Ann (00:03.026)
Hey everyone, welcome back to Therapist Uncensored. I'm Ann Kelly. And before we jump in today's episode, we have an exciting announcement. We have a conference that Sue and I are putting on this coming May 4th. And we're really psyched about it, aren't we?

Sue Marriott (00:19.962)
We could not do it without our partner organization, Austin IN Connection, who is sponsoring us. They are near and dear to our heart, certainly check them out. But what we are just really thrilled about is we're taking all the stuff that Ann and I have learned in clinical practice over the past 30 years. Everything we've learned on the podcast, everything we've learned from all of our expert guests and all the research that we did for the book. And we're going to bring it to you live. We invite you to join us from wherever you are. We know that many people won't necessarily be able to make it in person, but if you can, this is the event to come to.

Ann (01:09.086)
That's true, some people have asked, when's the event for us to actually fly in? And if you can and you have the resource to do it, we would love for this to be the one to do it. We're going to also have a meet and greet Friday night. The book launch is Friday night and so we're gonna have a gathering that should be a lot of fun, a lot of ways to connect to people. And then Saturday is a full day all day conference.

Sue Marriott (01:23.083)
It's more than a meet and greet. It's our it's our book launch party. And one other thing about the conference and then we'll move on, but it is gonna be different and we'll continue to share details about that as it, as we go, as it gets closer. But I'm just, it's not gonna be just your ordinary conference. We're gonna specifically do a deep dive into modern attachment, how to apply it, weaving in relational neuroscience, but also really incorporating systems and structures that impact how we feel, both our development, how we grow, and how we see ourselves in the world, but also our kind of more immediate sense of security in the world. So I'm really proud of that. And I think that that's really different than anything that's out there right now.

Ann (02:25.31)
Well, we're also going to have some group portions of it. So active participation, not just sit and receive, but an active participation. I'm also really excited about that.

Sue Marriott (03:10.238)
As part of the conference, inspired by the book, Lifting Heavy Things, which is a book by a person in the personal training field about using strength training as part of her therapy and part of her treatment of trauma and being able to use that with clients. We are gonna have a certified personal trainer join us who is amazing and works really holistically and you're gonna absolutely love her. And she's gonna lead us through some strength exercises, a different way of embodying somatic work and connecting us to our bodies and connecting us to the strength that it's gonna take for us to continue to do this practice of secure relating. That's one option. And

then the other option is we have another professional who will be leading a mindfulness practice at the same time. So all kinds of goodies coming at you.

Ann (04:08.071)
Don't worry, those of you hearing the word strength training, we're not gonna be bringing barbells or anything like that. It's gonna be something pretty doable and accessible, but meaningful, which is helpful to bring that kind of thing to an everyday life that's really doable and accessible to everybody.

Sue Marriott (04:15.262)
Yeah. Accessible, very accessible. That's right. And so for anybody from out of town, we'll have some welcoming. And then on Sunday, I think we've got some volunteers that are gonna be continuing to do cool things so that we wanna help you all meet each other. And again, do what we say we wanna do, which is build community.

Ann (05:51.966)
So let's dive into today's episode. So we have personally close to us experienced somebody that we love dearly with long COVID. And it's very, very relevant in our hearts. And I don't know anyone who can take a topic and dive more deeply than you, Sue Marriott. When she gets her mind to something and she cares about you and something's going on, you're going to know more about it than anybody else I think I can imagine knowing. And we decided that we wanted to bring this topic to our listeners because it's so relevant. Long COVID is impacting, they estimate about 10 to 30% of people who actually contract COVID are likely to have long COVID symptoms, and some people won't even know that's what it is. So we really feel like it's a very, very relevant topic in how it affects us emotionally and physically, as well as socially. So we wanna talk about it today.

Sue Marriott (06:58.442)
Yeah, totally. And Ann's right, I deal with stress by learning. So I have read probably more than my fair share, but certainly I'm no expert. And as we're sharing some of this, we're not medical doctors, not neuroscientists, just concerned people, and both personally in our life and also professionally. But my interest in bringing it on is more about the stigma and this is the thing that happens almost every time. If you say, you know, John is out with long COVID and with a brain fog or whatever, or this is more specifically, we're gonna be diving into Chronic Fatigue Syndrome, CFS. There's a whole problem with that, which I'll explain real quickly in just a moment. But what it stands for is myalgic encephalomyitis. That's what it, myelitis. And then they're also beginning to call it encephalopathy. Basically the difference between these is that one is acute. It's an acute neurological disorder characterized by attacks of inflammation, i.e. swelling of the brain and spinal cord. And then the other version of it where it's just ends with Pathy instead of Itis is it's a disease of the brain, which is very scary, even just those two differences, meaning is it acute or is this ongoing? And so the sub section of long COVID that we'll be talking more about today, is this those that are experiencing the fatigue, the brain fog - that portion of things and we'll get into that.

Ann (09:22.442)
So I guess that's a good clarification because we started off talking about long COVID and there's a lot of different elements of long COVID. It's not just one thing, right? It could affect the lungs, it can affect so many different aspects and so many different organs. And we're gonna specifically be focusing on the deep chronic serious fatigue and the brain fog element of it. And what constitutes long COVID is that its symptoms are on set within about three months of the initial.

infection with COVID, but that it lasts and that lasts without any other explanation and that it lasts and impacts your life in a significant way.

Sue Marriott (10:03.242)
That's right, it's not just kind of feeling a little bad. Yeah, and yes. And what's good about this is, they're getting better and better and they're learning more and more that there's many, many subcategories under long COVID. And they all kind of have their own trajectories and their own prognosis. So I encourage you to kind of look into that part of it. And we're gonna have tons of resources, of course, on these show notes. So you were gonna say something, I think.

Ann (10:05.551)
Right.

Ann (10:16.388)
Mm-hmm.

Ann (10:31.354)
No, I think it's such a relevant thing for those of you listening out there because it's either could be affecting you directly or somebody in your life, right? And I love that you started talking about the stigma because we really, if with lack of information out there and the pressure that we get, especially in our culture to be a go, go culture. And if you're slowing down, there is so much stigma to that.

and we're finding more and more how much of that can be damaging in and of itself, the stigma that it carries.

Sue Marriott (11:03.202)
Totally, that's why I wanted to do this. That's exactly why, is that I see that as I've tried that as it's affected us more personally and I've talked about it, the very first thing always is, especially when it's kind of, when you hear kind of it's, no, this is really a thing. Like this is impacting me too. People will immediately, you know, well, you know, do you think there's an unconscious reason that maybe

they wanted to blah, leave their job, or do you think unconsciously they might want to just be taken care of? Why not? We all kind of get tired and wanna call in sick, what about the, maybe

there's some baggage there. Literally, those words have been used. Maybe there's baggage there.

Ann (11:34.277)
Mm-hmm.

Ann (11:50.305)
Mm-hmm.

Right, and it's coming from a caring place. If you're this fatigued, something must be going on and we wanna help you fix it, right? And so it's coming from a caring place. Like, oh, is something else going on that if we tackled that underneath, then you wouldn't be feeling this fatigue. But there's a lot of implications in that, isn't there?

Sue Marriott (12:01.298)
Exactly, exactly, right. And so if that's.

Sue Marriott (12:11.894)
Oh, totally. And the, you know, you and I have talked before about like attribution error and how that, let's say you hear that your neighbor's robbed or somebody broke in, that in general, our first response is gonna be something besides, you know, empathy, oh god, that sucks for them, is gonna be some sort of, oh, they don't have a security system or.

you know, they don't leave their light on, or, you know, they do go out late and probably somebody followed, like there will be some sort of very subtle, that happened to them for a reason that we can see, and that therefore that's not gonna happen to me. And so, again, unconsciously, that there's a way that we wanna distance ourselves from something that rather than feeling helpless, or rather than feeling passive, that this could just happen.

we tend to create a story very quickly. So for example, the story gets created very quickly. Oh, that's baggage. If they would just deal with their somatic complaints and turn, like listen to their body and hear what their body's complaining about, then they would feel better, is a story. And it's a story that makes us feel better because we can then understand what's going on. And we know the, and believe me, everybody knows the answer. Everybody's got like, oh, this herb and this, that, and you really need to call this

Ann (13:24.851)
Right.

Sue Marriott (13:36.434)
homeopath and so on. And so my point in this one is just that very first thing is a little blamey. It's a little ableist. It's a little like we know and they don't. And it's not a, it's the normal, I do it, you do it, we all do it. So, but I'm trying to point it out because like you said, it's not good for the

patient. It's not good for the person who is suffering and what this will lead into is also been not good for the medical.

Ann (13:52.894)
For sure.

Sue Marriott (14:05.478)
care that they've received.

Ann (14:07.53)
That makes a lot of sense. And it's not good for the person doing it, right? Like because it means that we're pushing away from the connection with that person. We're not learning, we're not open. And full self-disclosure on this. I ran into somebody a year and a half ago maybe who was talking about their long COVID and I could feel the fatigue, the chronic fatigue. And I could feel my internal desire to distance.

had a little bit of judgment about it. I hadn't read a lot, didn't know a lot about long COVID. So it didn't make sense to me. And so I was making up stories. And I think it also has to do with like having to sit in the unknown, I didn't know this, you know. It's terrifying. And I then learned a great deal more about it due to our own experiences with it. And I have sensed, really felt my regret.

Sue Marriott (14:51.073)
It's terrifying, yeah.

Ann (15:02.698)
for the distancing that I did from this individual. I didn't distance from them personally at all, but in the conversation, because I moved to my own dialogue in my head. And so I wasn't fully present in that conversation. And I have since revisited that because I missed out of connecting to him and learning about his experience. And then I wasn't there. And I think how many times has this probably happened over and over and over again to people who have not, you know, any kind of chronic kind of

Sue Marriott (15:09.653)
Mm-hmm.

Sue Marriott (15:13.23)
Mm-hmm.

Ann (15:32.434)
disease or chronic fatigue that can't be immediately pointed to, this is the cause.

Sue Marriott (15:38.046)

Yeah, when we don't understand, we fill it in. I really appreciate you sharing that. It's the most natural thing in the world. And again, that's why we want to talk about it, is like, we want to educate you if you have someone close to you, or if it's you, that this is an unconscious defense that you're met with right away, and people project this thing in. And so we wanted to say, one, that's normal, but it's also happened from the medical community, meaning...

Ann (15:40.348)
Yeah.

Ann (15:50.59)
Mm-hmm.

Ann (15:55.05)
Mm-hmm.

Ann (16:00.934)
Mm-hmm.

Sue Marriott (16:03.734)
People have not been interested in research. People have not been, it's affected. It's a way of thinking chronic fatigue. People think they know what fatigue means because who has them tired? Who doesn't wanna get up sometimes? Who doesn't wanna call in sick?

Ann (16:17.818)
Let's slow down and talk about that. What about, before we move on, like what is the S, what is different from just general fatigue and the kind of fatigue we're talking about?

Sue Marriott (16:28.53)
Right, right. So, cause I will forget what I was gonna say if I don't finish it, if it's okay. Just this one point, but hold your thing cause I wanna come right back to it. Oh shoot, I think I just forgot, hang on. Okay, that's right, that's right. So that it has been trivialized and marginalized in the medical world, which has, so patients have a hard time getting assessed at all because it's hard to assess.

Ann (16:34.491)
Okay, jump to it.

Ann (16:40.762)
You were talking about the fact that the medical.

Ann (16:50.52)
Mm-hmm.

Sue Marriott (16:56.71)

and also treated because it's extremely hard to treat. But long COVID has really changed that to some degree. So that ME slash CFS, some people are preferring to call it the encephalitis because it will evoke a different feeling from people and that it is more accurate. So I'm just saying that there is a controversy about the name, even calling it chronic fatigue syndrome.

invites minimalization. It invites a little bit of a trivialization because we think we know what it is. But to get to your question.

Ann (17:29.677)
Mm-hmm.

Ann (17:34.438)
And we misunderstand that, right? All we hear is the fatigue, right? And from what I understand, and you have so much more knowledge than I do, is that really long COVID has brought attention to something that's already existed, and that is serious fatigue that comes from post-infection. And prior to all of our knowledge about this virus, there's all sorts of other viruses that could lead to this kind of post-...

Sue Marriott (17:38.113)
Right.

Sue Marriott (17:53.71)
That's right.

Ann (18:04.09)
infection fatigue that we don't understand. But now that COVID has come out and it's so universal, it's helped bring attention to the need to look at this kind of fatigue. Right?

Sue Marriott (18:16.086)
to this community, to this ME community, right, that really needs it. And we won't get into this here, but there is a kind of a medical argument that's happening. And again, it tracks the same thing. So there are people and researchers that will say, the problem is you've gotten it in your head, that it's biopsychosocial. You've gotten it in your head that you're sick. So you're in bed and then your muscles weaken, and then you're afraid of movement. And so then...

Ann (18:39.786)
Mm-hmm.

Sue Marriott (18:44.906)
and you get depressed, which causes you to be in bed, and that what you really need is this graded exercise therapy. And you need to push past it, you need to push past it. That has been debunked. And...

Ann (18:57.192)

Mm-hmm.

Ann (19:01.066)
Because it's horrible. It's a horrible outcome for this, right?

Sue Marriott (19:04.222)
Right, well, it's very controversial. And again, not being in the medical world, I haven't read all this literature, all the caveats, but from my experience and from basically now what the United States and the UK and the Canadian medical groups now are congealing around this idea that it is not biopsychosocial, this is not depression, this is not just in your head, that it really is an inflammation of the brain in the spinal column.

Sometimes it causes joint pain. But the big hallmark sign of it is this, what they call post-exertion malaise. And by exertion, they're not talking about after you run your marathon, you're tired. Exertion can be taking a shower. Exertion can be a hard conversation. Exertion can be, like, it's things that, exertion is just almost existing. But especially if you do a little more,

the activity causes something disproportionate. So if I go to the store and go to the grocery store and stop at the vet and come home, I shouldn't be in bed for two days. That is the marker. It's where the exhaustion that it causes is completely out of proportion to the activity. That's really the hallmark.

Ann (20:14.335)
Hmm.

Ann (20:28.114)
That's what we're talking about when we're talking about a deep fatigue. It's not a normal fatigue. And I think it's like people describe it as like just pulling the plug out. Like there's zero gas in the tank. And I think it is also the most painful part of this and the interesting insight that I've had is that it's non-restorative, right? So you can have this fatigue for most of us. We can relate to that kind of fatigue. We've had a really long day. We come back, we're exhausted, we're fatigued. So we go rest or we go...

Sue Marriott (20:38.785)
Yep.

Ann (20:55.622)
take a nap or we sleep and then we wake up with a sense of a new start, of a restart. And this kind of fatigue is considered non-restorative. So you could go to sleep, you wake up and it's not regenerative. You could be even.

Sue Marriott (21:08.678)
Exactly. That's actually one of the hallmark markers, is that it affects your sleep. It's non-restorative sleep, just like you said. I think of like, you know, when you're jet-lagged and you

are sleepy when you're not supposed to be, and then you can't sleep when you're supposed to sleep, and your brain is miserable. That's kind of closer to, I think, how it feels, except that you don't get the kind of restoration that just a couple of good nights of sleep will give you on jet lag.

Ann (21:12.333)
Mm-hmm.

Ann (21:19.118)
Mm-hmm.

Sue Marriott (21:37.886)
The person that we know describes it as gravity being turned up by like a hundred times, like that their body feels so heavy that even sitting up sometimes can be difficult when they're having a bad experience, you know, bad day, which that's one of the other natures of it is it kind of comes and goes. So it's confusing because they can look good and they can, you know, sometimes look fine. But the nature of this disorder is that...

it's inflammation. So at times they won't be inflamed and they're up and moving and good. Another quick point is that the post-exertion, one of the things that they talk a lot about is boom and bust where they do too much, but they're getting away from that now around like doing too much might be these life activities. So you wanna be careful about not blaming the patient.

Ann (22:33.662)
Mm-hmm.

Sue Marriott (22:33.87)
for if they call it a crash, that's the post-exertion malaise. And so that's just a little bit of a fine point, but rather than thinking of it like, oh, you know, because pacing is one of the things like staying within your window of energy is an important part of this, but it changes, that window changes. And then also sometimes it shows up 12 hours, 24 hours later. So it's very, very difficult to do that.

Um, yeah. So.

Ann (23:04.33)
Mm-hmm. And very hard if you think about it, so if this is something you can relate to experiencing post-COVID, and you hadn't maybe attributed to the fact that you may have literally physiological inflammation. And again, we are not trying to say we know the causes of this. This is not our expertise. So this is the research we're reading. But really consider the fact that what may be happening to your body is real. And...

If you think about it too, those of you that have this, that's not you but somebody in your life and they've had good days, you get hopeful, oh good, we're on the other side of this. And then they have, you know, one of the days you're speaking about to kind of pay attention to how it feels

emotionally to you because you may be putting unconscious pressure on this person to wait, you were better, what happened? What happened? Let's track it down because we got to fix that. And that puts a lot of pressure.

on both of you to think that there's a specific answer out there that needs to be solved. The effect of that could be quite detrimental.

Sue Marriott (24:10.314)
Absolutely. And yeah, as a caretaker, that it is, you know, how do you get that right? How do you hit that right note? And yeah, because this is somewhat, again, a marker of it is that you're unable to do, you know, normal activities that you used to carry out easily, whether that be school or work or just your personal, you know, self care. And

Ann (24:19.976)
Mm-hmm.

Sue Marriott (24:38.634)
And then suddenly somebody who is active and able to do those things suddenly can't. So really, really complicated for the caregivers as well. So the markers basically, non-restorative sleep, the post-exertion malaise, and exactly impaired concentration memory is often. Another one is orthostatic intolerance, which basically means

Ann (24:42.835)
Mm-hmm.

Ann (24:57.99)
brain the memory problems

Sue Marriott (25:08.118)
that if you stand up too quickly, you're prone to dizziness, you're prone to even passing out. And yeah, so that, I mean, very serious, obviously not psychosomatic. It's clearly, clearly not psychosomatic. And I'm sorry, I'm just going on and on. Let me just say one more. They say that there's no markers, they say that there's no markers, but there are markers.

Ann (25:23.956)
Mm-hmm.

Ann (25:29.274)
No, keep going, keep going, you have a lot to go for.

Sue Marriott (25:35.302)
There's markers of different things. It's just a matter of how you look. So if you look into the literature now, the testing, your blood might look fine and even a normal MRI might look fine, but there are more fine measurements. Like there's a type of MRI, again, I'll have to post this, but

I'm not gonna be able to explain it. But basically it really looks at the microscopic, stuff that a regular MRI can't pick up.

Ann (26:04.803)
Mm-hmm.

Sue Marriott (26:04.814)
and it will show diffuse impact across the brain. And then another way they measure it is the post-exertion malaise in particular, you measure, you do some activity and you measure all the things, you know, heart rate and respiration and oxygen uptake, all those things. And you look the same, everybody looks the same, you know, within, right? Like, you can't tell somebody

has it from that first exercise. It's the next day when you do it again that a lot of those biomarkers are gonna be completely different than the person who doesn't have it. So that's one way that they test for it, but guess what? You don't really wanna clinically test for that because then you're causing that post, that is the aerobic problem. In other words, it makes the patient feel terrible. So it's usually diagnosed with interview.

Ann (26:59.53)
Mm-hmm.

Sue Marriott (27:02.886)
and careful history taking. And people who are familiar with it can really, I mean, that's one of the problems with the research is it's a little bit harder to find because you don't have that blood test or what have you.

Ann (27:16.574)
which is what, to your point earlier, which makes the medical research lag behind, right? Because we want to be able to point to this clinical marker and the improvement in it. And if that's how we get research funding, right? And when you can't exactly point to the clinical markers of, oh, and then we do A, B, and C, and it gets better, it's harder to get that much resources and interest. And yet what we're saying is how important it is, A, for us to understand it.

research it more, care about it more, because it's impacting so many people across the world.

Sue Marriott (27:51.394)
Totally, and you know, it's been interesting too, because physicians are people too, and we don't like to not understand something, and we don't like as people to, it's a challenge to join someone in helplessness when your whole career, your whole life, is built on helping people. So, that gets really tricky, and as a matter of fact, we.

Ann (27:58.064)
Mm-hmm.

Ann (28:12.583)
Right.

Sue Marriott (28:17.822)
And some of the treatment that I've seen, we have a local long COVID center here in Austin, Texas. Takes forever to get into it. But even once you get into it, the physicians will tell you that they used to follow patients more closely, but it was too hard on the physicians and the patients to have visits too close together and not be able to see change yet. So they put the sessions far apart, partly

Ann (28:41.394)
Mm-hmm.

Sue Marriott (28:45.41)
partly to take care of the physician and the nurses and the, like, that it's very disheartening when you pour everything into it and you try. But the changes that we see in this ME-CFS or the post-COVID that looks like that are very, very slow. They do, you know, there is hope for sure. Right, but more of that, I think the point I'm making is what kind of what you're saying, which is that it's very hard to...

Ann (29:04.038)
Yeah, there is improvement over time, right.

Sue Marriott (29:15.538)
just sit with the passivity and the helplessness. We really want to know and we really want to help. And that definitely affects the medical care and it affects how these patients are treated. And hopefully in hearing this podcast, we can widen your window of both believing the person and having compassion and being able to put yourself in their shoes. When I think about being taught, honestly, I was saying the other day,

Ann (29:17.168)
Mm-hmm.

Sue Marriott (29:43.378)
I fall asleep pretty easy and I sleep all night and I wake up feeling pretty good. I need to every morning that I wake up be grateful that all the magic that happens when you're in a circadian rhythm and all those things are working. And that might not always be the case. And you know what I'm saying?

Ann (30:02.61)
Right. I do, I do. That's how I have developed deeper, like even the example I talked about, I think about the gentleman that I spoke with. And I think about in my own personal experience, I feel very grateful for the amount of energy that I just hold. I guess you and I actually hold a lot of

just natural energy. And I feel so much more exponentially grateful that I have that even, you know, like, and I think about the times

the days and I think everybody can relate to that where you've so fatigued for whatever reason, you didn't sleep or jet lagged and I could think, oh, I can't wait to go to bed. I can't wait to sleep because I know what it is like post this to wake up and feel good and that generally is what happens for me, right? And so if I stop to really put myself in the place of people experiencing this and they don't get to wake up, they don't get to look forward actually to going to bed to wake up.

and to feel refreshed and that they are likely going to feel this, some people for a couple months, some people for six months, some 12, some 18 months, some longer, right? That that kind of fatigue and if you stop to really put yourself in that place, it can develop, it can help you really connect and feel empathy and not do well. You know, have you tried this? You know, think about that. Think about our tendency. We spoke about that earlier.

to try to be helpful and to show our care through giving advice or my friend had this and tried this. And when you have that kind of fatigued and everybody that comes close to you has this solution, it kind of implies that if you would be doing something different, like you were mentioning earlier, if you would just do something different, you wouldn't have this. And we don't mean to imply that, but that's what we do. And to slow down and go, oh, that's not the case. This is real. This is a post infection.

Sue Marriott (31:53.682)
and brain inflammation.

Ann (31:54.766)
and brain inflammation in your body and to show, wow, that is hard. And what we talk about in our podcast about all sorts of other ways of connecting to the people we care about, we want to really promote that here. That secure relating to people going through this is really allowing yourself to imagine the experience for you and to connect in what their experience is. Because it's different for everyone. We're talking about one particular manifestation, but there is a lot of different manifestations of this. So the core...

goal here is to listen and trust and believe somebody rather than to project ourselves into it and then start going by own experience, which impairs our ability to go, how is it for you? And what is it that you need? And really listening. And I think we also have to touch base with a lot of our Western culture judgment and stigma on people that are slower.

that whose physical manifestation is to slow down and our stigma of that and our pressure to get moving. And the fact that we can't point to particular things makes it really hard for those in the workforce, right? Like when you have a particular event and you're out for a week, your boss expects you to be back and be back to normal. And when you have this kind of disability and people don't understand it, it's an excuse to have judgment and push people out.

and not have care or provide the kind of support that people need to keep their jobs when they're experiencing this.

Sue Marriott (33:25.01)
Absolutely, and there's a large ME community. There's one of the things that has been helpful for some of the folks that I'm aware of that are struggling with this are these peer groups. There's Facebook groups, there's ways to connect. I liked what you said though about listening to the patient. I'm calling it patient, family member or.

Ann (33:49.658)
Yeah, listening to the person struggling with this. Yes.

Sue Marriott (33:50.846)
spouse or child or listening to the person struggling with this. Thank you. That's that feels a lot better, actually. And asking them what kind of support, what would support look like for you? And let them guide you. And again, yeah, to believe them.

Ann (34:03.466)
Mm-hmm

Ann (34:09.638)
And to ask them, you know, think about it. It's hard for me, you know, if I've had, if I've had something go on and somebody else has a similar thing, I can remember when I was running and I had an injury. And so now every time, and then I was able to get better through this one way. And every time somebody had it, oh, let me tell you, right? Let me tell you about this great thing that I went through. It's tempting because we care, but to go, I have had some experience, are you interested? Do you have any energy to hear? Because it's just my experience. And to be open and say, no, thank you, but thanks for sharing, but no.

and go, I got it, right? Rather than pushing forward and giving the advice without it being offered or without it being solicited or welcomed.

Sue Marriott (34:47.522)
Totally, and as a matter of fact, probably the way, another way to be supportive would be to know that the person who is struggling with it also sometimes doesn't believe themself, right? Like if you think about when you call in sick or something, I keep saying that, but you know, there's a part, yeah, you probably could have gotten up and gone to work. And there's a part that is tracking like, you know, I could have gone, you know, I feel like I'm a little bit leaning into this sickness. Well, even like when there's, you know, I always like to have a fever.

Ann (34:58.467)
Mm-hmm.

Sue Marriott (35:16.955)
if I'm sick because I can prove that like, okay, I have a fever so now I can rest.

Ann (35:21.138)
That is so true. That it really particularly to you, you have a really hard time trusting that you're sick and leaning into it. And without this feeling of, yeah, like am I faking it? Right.

Sue Marriott (35:24.506)
Oh, God. Yeah.

Sue Marriott (35:30.326)
Right, that I'm making it up or yeah, that's directly related to my history. But it's true and I think that other people experience the same thing of like knowing that on one level maybe I could do the thing. So the people that are struggling with this, they have that too. So you being able to support them in believing themselves and in listening to their body and maybe helping them track because tracking is a big part of it. But that would be a way to be supportive of like

really helping them come to accept. One of the treatments that they used to recommend, I mean, by used to, I mean, recently, this is still a little bit controversial. Like I said, it was that graded exercise that now they are not recommending for people, even long COVID with post exertional malaise, it can be counter indicated. But there's also, to push yourself right, that this is not a good idea when you have it. It can make you worse.

Ann (36:21.042)
Right, to push yourself, meaning it like, yeah, just. Mm-hmm.

Sue Marriott (36:27.542)
But also there was a CBT therapy that they were really pushing and saying that there was evidence for. That's, again, the controversy is that was not good science. You can certainly look into that yourself, but I think where people are settling is the CBT that they're talking about, CBT meaning cognitive behavioral therapy, was helping convince them that it was in their head, right? Helping them

Ann (36:52.97)
Mm-hmm.

Sue Marriott (36:55.554)
push past their own internal barriers, that also is contraindicated, because in fact, that's not the case. Now, CBT therapy that helps someone accept what's happening and understand it and get more in touch with their body and listen, that's different and that's certainly welcome. That's not when you hear people push back about CBT therapy for this, it's the kind of therapy where basically the therapist is really trying to convince you that it's in your head. It's terrible.

Ann (37:03.23)

Right.

Ann (37:25.286)
Right, and if you just push yourself and don't give in, there's this whole thing of don't give in, right? And if you don't give in and you push yourself, but I really taking time to educate myself, which is a fourth or a half as much as you've educated yourself, but a lot more than I was educated a year ago when I was having my biases, is to really understand that kind of push past the pain is actually so counterproductive to this.

Sue Marriott (37:29.25)
Bright, that's right. Just push, push.

Ann (37:54.798)
and could create a lot more rebound and detrimental long-term effects. So doing the kind of CBT to say, what is it like for you to really listen to your body and to trust it and to communicate with it and that in and of itself and think how much of us in general could learn that, right? Like getting out of that push past the pain thing that we promote in our culture in general to say to really listen to yourself. And then this fear that if you listen to yourself, you're gonna cause some kind of weakness.

in you and how much that is not actually true.

Sue Marriott (38:29.874)
Absolutely, and I love what you were just saying. This is actually a really important thing that I've learned, and which is, it's easy to feel sorry. We were just kind of working on developing our empathy and putting ourselves in the shoes of not being able to get restorative rest. And then, then you feel all this like, oh, that feels terrible, and which can cause us to sort of pity or feel like, right, like less than.

And here's the thing, in the world of disability, one of the ways, again, I can't represent this, but I am learning about it, that they really talk about is a lot of these folks have been movers and shakers and runners and goers. And there's stories of, I had to slow down and I had to listen to myself. And I began to look around and see all these crazy people running around.

and not knowing that they're not in touch with their bodies, not knowing what they're missing by being still and slow. So this kind of, it's a different ability that you tap into with this slowness. For example, maybe more spirituality, maybe grappling with who am I if I can't produce. Those kinds of big, deeper questions that wouldn't be

gotten to and explored without this. So I'm not saying that it's a good thing. It's not something somebody would choose, but it's more about like, don't assume that you know what it's like for that person. And maybe some of the things that they are gaining from it, so that, and that helps us kind of be humble around like, well, that could be us tomorrow, you know? We get restorative

sleep today, but who knows what's gonna happen in our future of abilities that we have now that we won't have then. It'll happen, even just with aging.

Ann (40:08.819)
Mm-hmm.

Ann (40:27.986)
Right, right, that's a really good point. And when you said earlier, it probably isn't something we wouldn't choose, that actually isn't always the case, right? That's the, that because I think about how I could relate to that as everything that so many people went through just with COVID and the isolation and the pulling out of our everyday pace, there was a loss in that for many of us. But then there was a huge gain in that we questioned.

the kind of pace that we kept in the world. And a lot of outgoing effect of that where people did change their lives. And I think to your point, when people have had to go through all sorts of, if they've lost their sight, their hearing, or this kind of energy level, they gained such insight that we don't have. They have all sorts of wisdom. So I think your point, I love that about, instead of having a pity, oh, I'm sorry for you, let's get you back to where you were before, is wait, let's listen.

Sue Marriott (41:25.152)
Right.

Ann (41:26.174)
Let's listen to where you are now. Connect to that and learn from it. What's it like? We could all learn to get out of this chronic pace of feeling guilty if we slow down, which is part of the effect of this, right? They have to slow down. They don't have a choice. Removing the guilt and also like, wow, what are you getting from that? And us learning from that instead of assuming that we're over here where we should be and we have to get them back there. It's, oh wow, having to really slow down welcomes all sorts of different parts of the.

of seeing the world that we wouldn't otherwise have.

Sue Marriott (41:56.59)
Totally, it makes me think of altered states or even psychedelics. You get in touch with something that is right there, right? But in a different state of mind, it looks and feels different and we gain access. So one of the things that, one of the books I've been reading lately, Brilliant Imperfection by Eli Claire. I can't remember what the subtitle, oh, Grappling with Cure. So what you said was,

Ann (42:04.677)
Mm-hmm.

Sue Marriott (42:26.434)

kind of getting them back to how they used to be. And that I love that you said that because yeah, the notion here is just what you were talking about, like coming to accept something you might not have chosen, and coming to accept that and then yeah, finding peace and being where you are and the advantages, and then being open to what's gonna happen in the future. We don't, it's not necessarily about getting back to where you were.

Ann (42:28.552)
Right.

Ann (42:38.772)
Mm-hmm.

Sue Marriott (42:55.166)
It's about growing from where you are today. And I think that that's actually really beautiful. And so the disability justice folks talk a lot about kind of the medical industrial complex and creating cure and like too much of a focus on cure. And I really have found that useful. And I think a lot of people with new chronic illnesses are gonna have to go through their own process of like, how do I adjust to this?

Ann (42:55.387)
Mm-hmm.

Ann (43:16.691)
Mm-hmm.

Sue Marriott (43:25.322)
And I'm saying chronic, the thing I don't want to, I'm afraid people are like, oh no, am I going to have this forever? You know, we don't know, but it definitely is not, you know, it's not a quick one. And some of the stuff they do know about ME-CFS is that it can be years. This is different necessarily from long COVID with post-exertional malaise. Is that the same thing? Hard to tell. But with the ME and the ME community,

Ann (43:31.482)
Right, right, we don't want to imply that, no. It's not, mm-hmm.

Ann (43:44.179)
Mm-hmm.

Sue Marriott (43:54.69)
You know, this, it can last for many, many years. And this is part of why, you know, it matters and it's affecting people. And we really want you to get the attention that you deserve and you to get funding for the research that needs to happen on this. And for you to be taken seriously by your medical doctors. That's our message.

Ann (44:15.49)
And for you to take yourself seriously to insist on being taken seriously. I think that's like to say and to also slow down for all of us and to kind of go, “oh, what is it that we in this experience as we accept it and we also work on being our best selves with it”. Part of that is just like, “oh, what are my, what are the opportunities that are being offered and not just seeing everything through the cure model?”

Sue Marriott (44:17.698)
- to believe yourself. That's right.

Ann (44:43.218)
Like what is here for me right now as I experience, what am I experiencing? And we all need to learn from that no matter what we're experiencing in our world to be able to slow down and go, we are here right now in this moment. Whether it's what we're experiencing or somebody we love and learning to do that just really exponentially adds to connection and care rather than - it's like being with somebody rather than that tempting, “oh, let me tell you about the doctor that I have.”

Sue Marriott (45:01.902)
That's right. Secure Relating.

Ann (45:12.446)
We're missing the moment of just being there with that person, which is, we know also is the most healing for us together.

Sue Marriott (45:19.422)
Right, and when you're the person that's down and you can feel somebody wanting to help so much, at least, I think for many of us that have been socialized to be caretakers, then we start taking care of them, right? Like, “oh no, I'm fine,” and “oh, I'm much better today than I was yesterday, right?” Then now not only am I sick, but the person who's trying to take care of me, I'm taken care of - don't put that labor on these folks.

Ann (45:40.678)
Right, I'm having to like assure them rather than just be with them. Yeah. That's really a good point. In our show notes today, by the way, I know we're covering a lot, but in those in our show notes for today's episode, we'll put a lot of the resources and references, including some support groups and things like that for you to be able to access.

Sue Marriott (46:04.014)
Absolutely. So thanks for listening everybody. And just love your people, whatever condition they're in, just love them, love yourself. Put your hand on your heart. That beating heart means you're human. And so are we and we're alike and together. And just really appreciate you listening.

Ann (46:26.154)
Thanks for listening and we'll see you around the bend.