again, you've got nanoprobes that are healing them as they're going through all of this. But I would definitely see it more as-- With the assimilation, then coming out of, and then especially, Seven or Hugh or any of their journeys, becoming an individual and a person again. I think Seven is a great example of complex PTSD, which raising my hand also have-- I have so many diagnosis, I just don't remember to include them all anymore.

Aliza: You should have a Venn diagram, because I think it would be a circle, because it seems like we have a lot.

Heather: Or we need the Mariner image where she's pointing all the red strings to-

Sue: Oh, yeah.

Aliza: Yeah. [laughs]

Heather: -all the different things. And again, it emphasizes how comorbid so much of this is, and like how things are connected. Most of us, fibromyalgia especially, is usually diagnosed later in life. It's not diagnosed in children. Or at least the last time that I went through and read the most recent medical data that we had, it's not common in children. For me, I'm very convinced or believe that it was the trauma that I experienced as a child is what led me to develop fibromyalgia. And then, the compounded trauma I have experienced throughout my life, whether from sexual assault or bullying, there are a lot of effects of being an autistic person and not fitting in.

The CPTSD comorbidity with the autism community and the ADHD community is very high because of the bullying that we experience. And so, that's typically there. It's overwhelming. It's interlinking. And the sad thing is it creates a physical response in our bodies. But this whole point was supposed to be about the Borg.

Aliza: Yeah. It's really--

Heather: And I think that when you look at Seven and her transition, that evidence is there for complex PTSD and for the types of pain that she suffered, moving away from the Borg or I guess technically she still-- Well, okay, I'm going to get away from that rabbit hole of going down.

Aliza: There is such a rabbit hole, yeah. My brain is also spinning out on it.

Heather: But it's a fascinating question. I think it's fun to think about.

Aliza: Yeah, me too. Well, our third really quick touch upon is another frequent question I have seen, which is talking about Geordi’s painful VISOR. Now, we know Geordi is blind, and that is a physical disability. It's also a visible disability for him, and he wears a VISOR. But what we don't really talk about or see represented in *TNG* very much is his pain. And I came across this amazing article. I really encourage you all to read the whole thing. It's by Janet Jay. Will link in the show notes. It's called What Star Trek Got Wrong about Geordi’s Disabilities. She talks about what she thinks they got wrong. She does some really great referencing of Geordi’ bio, even some ableism that even as they created the character, they were just infusing ableism about his functioning or abilities.

And then, the passage that I think is super relevant to this conversation is where she says, “Speaking of, what about the damn pain?” I'll just do a really quick overview. So, she says “In the first episode of *TNG*, and I forgot this, totally forgot this, but they established that the Visor causes Geordi constant pain in that first episode. The doctor brings up meds, which he rejects surgery, same; finally, electing to just deal with it.” And then, she says, “Where's the pain? I don't see where it is in his life, which would absolutely be affected by constant pain, where is it in his decision making? Where is that lifelong pain in his demeanor, in the lessons he has learned, in the relationships he has, in the person who he has become?” It's like, “Oh, my God, you're so right.” And then furthermore, she says, “That's two disabilities to deal with, not just one. Having constant pain completely changes the decision-making equation.” Except in *Star Trek*, it seems. Yeah, so I thought that was so amazing the way she laid that out, and what do y'all think?

Sue: This is the one that I really couldn't stop thinking about when we were talking about doing this episode, because I remember that scene with Geordi and how they give us that backstory and establish that pain, and then it doesn't really get mentioned again except when somebody brings up implants, and just even a scene of Geordi popping off the VISOR and closing his eyes--

Aliza: And rubbing his temples--

Sue: It's a rough day. [laughter] We don't see it at all. And it also ignores that oftentimes, chronic pain and chronic fatigue go hand in hand because you were expending so much energy living your life with that pain. And we certainly don't see that in Geordi working around the clock in engineering.

Aliza: Mm-hmm. Oh, yeah. All really great observations. Heather, what do you think about it?

Heather: I think we can agree that *Star Trek*'s disability representation has not overall been great. I think that *Discovery* did a better job, but overall, we don't have peak representation, and I think it leads to that conversation that always happens when you're talking about someone who is disabled in the future and somebody else comes back and says, “Oh, it's all cured in the future. There's a medication for that. There's this, there's that.” There's some validity there. There's a big conversation to be had. And I don't know-- Again, it's another podcast over the, yes, there are some of us--

Like in this article, there's a quote underneath that section from A Person On The Internet, it says. And it says, “As someone who deals with extreme chronic pain when he was given an option to wear ocular implants and was told one of the side effects was that he'd no longer be in pain. I was kind of livid when he said he didn't want it. Chronic pain wears on you a lot. I've tried everything to get rid of it, including surgeries that had a chance for paralysis. His storyline was clearly written by someone who had never dealt with a long, sustaining, never-going-to-go-away pain.” And I think that for people with chronic pain, I will admit myself, I take medication for migraine when I feel a migraine coming on, because I don't want the disability of the migraine. I have to go in bed in a dark room with earplugs, I cover up my eyes and I cannot function. So, if I can take a medication to prevent that, I'm going to do that.

I think that chronic pain disability differs from someone who uses a chair or another aid because the flip side of that conversation is that-- Let me find this, there's another really great article, and I of course won't have the link right in front of me, but where they are talking about this disability erasure and how it devalues a person existing as they are by trying to suggest that there's a cure, a remedy that you've taken away whatever's going on so they're no longer in the chair. And I think that this plays into the episode that we're going to talk about. But it's a big conversation to be had. And again, I think that when it comes to disability, it's not a monolith. And there are people who are disabled and proud and happy to live with their disability. I say happy in a very--

Sue: Content.

Aliza: Not literal--

Heather: Yes.

Aliza: Yeah. Mm-hmm.

Heather: Yes. They are content with their life, with their disability. And there are people who have a type of disability and they'd rather not have it. And they would take the option of having the VISOR without the pain. But it plays into the reality that *Star Trek*'s disability representation isn't very strong. And it kind of counteracts with that idea of what is cured or made better in the future, and I think it's very confusing. And when you look at *Star Trek* as a metaphor or an allegory for current life, it doesn't work because then we aren't seen. Like, we aren't present in that future.

Aliza: Yeah, this is something that I like as an actor, as a writer, screenwriter, aspiring TV screenwriter, yeah, I think about that a lot and I try to include it in my characters and in my writing. Those little moments that may not be noticeable but are absolutely there and are absolutely part of the experience of being disabled. Whether it's with chronic pain or with a visible, mobility or whatever it is, these are parts of our lives that we can't ignore, but we never see that really in these TV or film characters.

Sue: I read that comment as well in this article, Heather, and I'm trying to remember when Geordi was offered ocular implants on screen because it wasn't before he actually got them. And I think it was either Pulaski or the Doctor in *Ethics*. So that perhaps again, memory, brain bad. So perhaps it was not the ocular, the same as the ones he ended up getting before the next gen films. But that's mixing in and out of universe, I guess my thoughts on choosing to continue to be in pain. We don't know where on the scale Geordi is. We don't know if he's at a 1 every day or at a 6 every day. And I certainly know people who are at a 1 every day and choose to remain there instead of having a surgery, a knee replacement, a hip replacement because they're afraid of the surgery. Not necessarily the surgery itself, but like what does that mean down the line? What does that recovery look like? What are the chances of improvement? etc., etc. So, there are other things I think sometimes to consider depending on where you are on that pain scale on a regular basis.

And there is also, at least in Geordi's case, he has a much larger spectrum that he can see and analyze than with a typical human eye. So, if the ocular implant were like, “We'll grow you a new pair of eyes,” he would be losing ability to get rid of the VISOR in that case. If they're able to create the mechanical eyes like he has in the movies, he's not losing ability. So, not losing ability and being pain free, that seems to me like a win. But he also-- Like, maybe there is a vibrant VISOR-wearing community that he doesn't-- I know that sounds silly, but that he doesn't want to leave. I've seen multiple stories about the deaf community and saying that they-- Several people say that they would not choose to hear because they don't want to lose that community.

Heather: Yeah, same, same.

Sue: It's interesting and it's individual. So, we can't-- No judgments.

Aliza: And I want to also shout out the folks who say their disability is a superpower, being in a lot of Reddit threads and a lot of groups and stuff about autism right now as I learn more and more about myself and autisms, there are plenty of autistic folks who are like, “My disability is a superpower. I can do this with my brain. I can perceive things. I can see things.” And I know there is also backlash in our disability communities when people say that, because I think the fear is, and it's a valid fear because it happens, is that abled people will hear that and be like, “Oh, you're autistic? You have a superpower.” And just paint us all with that brush. But that's not how we all feel. That's not how everyone feels about their disability. But I think there's still space for the folks who do feel that way to feel that way. I don't know. I just wanted to create that space for them, because I feel that way sometimes, too, I think. Because of the way my brain works, I became a writer, I became an actor. I'm a really good DM and GM because my brain works in this very specific way.

Heather: I think it's really important when that comes from the person with that developmental disability. So, autism, developmental disability, there are other disabilities. I think it's important when it comes from the person possessing it. And it's very different when it comes from people assigning that to us. Because then and again, we even see it with

Geordi and how people refer to Geordi. But we see in the episode that we're going to talk about where people say that, and I'm like, “Listen, I'm just surviving. You may look at me and think, ‘Wow, you go to the gym and you lift heavy things, but you've got this pain disorder and you're disabled and you're amazing.’” And I'm like, “No, I'm just me, and I'm just living my life and doing the best I can.” So, I don't necessarily want that. And it's the same as people who say, “Oh, you're an inspiration.”

And it's really tough because truly I believe that it comes from a good place. It comes from the intent of sharing admiration, and it's not meant to infantilize or harm people, but it still does send out the wrong message at times for the community. And so, I think it's. It's great when we can look at ourselves and say that we feel empowered by our disability. And it is different when it comes from abled people.

Aliza: Yeah. And part of our experience is both being empowered sometimes, but also being debilitated by it. So, it's not like an either/or.

Sue: Absolutely. Multiple things can be true. I can have excellent pattern recognition and still be 15 minutes late to everything, no matter how damn hard I try.

[laughter]

Aliza: I feel like these three little-- In my outline, I put the amuse-bouche, the appetizer, the aperitif. These little topics all tie into our main course, which is Melora, *Deep Space 9* episode, Season 12, Episode 6. For our listeners who haven't seen it, Melora is an Elaysian cartographer who is an ensign in Starfleet. She's the first of her species to join Starfleet. The Elysians are from a planet that has low gravity. So, their physiology is not adapted for gravities like earth or the stations. At the beginning of this episode, we learn a lot of this exposition that Bashir and Jadzia talk about as they prepare for Melora's arrival to the station. They talk about the accommodations she needs. Bashir is putting together a wheelchair based on specifications she sent, but then he makes some improvements, “without asking her.” And that's not going to go over well with our girl, Melora, as you can probably suspect.

Julian also explains to Dax that he's done research on Melora. He seems to be fangirling over her or fanboying over her. He's like, “Oh, she's so awesome. She refuses to ask for help.” I was like, “Oh, God, what the fuck.” [laughter] He says, “Once her basic needs are met, she just wants to do the job and not get any special treatment or help in order to prove that she can do it like anyone else.” And of course, there's a lot of ick in that sentiment that I'm sure a lot of disabled and chronic pain people might be feeling right now.

So, Melora arrives at the station and, as Julian said, she's very strong-willed. She's badass. She's very adamant about not being treated differently from any other crew member. And from the start, the actress who plays her, Daphne Ashbrook, I think she does a great job of literally the first shot, the first moment we see her on screen, she is like entering the airlock and she throws herself kind of like falling onto it. And you can see the pain in her face. You can see her shoulders tense, you can hear her breathing is belabored. And she's already feeling the effects of this major shift in gravity. Ooh, that moment for me, sorry, I don't want to jump ahead, but yeah, I really like how she portrays this because physically I think she does a good job of showing it and the breathing and all that, those details are great.

So, long story short, Melora usually has anti-grav unit that she can change her environment wherever she's working to make a better gravity for her. But according to Julian, that's not possible on DS9 because of the Cardassian tech of the station. It's not compatible with her tech.

Now, there are lots of chronic pain themes in here. There're more details in the episodes which I'll get to once we get to those subtopics. But I guess to start, I think there's this major theme for me about pushing yourself versus pacing yourself. And Melora does not do a great job usually of assessing her abilities in a moment and she overextends herself. She ends up falling at one point and she can't get back up and she still doesn't call for help. So, she's very, like I said, strong willed, she's kind of stubborn and she wants to just prove for, good reason, she has been ostracized and treated differently in a way that she doesn't like. So, yeah, what are y'all thoughts about Melora's pacing versus her pushing? Do you think she has a good balance or any balance?

Sue: Oh, not at all. [laughter] But I also get it.

Aliza: Yeah.

Heather: Me too.

Sue: Her entire existence in Starfleet, I'm sure she's been basically infantilized or felt like she's not the one able to make her own decisions or that people are always trying to coddle her. And I'm sure we've all had similar experiences, and I think the natural reaction to that, at least for me, is to go out and be like, “I have something to prove.” And-

Aliza: Oh, yeah.

Sue: -that doesn't usually end well. [laughs]

Aliza: Right. Sorry I skipped over this but, Sue, you also wanted to say that we have talked about Melora quite a bit back in a previous episode of this show.

Sue: Way back in Episode 58.

Aliza: 58, wow. 58 or 38? You sure it's 58?

Sue: Oh, 38. You're right.

Aliza: Yeah.

Sue: 38.

Aliza: Yeah. And that episode is called Disability and Ableism in *Star Trek*, if you want to go check that out after you finish this one. And yeah, I just want to say she has multiple disabilities here. It's the physical not being able to move in this gravity as easily, it's also the pain she's feeling, like that burden. And so, that's kind of the angle-- Even though we've talked about Melora a lot before, that's the angle that I'm seeing this episode through, which overlaps very heavily with the physical disabilities of course.

Sue: Imagine going through your entire day draped in a weighted blanket. That's the best way I can imagine what she is experiencing being in too heavy gravity.

Aliza: Right. And the blanket is made of lead.

Sue: Air.

Aliza: Yeah.

Heather: Air.

Aliza: Yeah. It actually is very-- There's so much pressure from air we don't perceive and realize. Yeah, Heather, anything about pushing and pacing?

Heather: I think we're good there. I think one of the things that I take away from this episode now versus previous years, when I've seen it, is the reality that it is the environment that is disabling Melora, I think that is so important because that is the reality of our life. You know, not necessarily-- Yes, as people with chronic pain, but especially people who use aids trying to get around, and that comment really stood out for me from Dr. Bashir that the Cardassian tech wasn't compatible with her needs or whatever. And it's like, that is the reality of many of the spaces that we function in, that our environment is not made for us to exist in properly. You have places that don't have ramps. I think you have Melora tripping over the doorway, and that was just such a great line where she-- I don't know if I have the line saved where she pointed out, like, “Why is there a lift here? Who does this?” Because anybody, I mean, I would trip over that. And so, I think, there are big conversations to be had around how the environment doesn't make it any easier for people to get around.

Yeah, that's just something that I didn't-- When I watched this episode in the past, I didn't think about it as much as I do today. And again, I don't use a chair. I, on occasion, might use a cane. But just moving around in the world and, like, “Okay, here's your only option are all these stairs, there's no elevator,” where are there accommodations and where are they not? And especially for someone like me who may have gone from-- Again, I've had these disabilities throughout my life, but I wasn't always aware of accommodations. And so, one of the-- Hopefully, this is not a tangent, but one of the accommodations that I take for myself now is when I fly on airplanes, I use the preboarding and I use that for a variety of reasons. You can select that for yourself and go up and be able to get into the plane, onto your seat before the mass of people, and being crunched up. Okay, I don't need to justify why I need it.

But you know that's an accommodation that I didn't know was there before. And it's also an accommodation where I get weird looks and I get judged because again, I don't look a certain way. But I think that when we're more aware of how an environment could better serve us, you start to notice those things and you can see how failures in design really prevent people from just moving around and getting to places where an able-bodied person could.

Aliza: Yeah. Just to extend that thought even, yeah, the chronic pain or the invisible disability obviously overlaps heavily with physical disabilities in needs and access. And I think the layer that we don't see which affects both is time. That's not something we can quantify. It's not a ramp. It's like a metaphorical ramp, I guess, to have more time to board is absolutely an accommodation. I'm glad you said that. I didn't know that either. Thank you.

Heather: Yeah, yeah. I won't say that seeking those accommodations is always easy, but it does-- I just want to emphasize, I guess, that sometimes it takes a little extra from us just to advocate for ourselves. Again, it takes a certain kind of bravery to get up there and seek that accommodation when you may not look a certain way or fit other people's perceptions of who should be seeking that accommodation.

Aliza: Yeah.

Sue: And what's wild is, at least in my experiences working with conventions, especially in Dragon Con communities, new people, even people who've come for years will start saying things or asking questions like, “I have sciatica. Can I bring a stool to sit down in line?” And people who've used the disability services options for years will say, “This is exactly what this accommodation is for. Please go talk to disability services.” And 99% of the time, the reaction to that is, “Oh, but I'm not disabled. I don't deserve that.” So, they have this perception that there's something wrong with it, I think. But when I see that conversation happening, I always try and jump in and say, “If the accommodation will help you, you are disabled enough for it. That’s what it’s there for.”

Heather: Yeah. And disability is not a dirty word. It took me time to adapt. When I got that fibro diagnosis, the friend that led me there said, “It's a disability. You can identify as disabled.” And I was like, “Wow, okay.” Then throughout my life, come all these other diagnoses, and I'm just like, “Yes.” And especially when you're laying there in bed unable to move like, “Yes. Clearly, I am disabled. But there is a stigma around the word. There are conversations even within the disability community that I see over whether or not someone wants to use the word. And look, you don't have to. I have a hate-love relationship with certain labels. I think labels are sometimes really great and empowering. Other times, they're too-- like, put me into a box.

But when it comes to disability and claiming that word as a way that I represent myself, it empowers me to live my life with better access, better options that will help me not have a flare because I've been so stressed out, not have some kind of incident, not have a meltdown. Those are all there to accommodate you. And I think that the way that you portray that question to people is really great, Sue, because you don't necessarily need to be like-- You can embrace the term disabled. It's not a dirty word, which is what I would say, but I think you can seek that accommodation. If it's going to help you, if it's going to make life easier, then yes, go for it. The worst that anyone is going to do in these situations is say no. And again, still, if you believe that you have-- And I'm not saying we're all entitled to everything in the world. I'm saying that you have the right to pursue those. And even when someone does say no, you still have the right to advocate for yourself.

Sue: Right. And it's just the idea that everyone thinks anyone seeking an accommodation is there to abuse the system. And yes, there are going to be people who abuse a system anytime there is a system. Those people exist, but they are the minority, because there is a stigma that comes with having that disability services sticker on your convention badge or having a visible accommodation or anything like that. So, just believe that the people seeking or using accommodations are doing it because it helps them, and they need to/want to.

Heather: Yeah, Can I-- There's just something I wanted to bring up that sort of slides into this discussion in the way that we perceive people with disabilities. And one of the questions that comes to mind with this episode now, because this episode for Melora, she's framed as a love interest. And when I went back and looked up kind of the history of this episode, the person who wrote it, who did use a chair, envisioned her as a female. As a female [sighs] and a love interest for Bashir, and “Zero-gravity sex with Bashir was a prime element to the story in my mind.” says the writer, which is just--

My thought is, what if Melora didn't look the way that Melora does? Because Melora is a very attractive human being, and there is a privilege that comes along with that, that I know is not extended to all people. If you don't look a certain way, you don't get treated that way. And so, it just begs the question for me how might people have treated her differently if she didn't look the way that she did? What would her experience have been like on that ship? Bashir may not have been interested in her. And while, Bashir in this episode is, yes, in his mind, he's trying to help her, but she doesn't want that. Like, she doesn't want to be fixed. She doesn't-- Yeah, she explores that idea and she goes along with the treatment, but ultimately comes to the decision that, “No, I won't be who I am if I change in this way.”

But if she wasn't this love interest and didn't have Bashir pining after her and trying to find all these ways to, we'll just say, make her life better in his own mind, what would the story have looked like? How would it play out? Because that's very real. People don't get treated the same way. If you're not conventionally attractive, you are often overlooked. When you're disabled, when you're in a chair, you are often overlooked.

Sue: Yeah, it's part of the infantilization that there's an assumption of like, “Well, since you're so much like a child, you obviously can't be interested in relationships and sex.” That's why I'm kind of on board with the relationship with Bashir, but if he weren't being such a douche nozzle the rest of the episode, maybe, I don't know.

Heather: [laughs] Bashir.

Sue: Yeah. Season 2 Bashir.

Heather: Yes.

[laughter]

Aliza: To tie into the accessibility, you both brought up such great points about accessibility. We're still in a moment where our individual needs as disabled people are not seen as something the rest of society has to, or needs to, or should, or has a responsibility to help with or provide. We have the ADA. The ADA, which protects us in some ways, but there's a lot of gaps of access still, even with the American Disabilities Act, when it does get enforced, which a lot of times, people don't comply to those rules and nothing happens. It doesn't change.

But my point being, another strong theme I find in this episode is interdependence. And, Heather, you touched on this. Sue, you touched on it too, where the environment is what is not accessible to her. And instead of being able to make the environment accessible to her, her body is the one that has to change and adapt. And there are things that other people can do to help. There are things that Bashir does and Jadzia. They do some things to try to help her as much as possible, but ultimately that burden literally, the physical burden of adapting and moving through this painful environment is all on her. She's the one shouldering that burden.

And I think that really relates to a disabled experience. You're always having to create access for yourself, advocate. We've said advocacy a lot in this conversation because that's a part of being disabled, having to constantly advocate for yourself or not and not get the things that you need. And I personally wish that we had a society that was more about like, “Let's make this accessible for as many people as possible, and if this space isn't accessible, let's move to one that is.” And it's just a given, and didn't have to always be the burden of the disabled person to have to say something.

And also refusing to wear masks is another way that environments are made not accessible to disabled people who are immunocompromised or have other reasons why getting not just COVID, but other bugs and viruses and things could be really detrimental to them. But we have a society that refuses to wear masks in the grocery store and on planes, for God's sake. Like, that's the place you should absolutely be wearing masks, but so many people just refuse to do it. And it doesn't matter that it makes the space less safe and less accessible for a lot of people. That's their problem.

Sue: There's even just physically, it sort of blows my mind that we have the ADA, but it still allows buildings of a certain age to not have to be accessible. If the ancient sites in Europe can put in a chair ramp, why can't a theater put in an elevator?

Aliza: Ooh, that's a word, Sue. [laughs] Yeah.

Sue: It makes me enraged.

Heather: [laughs]

Aliza: Yeah.

Sue: Buildings are not more important than people.

Aliza: Mm-hmm.

Heather: Correct.

Aliza: And having to spend money, and saving money, and saving effort is not more important than people's access.

Heather: So many of us have some type of disability and we're not referring to ourselves as disabled because we don't see it that way or don't want to use the word or whatever, but the reality is that that accommodation helps. And even though so many of us still have these issues and these disabilities, the disability community as a whole still tends to get left behind, overlooked, and ignored. I want to live in a more compassionate future where people do think about the well-being of others and not just themselves. And I hope that we do get there. *Star Trek* teaches us compassion. And we heard many times in this episode that talk about interdependency. And I think Bashir said something very specific too, we all help each other. Nobody can do this on their own here. That's why this conversation is so important.

We have to look at ways that we can help one another and really push for our legislations, our politicians, our governing boards to pay attention and to make those changes. It starts with us. This is what I learned from Trek the Vote. It starts with us having those conversations, going to people that make the decisions and really pushing and again, advocating for changes to be made, whether it's relevant to ourselves or whether we're an ally, and that can be said about all different subjects in today's world, but it's starting from the bottom, pushing up and trying to protect everyone instead of every man out for their own or every person out for their own.

Aliza: I think we all have touched on this, but like, I just want to say it. There's so many different areas of advocacy that have come up in this conversation in terms-- like, in that overlap with disability. And I just want to point that out. I know you two realize why that is, but just for our viewers, disability impacts so many people. I looked it up and it's saying something like 15% of the world population. I've heard it was 30% of Americans. I'm not seeing that figure, so I'm not sure where I saw that. But it's somewhere between there, like 15% to some upwards of 30% of Americans are disabled. A lot of us will experience some type of disability as we age. Sue, you kind of touched on that too.

And I think the overlying point is accessibility benefits everyone, everyone. And we need to be looking at helping as, just as you said, Heather, helping the people with the most need and go from there and make sure we cover as many bases as possible with our societal access. Any other takeaways about this episode or just the general conversation about chronic pain?

Heather: Hey, it's not my favorite episode, right?

Sue: *Melora*?

Heather: Yeah, it's really not, but I love that this episode continues to inspire these types of conversations and that when I go back and look at it over the years, because this is what, 30-- This episode's almost 30 years old at this point, 25 or something. I can't remember where we're at with our anniversaries. But I'm always able to take away something different. And I love that *Star Trek* does that. And I love that *Star Trek* has made a point in more recent series to do a little bit better with disability representation. That's a positive and I like that we see it more and more in media, but I think that we as human beings just need to strive for that future by advocating for ourselves and each other, as we've said. So, thanks, Melora, for inspiring such a really lovely conversation.

Sue: Whenever I think about the concept of accessibility benefiting everyone, I am reminded of a conversation I had about curb cuts, like when the sidewalk dips at a corner.

Heather: Yeah.

Aliza: Mm-hmm.

Sue: Those, of course, were first put in for wheelchair access, but they benefit strollers, they benefit somebody pushing a shopping cart, if you're wheeling a suitcase with you. And that is the example I always think of how accessibility benefits everyone.

Aliza: If you're using crutches.

Sue: Mm-hmm.

Aliza: If you just have a sore leg and can't bend it as much that day.

Heather: Yeah.

Aliza: Yeah. Mm-hmm. Well, I just-- God, I love this conversation we had. And thank you both for being in this space with me. And y'all are amazing. Sorry, I just need to gush about you two for a second because I'm really just feeling so seen and heard and you both have expanded my view as well on chronic pain in *Star Trek* and in our world, so thank you both.

Heather: Thank you. I remember, I think, when you got your diagnosis, I think you were at STLV that year, and you asked me-- Because I had been pretty vocal about mine and my life experience, and you had asked about it. And we're looking for support, which we need that support. We need these conversations. And so, again, I'm really grateful to be here. I know I said it earlier, not on the podcast, but it's always truly been a privilege to be on this podcast and to share space with all of you. Your work is so important, and you talk about *Star Trek* in a way that I don't think anybody else does. You have provided 10 years of invaluable content. Ugh, I'm too emotional. I always cry on podcasts, why does it happen? I'm not going to cry.

Sue: Oh, you're going to make me cry.

Aliza: Yeah, I'm already crying. [laughs]

Heather: No, you've really done exceptional work. And as I said, when we look back at fan history, people will be talking about Women at Warp and your contributions to fandom, and so thank you again. It's really special to be a part of this.

Aliza: Oh, thank you, Heather. Well, that's about all the time we have for today. [laughs] Heather, you angel, where can people find you on the internet?

Heather: The best place to find me is just *trektivism.org*. I'm very passionate about what we're doing and trying to amplify the people and the organizations out there that are trying to get us closer to that *Star Trek* future. So, you can find us @*trektivism* pretty much everywhere, and then you'll see me through there, but that's really where my voice is. As well as the annual Trek talks, annual telethon that will be in January this year, we’re raising money for Hollywood Food Coalition that feeds the homeless in LA, that's the stuff that I'm really focused on, so feel free to check it out. Thank you.

Aliza: Amazing. Sue, where can people find you on the internet?

Sue: Right now, just over at our show website.

Aliza: Fantastic. And I'm Aliza Pearl. You can find me @*alizapearl* on Instagram, Blue Sky, Hive. I still am on X, just whatever and a couple of other places on the internet. But *alizapearl.com.* I have a lot of gaming stuff coming out into the world that I'm really proud of, so please do follow me and stay tuned.

And to learn more about our show or to contact us, visit *womenatwarp.com.* Email us at *crew@womenatwarp.com* or find us on Facebook or Instagram @*womenatwarp*. Thank you so much for listening, y'all, and I hope you have a great day.

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