

Philip King-Lowe

Hey, Carole, how are ya?

Carole Jean Whittington, Beyond Chronic Burnout Podcast

I am fantastic. Philip. I'm so excited to be doing this series with you, because there are so many different elements to self-care and well being, and I think that also incorporates our allies in how they are incorporating our authentic voices. And I love, love that we're having this conversation today.

Philip King-Lowe

Yeah, me too. Lee. Anne Reuber, thank you for joining Carole and I on this episode of Today's Autistic Moment for our Summer Self-Care Series, and I so look forward to what you're going to share with us today. So thank you for joining us.

Lee-Anne

I'm so grateful to be here. Thank you for having me.

Philip King-Lowe

You're welcome. All right, so you know this, this Self-Care episode is about wellness for all Autistic bodies, and this is a great time to really be talking about this because of the tremendous emotional stress that is on our bodies. If you did not hear my show with David Gray-Hammond at the end of May, where we talked about Physical Autistic Leadership and how our neuro stress really does a lot to the body, and that's one of the reasons why we often have difficulties explaining to physicians what's going on with our bodies, because they're not necessarily trained to understand how Neurodivergence is as is physical as well As neuro our brains. So we're talking about this great topic in a year when the stress is just piled on, piled on, piled on. So, you know, I'm so grateful we're going to have this discussion. So let's build a foundation for this conversation. And what does

the topic of Self-Care: Wellness for All Autistic Bodies mean, as we say, one of the multidimensional characteristics of being autistic is physical, you know. So, Lee-Anne, why don't you start and then Carole, of course, ask your questions or give your points as you go on. So go ahead, Lee-Anne.

Lee-Anne

So for me, and I want to start with saying, you know, part of the excitement of me being in this conversation is to share, but also learn, you know, to learn from, from both of you, and to learn from, you know, other people in your audience. For me, when I think about self-care and wellness and the physical, mental, spiritual, emotional aspect of well being. Obviously, you know, if you once, you get a chance to know the work that I'm doing, it's all around making sure that everybody has access to movement, to meditation, to, you know, different wellness tools that are going to meet you where you are, so self-care and this, and especially at this time right now that is so heightened, there's so much heaviness that everybody is carrying, and you know, the ability to have tools to help manage that stress, to help really care for ourselves, internally and externally. I just I can't think of anything that, in my perspective, is more important than having that space and those tools to be able to help ourselves and support ourselves through times like what we're experiencing right now.

Philip King-Lowe

Exactly. So much.

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And you know, Lee Anne, what I really was so impressed with, and I really appreciated was that in in your app for all bodies you were very aware of, and making sure to integrate all different forms of accessibility for how someone takes information in, and how they process that and use it for moving their body. Can you talk a little bit more about the different layers of accessibility and how you've put those together for us?

Lee-Anne

Yeah. So first of all, we're just getting started. We've spent a lot of time really talking to people and really getting to understand, you know, where are all the barriers, and how can we create a space where people feel like they can show up exactly as they are without trying to change themselves to fit a certain mold, which is, unfortunately, the way that the fitness industry, kind of as a whole, has been established. To create a space where you can be fully who you are, as you are, and show up and, you know, engage in that self-care and challenge yourself, if that feels good. And by challenge I meet sometimes that means by, you know, doing hard things that make you sweat. Sometimes that means by sitting in a yoga pose that might make you feel uncomfortable, that might, you know, try to open up your hips in it in a certain way, but really to create a space that all bodies can show up and feel valued for exactly as they are, who they are, how they are, and have access to different movement opportunities that are going to meet them there. So it's come through just many, many, many learnings, and now with our first product, our first version out there, we've created a mobile app that's accessible for people that use assistive technology. So you can navigate the app using a screen reader and other assistive tech. The technology allows for customization of experiences. So the caption text size can be customized, the color contrast can be customized. You can adjust the volume of the instructor separate from the volume of the music. So you have that customization that is important for many people, especially those who are hard of hearing. So on the technology side of things, we really thought about accessibility and how we can use things that do already exist in the fitness and wellness space that we don't typically see them. And then, of course, you know our future plans are, are actually developing more and more technology based on that customization. How can we make it so that you get to create the experience that's the most impactful for you? And then, along with the technology, we've created multiple class options and versions so that again, you know, we're really meeting people where they are

on that day. That includes, first and foremost, bringing together an incredibly diverse instructor community. So we have instructors who are blind to have low vision, who are deaf, who are hard of hearing, who use wheelchairs, who are Autistic, who have ADHD, who have who don't have any disabilities, and we all work together, thinking about how we can create multiple options of each class so there are standing or full body class options, classes that are seated, but do include some lower body movement classes that are seated that don't include any lower body movement and classes that are taught with American Sign Language. And then all of our instruction is provided at a level of detail, where people who are blind or not following along the video file can participate with the audio file independently. Again, this is our first kind of go at creating this accessible and inclusive offer. And we have a lot more that we want to do. And really it's coming from learning that we're gaining from members who are sharing feedback about, you know, how we can do even better, or ways that we can think about, you know, even more accessibility, or that customization of experience. And then, of course, including, so including, for me, is it's not just about, you know, we're, we really do kind of center, I guess I would say, or we put at the forefront people with all kinds of different disabilities, and we want to include social circles. So we want to include their, you know, family, friends, caregivers, co-workers, who might not have a disability, but that enjoy, you know, working out or taking yoga classes together, because most of us actually enjoy that experience of being able to do something with a friend. So another aspect of our technology is actually the ability to stream two different class options at the same time. So if you were taking a yoga class with a friend that uses a wheelchair, they could take the seated class version, you could take a standing or full body class version and you could participate at the same time.

Philip King-Lowe

I want to kind of turn our attention specifically to Autistic individuals. Yeah. What sorts of things have you and those who work with Autistics found that

tends to affect Autistic bodies? You've named a lot of various disabilities, and I'm glad you have because of course, July is Disability Pride Month, but when we talk about Autistics, especially since our brains are unique, and our brains function differently, and it does affect how our bodies work. For example, I have learned over the past few years that being Autistic for and ADHD for me, actually affects how my brain and body coordination communicate. I have a delay that that it can depend on what kind of a day we're in, but there are days when I have to put a lot of thought before my body moves. Yep, you know, so not just that example, but can you talk about how your program has really impacted the lives of Autistic people?

Lee-Anne

Yeah, so I'll tell you. You know, we're just starting to collect feedback. So we just launched a couple of months ago to initial users, and we're just starting to take in feedback. So in terms of the extent of the impact, the kind of the three things that we're hearing most are access, so the ability to actually, you know, find something that that is going to support the needs of the people that are using our platform, the representation is the next, you know, big piece when it comes to the impact that it's creating and also the intention. So people understand that this is just our first kind of version, and we have a long way to go in terms of how we're continuing to develop. But what I'll say just in terms of, you know, how we've thought about putting this together, and how we've included, you know, through lots of different conversations, surveys, that type of thing, you know, thinking through how we can best set this up for people who are Autistic. It comes down to, you know, many different aspects. And I kind of, I'm thinking, I'm sitting here thinking about this, as far as what I'm going to say, and knowing that the experiences that we've heard about are just the experiences of those individuals. So, we're really looking to collect more feedback. And I'd love to hear from you both about your thoughts on what we've put together so far. So you just mentioned that kind of mind body connection, and that there might be a little bit of a delay. So, there are a couple of things that we've

put together that are hopefully going to be really supportive and structured. One thing is that we have a movement foundation library. It actually has two to three minute videos where you can learn about the breakdown of each exercise, or the breakdown of each pose, so that you can practice those things and understand the form and how things should feel and what should be working, so that when you actually go to participate in a class and you're practicing those exercises, you're better prepared. It also one of the things that we're putting together right now are called signature classes, and these classes draw from a specific bank of movements, so that no class. Two classes are the same, but they only use the same movements, and that provides a sense of structure and predictability without getting boring. So for someone that might have, you know, maybe doesn't know a lot about the different exercises, or maybe it's their first time taking a yoga class, and they're really just learning. And if there is that additional kind of mind body connection that might have a lag time there, we would encourage people to practice the movements and then participate in a signature class where they really understand what is expected in that specific class and feel a lot more confident and prepared in going in there. So that's what I would say. We've kind of started with. There are other things that we're working to develop in terms of technology, to continue to provide customization. And here's something I'd love. Your initial thoughts on the idea of remove distractions toggle so that you can actually you know, some of our classes have different backgrounds because our instructors are teaching remotely. There are sometimes some different sensory stimulations that can happen in the background of things and take away from the attention of the instructor, so things like the ability to toggle off distractions where it's removing the background, it's actually removing everything except for the focus on the instructor or any props that they might be using in that class. That's one of the areas of technology that we're working on building right now. It's not currently in the app. It's just something that we've started building on.

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So I will honestly say, one of the things that that really sparked my joy around what you've put together, and you know, just from the wellbeing perspective, and as an Autistic ADHD woman with co-occurring health conditions, because that is very prevalent. So, you know, I'm also dyspraxic, but I have pots, I have hypermobility, so I have to be careful about how I extend. And I liked the way that the thoughtfulness that you put into this really raises the awareness of these are the different elements that no one else is talking about, like when we're talking about fitness for our bodies. Y'all have really put a lot of thought into, okay, here's how we can support different brains, different bodies, different ways of processing information. And I like that there's a lot of flexibility, but I like that there's also this sort of community sourcing of knowledge, because you're always asking, like you asked me, like Carol- Jean, tell me what you see here? What did you experience? What were your thoughts? You know, and I have found that to be just one of the things that we don't see enough of is that there aren't enough spaces that are saying, hey, we want your voice. We want you to tell us what's working, what is something that would support you more. And that was the thing that I was really drawn to about how you've started to build this. And I think that's a lot of what Philip was really concerned about, or really wanted to make sure. I was like, hey, we want our voice in this, you know. And that was one of the things that I saw, was so core to how you put this together, because I felt really included for the first time in any type of fitness app, because I've used lots of them. I mean, I've used fit on and all different types of things. And I'm always having to figure out how to accommodate and adjust for my body and my physical safety, especially with hypermobility. And I was really, really excited, because it was already, it's already there in so many ways, which is so incredibly nice and like, just from the perspective of you know, what are the things that make us feel safe? And one of those things is not just being seen or acknowledged, but being able to step into a container that's like, Hey, we're already including you. You aren't just included. You're here, and we want you to be part of the

community and active voice in this community as we're creating and developing more. And to me, that is so key. And I think Philip also not going to speak for you, but that's, you know, I tend to think that that's our heart is like this, you know, not just that we get a spot at the table, but we have a voice, and we are actively part of that leadership and development.

Philip King-Lowe

Yeah, one resource that I do want to introduce you both to, if you haven't heard of it yet, is a resource that we have here in St Paul, Minnesota. It's called Mad Hatter Wellness. That company actually puts together programs relating to sexual education as well as health curriculum that educates and empower people, empowers people with intellectual disabilities and their support systems. I have interviewed one of their former clinicians, where we talked about back in 2021 now, but we talked about, you know, dating, sexuality, relationships and consent and all that sort of thing. Their work is absolutely brilliant. And then moving on to another piece of this, because Lee-Anne and I talked about this through emails, one of my principal concerns with any app that discusses people with disabilities, Autistic people too, is what we say and do for Autistics living in larger bodies. Back in October 2023 Kelly Lenza, they are this individual who is working to address fat phobia among Autistic Adults. Because of how much many of us who are Autistics in larger bodies, are always given the lecture by healthcare providers and so on and so forth, "if you will Only just lose the weight, you will feel better." And you know what Kelly Lenza and I have to say is, you know, we've actually written it into our records that discussion of weight loss is not going to occur at this appointment. Okay? We are tired of people giving us the drill, if you will. Yeah, that you know, people, Autistics, disabled individuals in larger bodies, deserve a lot more respect and less about the weight loss than how to live comfortably as an individual in a larger body. Can you talk a little bit about that Lee-Anne?

Lee-Anne

Yeah, and, you know, I was so excited that we, we started to just kind of touch on this subject through email, because it's really, really important to me. It's the intention in what we're doing is to create a space for all bodies, and not to create a space for all bodies. And then, you know, judge which bodies are okay and which ones need improvement, not at all. And, you know, unfortunately, you know, the fitness industry, in many, many ways, the yoga industry, kind of, the wellness industry as a whole, has been established as this industry to get you to conform to looking a certain way, and unless you look a certain way, or unless you're trying to look a certain way. You know exercise is, is really, it's, it's nothing but to change your body. And that's the complete, just opposite of what we're looking to establish in our community. I myself, you know, battled eating disorders, obsessive exercising. I can recall as a child watching my mom's, you know, workout DVDs where there would be three very thin women and there would be one of those three women that was just a little bit less than the other two, and she was always the one at the back corner doing the quote, unquote, modified version. And it's, it's those things that I recall that you know, the diet industry, the fitness industry, it's so deeply ingrained this idea of what our bodies are supposed to look like. And then, you know, we can take it further, how our bodies are supposed to move, and how valued our bodies are based on those things. And you know, we want to shatter that that should never, ever, ever have been the reason that we show up and move our bodies and exercise, and the things that we eat and the choices that we make shouldn't be related to the size on any of clothes you're wearing, the weight on a scale, any of those aspects. It really is a way to honor your body and love your body and respect it and appreciate it. And so you show up and you give it that self care that it needs through movement, and you do it in a way, not as punishment, but because you respect and appreciate and love it. And that is the essence of what we're looking to create in our community, is that you get to show up exactly as you are. We're not going to ask you to change. We're going to give you the space to be who you are and to access movement in a way that feels good for you.

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It's so important. And I'm I want to share something really personal here, because I this was a big thing for me because I'm almost 5'10" I'm over 200 pounds. I'm not a little woman. I'm curvy, and you know, my weight has always been something that's been hard for me in my adult life because of some trauma that I've experienced, and I am in perimenopause at 51 and so my body has really changed lately, and it's kind of uncomfortable, and with dyspraxia, because I've put a little weight on my balance, my vestibular has been off, and so I've been a little uncomfortable in my body, As it's recalibrating, and I know for me, joyful movement is how I get back into that place of where I found my center of balance and I feel good, but I did something that I'm really proud of, because I'm getting my master's in public health, and one of the things that I'm specifically focused on is our well being and our health care for Neurodivergent brains and bodies. And when I went to the doctor's office, and they always want you to get on the scale first, and I looked at her, and I said, No, thank you, not today. And she kind of looked at me, and she was like, okay, she thought I was kidding, and she kept walking. I was like, No, I'm serious. No, thank you. Not today. Let's just go straight to the exam room. And it kind of threw her off, because that was like her routine, but I wasn't going to allow myself to be weighed that day, because that didn't feel good for me. That wasn't mentally going to feel good for me. I know where my body is, and it was such a beautiful thing. Because then we got to the room, she was like, are you okay? And I was like, Yeah, I'm fine. And I explained to her, you know, why? I said no and how. And she was like, I think that's so beautiful. She goes, I think that might be something I try.

Philip King-Lowe

Yeah, no, Kelly, Kelly has Kelly Lenza, when they were on, you know, explained that you can tell a doctor. No, that is not something I want you to do, you know. And you know, David Gray-Hammond and I said this, and so

did Kelly Lenza. If you happen to be at a doctor's appointment and the doctor or any of the healthcare staff is not respecting your wishes, it is okay to leave the appointment absolutely you should not feel.

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You don't have to explain.

Philip King-Lowe
Right. Exactly, yep, yep, yep,

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You can just leave it's you're right. And you know, something else I want to talk about to Philip, when we talk about larger body sizes, my friend Diana Dimmock is a phenomenal advocate, and she has a company out of Canada called accessibility for all bodies, because one of the things that gets missed so often, and I'm finding that this, is we have a higher rate of occurrence in the Autistic population. It's seeming, you know, I'm seeing this pattern with lipedema, and lipedema actually impacts your body size, because it's a lot of hormone and a lot of extra storage through stress. And as Autistic people, we are so dang stressed. You know, as a burnout researcher, I'm always looking at what are our stress levels, and so I love that we're having this conversation around the different layers of wellbeing and how we're moving our body. So thank you both for this today.

Philip King-Lowe
No, no very much. So I couldn't agree more.

Philip King-Lowe
As we're moving into my second question, which, you know I like to talk about how autistics are engaging in this, and this is where we really want to really talk about some of what we're already been saying. You know, how do

we help Autistic Adults? And this is where I also love to talk about all of our intersectional communities, because they're so beautiful. And like I said, we're all feeling the stress, you know, getting, getting, uh, Autistic Adults of all body types who are feeling this, you've got to have a "normal brain." No, normal is a relative term. I don't think it really applies to everybody, okay, but that's how the word they use. But the point is, is that, how do we help them get engaged in wellness work, given the stressors that we're given? Go ahead, Lee Anne and please start talking about that.

Lee-Anne Reuber

Yeah. I mean, we are actively out and looking for people who want to be engaged so that we can really get to understand more and more and more how we can create the experiences that are going to be the most impactful. One of the ways in which, you know, we've put together some initial content is making sure that we have very short class opportunities. So classes that are five to 10 minutes in length. For some people that are looking to establish a new routine, or might be the first time that they're actually going, you know what? You know, this is something that's important to me. If I found a space that I feel safe to show up and move my body, here's a way for me to kind of start to engage in that I'm having shorter, kind of Bite Size opportunities for people to show up and move their bodies and get that sense of accomplishment. And, you know, potentially, if it's in the middle of your work day, maybe that hits the reset and button for you in, you know, in a few different ways, or it just helps you to get out of the kind of all or nothing mentality that many people have when it comes to exercise, thinking that it needs to be five days a week, 60 minutes every time and it and you're, you know, you should be feeling like you're going to puke or all of your muscles are sore afterwards. That's not the way that you need to think about movement or a routine when it comes to exercise or yoga or wellness at all. And so we like to offer bite size opportunities for people to come in and get used to the experience of moving their bodies in different ways. And we have cardio classes, strength training classes, yoga classes, we're

working on dance classes, kind of coming back to this joy in movement. That's really what we want to provide for people, is that safe space where they feel themselves represented, where there's that sense of belonging, where there's that, you know, accessibility and there's options that are going to meet people where they are, but also where it provides an opportunity to actually develop a long term habit of self-care and showing up and moving your body. So, you know, we've started with a few things based on our instructors who are sharing their specific experiences and what helps them, as well as members who have come in, who are Autistic and are sharing their feedback on the things that are really beneficial for them, and that is essentially how we develop. We move intentionally and methodically with feedback only. We don't go and create things that we think are, you know, the next best thing. We might have ideas, but ultimately, everything that we do comes from people who are sharing about what's most impactful for them and their experiences, and that's what we go and build.

Philip King-Lowe

Yeah, one of those things that I'd like us to bring into this that's important to be engaging is Autistics who live with chronic pain. All right, this is a very important topic, because a few years ago, again, there is we have a licensed social worker who works with Autistics experiencing chronic pain, and one of the reasons She does what she does is because of what many don't who are not Autistic and not experience with Neurodivergence just don't get is the role that sensory processing plays in how Autistics experience pain. And that can be like, for example, up until 2018 I was uncomfortable. I had some trouble getting up and down. I was using a cane, but I wasn't terribly uncomfortable. Then in 2018 My God, it was like, where did the pain come from? How did it happen? And it wasn't until I was working with my therapist back then, who has a great working knowledge of Autistic people, explain to me what had happened with sensory processing for me, and this is where it is helpful for people to understand that in my particular case, a therapist pointed out when I was feeling okay, but a little bit uncomfortable.

My sensory processing wasn't telling my brain that I was in pain. Then when I started really feeling it, those neurological receptors were making up for all the time for the amount of pain I was already in my brain, just hadn't started processing it yet. And when it did start processing it was, you know, it's working overtime, so now you feel like it's extremely intense. That's what was happening. And you know, the name of the social worker here in St Paul is called Erin Brandel Dykhuizen, and it's an interesting name to try to spell, but and she knows that. But the thing is, is that what she helps Autistic people do is learn to engage with their pain, even to the point of learning to talk to that pain, to the point of learning to even do a little hypnosis therapy with that pain, because what they need to understand that pain is real. And when she when someone says to her, like, what I just the story I shared with you, she's like, you know, I'm sorry. No doctor understood that. But what they did and what they didn't understand is, for you, that pain was more than real, it was traumatic, it was affecting your life. And I can tell you that being an Autistic who lives with chronic pain, it's an experience that really changes one's life. And the thing is, it can affect everything. In fact, one of the things that can affect is how much more sensory input you can take during the day, yeah, because you've always got that pain just it's there, okay? And so, you know. So as I say all that, and again, we're talking about engaging. We're talking about Autistics learning or starting to listen to their bodies. One of the and before I let you talk, one of the points that David Gray-Hammond brought up a couple months ago was that remember that our bodies is what we what we reside in our brain resides in that body. And so one of the messages we're given through this ableist society through all the stuff that we're hearing right now is don't trust your brain and don't trust your body. So over time, Autistics get this message of not listening to your body, and part of wellness is doing just the opposite. Talk about that if you want, if you want, both of you, please.

Lee-Anne Reuber

I'll start with my experience with yoga. Actually, is the experience that helped me to understand the concept of listening to my body. As I mentioned, you know, I went through a lot of different experiences related to diet and exercise that were very toxic. You know, some of those things still kind of bubble up to the surface every once in a while, and I am aware of them. But when I first started engaging in yoga, it was the most terrible experience that I could imagine. It was just when it was starting to be trendy, and so I was going to hot yoga classes with my friends because it was it was starting to be trendy, but the entire time, I hated every moment. I was racking through my brain in all the things that I needed to do afterwards, you know, after the class. Here's all the things I need to do. Oh, we've just got finished on this side now we have to do it on the other side. I'm going to have to figure out when I'm going to get a real workout in, because at that time, my brain was so focused on, you know, that kind of extreme form of exercise, and I stopped going to yoga. I was not in a place where I could accept the idea of being able to sit with myself in different poses, in different movements, or in stillness and actually hear what you know was coming up, what my thoughts were, where I could actually connect to my body and be in tune with my body and what it needed. And so it wasn't for quite a while until I found a different form of yoga practice, which was much more you weren't focused on thinking you were focused on movement, but I became so engaged in the movement that it kind of opened a window into yoga. And so, long story short, yoga helped me get comfortable with the silence and the stillness, and then it created a space for me to actually get curious with myself about my body, and get curious with myself about my mind and where my thoughts were and especially those thoughts that kind of run in the background, you know, throughout the day, all day, every day. Most, most people aren't aware of those scripts that can be running in the background all the time. And so I'm really grateful that I was given that experience and my approach to yoga, I am a yoga teacher. My approach to yoga is very much, you know, working to create that space. There's no illusion of perfection, or we're not focused on the pretty

poses, or how flexible you are, any of those aspects. It's really about creating this space so that you can connect your mind and your body and actually get to understand, you know, what your body's telling you in certain scenarios, whether it be in movement or outside, in everyday life, and it's, it's healed so much of the eating disorder aspects, because, you know, I wasn't, I didn't learn about nutrition. I just was focused on counting X amount of calories, because I felt like at the time that was, that was, again, the trend, or that's what everybody was doing. I couldn't, I couldn't have one square, have a chocolate bar. That would be unfathomable to me. If I was going to eat a chocolate bar, I'd eat the whole chocolate bar or, more often than not, I just restrict myself so heavily that I couldn't possibly eat a chocolate bar. I'm now much more in tune just with the things that the nutrition that feels good for me, the amount that feels good for me, and it changes all the time, but that's the whole point of being in tune with your body. Is really being able to listen to, okay today, what, what's going to fuel me, what's going to feel good, also, what's going to taste good. Because I love food. I really enjoy food. I want to enjoy the experience of food. I'm not, you know, I'm not trying to get rid of that. And similarly, with movement, sometimes I have a schedule that I'm like, oh, today is a day that I want to focus on, maybe lifting heavier weights. I'm trying to keep my muscle mass as I'm getting older. But if on that day, I show up and my body says, No, today is not the day for lifting heavy weights. Today is the day for slowing down. Maybe it's a walk, maybe it's yoga, and maybe it's nothing at all. There's no more guilt attached to that. There's no more shame for not you know, keeping that very rigid strict, this is what wellness is supposed to look like, and it's because I developed that relationship with myself and that quiet space to actually be able to know what feel, what would feel good for me.

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It's such a big place to get to this moment where you can allow space for your body. I know for me, very similar to Philip's story, I still live with chronic

pain. I'm I have MCAS and hypermobility, and I have pots and several co occurring conditions that affect the inflammation in my body, and that's constantly changing. So like, right now, my hands hurt, you know, it's hotter outside here in the Deep South, so I was out, you know, with my husband yesterday, planting some flowers and things. And so today, my joints hurt. They're more inflamed. And there was a time where I, like, recognized this, but I pushed it down because I had this programming from the world that says we're supposed to power through and, you know, success means, you know, especially in exercise and body movement, you're gonna be uncomfortable. Well, okay, so I'm gonna be uncomfortable. But I had no gage, because I'm also alexithymic, and I had also, you know, tuned my body out at such an early age because the world said, Oh, you're weird. You're doing it wrong. Don't be so sensitive, you know that can't possibly hurt you. And so I'm like, Oh, well, I must be wrong. It's not safe for me to say that, because everybody else is saying something different, right? It's not their experience. So I'll just be quiet and I'll push that down. And I learned to do that for 40 years, and in the last decade, it has been this beautiful place of being able to allow space, to just let my body talk to me instead of silencing it, and to recognize that I had lived in a high degree of pain every day, and had not realized and had not acknowledged it, and had not been kind to myself in that process of when I was hurting, because I thought I have To keep going, because it's not safe to stop.

Philip King-Lowe

Yeah, and you've said on various occasions, Carole, pause is okay. We just aren't used to telling ourselves that, you know, does that sound about accurate?

Carole Jean Whittington, Beyond Chronic Burnout Podcast
There's power in the pause.

Philip King-Lowe

Yeah. Absolutely. Absolutely. And I think it's we really should bring in here about how many Autistics live with fibromyalgia? Yes. Yeah. I mean, it's, it's almost the, I hate to say it almost a guarantee that somebody will, some Autistic will have that, and they share with they've shared with me how there are just some days when the answer is no to pretty much everything, just no because of how much pain and how much discomfort they're in.

Um Leanne, can you talk about how you help Autistics, or anybody who is working with that particular one? Because, as I say, it's a big one for many Autistics. And you know, I'm going to venture to say one thing. I happen to believe that the Neuro part, you know, one of those multi dimensions of Autistic people, we are neurological. There's no escaping that, no matter how much we want to try not to or think we should. But there has to be something about our neurology just being different that might impact that. Lee-Anne, you want to talk about some of that.

Lee-Anne Reuber

Yeah, so in terms of, you know, somebody that has fibromyalgia, or frequently changing needs or frequently changing pain levels, I think about some of the people that you know I've worked with that have MS, and similarly, every day is a different experience. So again, you know, thinking about the different options that we've put together for people who want to show up and feel like even you know on a day that the capacity, the capacity that they have for movement, might look different than the day before, there are different options. There those, those seated options. And of course, we're kind of thinking about, what other options could we provide that can meet people where they are? The other thing I would say is, you know, one aspect that we've included is some meditation. Meditation is a really beautiful experience. It can be. It can feel really challenging for people at first. It certainly felt challenging for me at first, because I did. I spoke about it in the yoga classes. My brain was just going, going, going with all the things that I had to do so to actually allow myself this space, to slow down and, you know, notice thoughts without trying to control them. You know,

understanding that meditation is not a space of just silence. It's a space of noticing and just letting things come in and letting things go out.

Meditation is something that I would really encourage people to work on as another way, even though it's not necessarily related to movement in the body, it's another way for you to be able to connect to your body and to be able to really understand, you know, what's happening. And the other kind of side of it, from my perspective, is, is a mindset piece of it, and the mindset piece is that get letting go of guilt or shame related to, you know, I'm in pain today, and I'm not going to keep my routine that I established, that I set, you know, specific wellness goals or exercise or strength or mobility goals, whatever those are, most times when people set those goals, they have a pretty specific routine that they're setting to achieve those and that's great because we want, we want action plans in order to achieve goals, but giving ourselves that grace throughout the process. It is really about progress and not perfection. And those days where, even if it's multiple days in a row, where your body is saying not today and the next day, it's saying not today, it doesn't it doesn't discount all of the you know, the days before and the weeks before, and your body is an incredible vessel that remembers that muscle memory and remembers, you know, that flexibility. So, when you have capacity to go back into an exercise routine, your body will meet you there. So it is really about the grace and not the shame or the guilt of not showing up. And that, again, stems from listening to your body and knowing that, hey, it's saying not today.

Carole Jean Whittington, Beyond Chronic Burnout Podcast

And sometimes that not today is the place where we start to really reclaim our personal power to say it's okay, that it's not today that compassionate curiosity. So I'm a certified meditation and breath work instructor, and one of the things from our neuro distinct perspective, especially around meditation, is that we have to sit still, and it's about having no thoughts at all. And that was kind of how I learned and where it was presented. I was like, Whoa, no, I cannot do that. That is uncomfortable. There is no way in

heck that I'm gonna sit still and not have thoughts. It makes me want to jump out of my skin. And I also have like, pervasive demand for autonomy. So don't tell me how to do stuff, right? Literally, experience this on my own. So there's this really beautiful place that I teach from for that which I think really makes a big difference, and it made a big difference for how I began to get compassionately curious, to allow my body to speak to me and to learn how to listen, because it's, it is, it's, it's a skill that we develop over time, when we feel safe, when we have internal, emotional safety and self trust, and we feel like we belong to our bodies. And for me, it was I had to move to get to a place and have rhythm like vibrational resonance through my body. So I found it through the way that my feet hit the pavement, whether it be jumping or walking or running or whatever it was at the time. And it was about, how am I beginning to just create space for my brain to change all of the fast hyper movement? Because I would have, like, 400 tabs open and 20 tracks of music all going at one time, right? And it's like, how do we start to do that? And I love that we can have an approach that doesn't look like what we think meditation is, but it can be this very centered of what feels best for you. So if you just want to move in sway, if you just want to, like, you know, float and feel like you're, you know, a bird. We did this meditation not long ago in kundalini, where you were like flapping for timing, like you were a birdie. You were like moving your arms, and it was just with your eyes closed, you know, if that was comfortable, just all these different ways that we can begin to approach moving our body for well being, because it's about the joy, it's about the conversation and the relationship that we have with our body, annual and as Philip mentioned, fibromyalgia, it runs between 40 and 65% of the Autistic population and people who are tested for fibromyalgia that align with Autistic traits and characteristics. So you know these types of things, you know, including MCAS and all these co occurring health conditions, they show up in how we have a relationship with our body and how the world has said either they view it as right or wrong, and then either we take that messaging or we don't. And so I think it's also when we're talking about self-care and well

being that to really open up the conversation and just the thought of, what's the compassionate curiosity I can have today around the relationship, the communication that I am creating and establishing with my body.

Philip King-Lowe

Lee-Anne, can you please share with us, in these last few moments about how to find this app, what it is, how they can find it and maybe a little bit more about how they can use it.

Lee-Anne Reuber

So it's available in both the Google Play Store and the Apple store, so people can go and download it. It's optimized for mobile right now. You can use it on a tablet or iPad. It's not optimized for web based yet. That is coming. And even on the tablet, it's there are some things that we're working on improving that experience, but it's available in the in both stores for people to be able to download. I love connecting with people if they're checking it out even before they check it out. If people want to connect with me, they can do so on LinkedIn and through our website. But yeah, find it in.

Carole Jean Whittington, Beyond Chronic Burnout Podcast

What do they type in to search for this app, Lee Anne?

Lee-Anne Reuber

They type in Sekond Skin Society. And second is spelled s, e, K, o, n, d, there is a name, a story to that, that name that may need to come on another, another conversation.

Philip King-Lowe

Yeah, yeah, um, we didn't really touch on the third question, but we kind of did, but I want to overlap, you know, let's conclude this conversation, if you will, because I think what we're already talking about is how our brain and our body are interdependent upon one another. And, you know, I have to

end this discussion by talking to our LGBTQ communities, where sometimes getting access to things is being so politicized right now. I just want to say, let's say, and then I'll let you all finish for me. What additional stress that you're experiencing earlier. Lee- Anne brought up the point of meditation, which I think they now call that mindful meditation. But I want to also say that that practice that you're speaking of is has a version in every religion of the world. Okay, for example, I am a contemplative Christian, and what Lee-Anne is talking about for contemplative Christians is called Centering Prayer, where you sit quietly, you listen to your breathing, and then the thoughts come in. And the thing is, what we don't realize is how much all this stuff with our bodies and our brains actually clutter. We collect clutter. It's like this giant bunch of piles of things, okay? And we don't know, we don't exactly understand how much of it is occupying our space. So the whole point of mindfulness meditation, centering prayer, or whatever you call it, forever, whatever religious practice you do or don't do, it's sitting there and it's letting these thoughts come into your brain. But instead of stopping and thinking you're just letting it go, you're just letting it go by you, and as you begin to let all this go, you then start to feel like, oh, now I've got some empty space to work with, literally. Now let me just say the kind of letting go we are talking about is not how some spiritualists may gaslight some of us who are Autistic, larger bodies and all that. We're not talking about your identity. You're not letting go of it. You're just not letting it occupy the space in your brain so that it like stops your life for or it stops you because of some kind of trauma. Actually, what you're doing is you're actually seeing that stuff, and you're letting it go so that you can live more peace with yourself as you are. So I'm gonna let Lee-Anne finish out by, you know, talking about this interdependent piece. And, like I said, then we'll finish up for the day. Go ahead.

Lee-Anne Reuber

Can I just make a comment that I think is important, and it's the way that we are thinking collectively when it comes to what we're creating. This

idea of what should be, so what fitness should look like, what meditation should look like, what yoga should look like, what our bodies should look like. One of the things that we talk about in our instructor community is if we didn't know anything about the fitness industry, the yoga industry, the dance industry, if we didn't have it structured in such a way, how would we want to create it? And by having so many incredibly diverse perspectives in this conversation, it creates a really super interesting, fun, joyful, curious exploration, where all of us in our own different experiences, our own different perspectives, our own bodies, get to go, hey, you know I would, I would love it if it looked different, like this And meaning, you know, not in this kind of box that it's currently been established. And so I share that just because people have this idea of what meditation is or should be. And at the core of it for me, meditation, and it can be prayer, and it can be, you know, mindfulness, you it can be called many different things. It's really just creating the space to just be, to be with yourself. There is no right or wrong way to do it.

Philip King-Lowe

Right. Exactly, yep. And that's part of the interdependence that's sort of there. It's maybe not the easiest thing to put into words, but it's still there. And that, you know, I think the ending message here is to understand that. I mean as Autistic individuals with whatever co existing health conditions, disabilities, there may be, what we are all saying here today is that you, as you are, is just fine. It's already perfect. What's missing is a societal acceptance, and that part of wellness is you making a space for yourself with the help of others. Guarantee you know that says it's okay just to be you here. 100% yes, and that you can find wellness as you are, being who you are, okay, because you're right Lee Anne. What's been happening is you're supposed to fit into this mold, and that's exactly what's happening with all of our communities right now that, you know, they're looking for cures. They're looking for, you know, explaining an epidemic, which, you know, we could go on forever with that one by itself. But the point is, is that it's all about

acceptance and just finding joy as you are, you know, and exercising yourself as you are. You know, I had a spiritual director once a long time ago, I was talking about something completely different, but he said to me, you already have that strength to do what you need to do. You've got that that that muscle that always already tells you what to do. You just have to exercise it to strengthen that particular muscle. And the one muscle that so many of us Autistics with various disabilities continue to be told. You know you can't use that muscle, that muscle, you know, that muscle doesn't work. But actually it's not what's working. It's not it's what's being accepted as already working the way it works for you. And that the key to wellness is starting with where you're at, accepting where you're at, and learning to bring wellness to yourself exactly where you are. Do you think that's a proper latest, proper statement Lee-Anne?

Lee-Anne Reuber

Absolutely. That's exactly the essence of what we want to do. We want you to feel like you can love and value who you are and be in a space that also loves and values who you are exactly as you are, and isn't asking you to change, but is going to keep showing up, and you know, using the feedback that we're getting to continue to make the experiences even more impactful, so that you can show up even more fully as you.

Philip King-Lowe

Right. Good. Lee-Anne and Carole Jean, thank you so much for joining me for this incredible conversation. Wow, and please follow those suggestions that Lee-Anne gave as to how to find the app and that sort of thing. Carole Jean, what do you have to say at the end here?

Carole Jean Whittington, Beyond Chronic Burnout Podcast

I'm just thrilled to have had this conversation today, because I think this is one of those things that we don't talk about nearly enough, and I love that Today's Autistic Moment brings this type of conversation to the forefront.

And I just want to say thank you to Lee-Anne and all of the instructors that have come together as allies and as collaboration partners to create a space where joyful movement and well being that place to experience our bodies, to experiment with what feels good for us, and to Do it in a way that meets us where we are, where we feel safe and secure. To do it, it's Sekond Skin society is such a beautiful thing. So thank you for that.

Lee-Anne
Thank you.

Philip King-Lowe
You're welcome.

Transcribed by <https://otter.ai>