

Brain Club®: The Podcast - S1E16 - ABB Behind the Scenes Part 1

TRANSCRIPT

Mel Houser: *Hello! Welcome to Brain Club: The Podcast, a space for learning, unlearning, and reimagining new ways of being together in neuro inclusive community. I'm Dr. Mel Houser, Executive Director of All Brains Belong Vermont.*

Brain Club is All Brains Belong's weekly community education program where we demonstrate our approach to neuro inclusive culture through community panels, guest speakers, and book chats. It's a place where we shift broader community awareness about the issues of concern and importance to neurodivergent people in our community and promote new ways of thinking and being in community together. It's a place where we transform culture by modeling what's possible. An invitation to think differently about health, connection and how we build systems that include everyone. Each episode features community panelists, sharing perspectives and lived experiences. We hope you'll listen with curiosity and reflect on what it brings up for your own life.

Everything here is for education purposes only and not medical advice. [00:01:00] Before we get started, our book is launching, *A Failure of Imagination: How the Healthcare System Fails Neurodivergent People*, and *What We're Doing Instead*. Visit allbrainsbelong.org/book to get your copy

In this episode, we're passing the mic to three of our Brain Club community moderators, Amy Noyes, Elizabeth Carney, and Mkazas. They're interviewing me for a behind-the-scenes look at All Brains Belong and our origin story.

I don't know what you're gonna ask me.

Amy Noyes: Yeah, so just to get, just to get started with that, first question, so many neurodivergent people end up in burnout and their employment becomes tenuous. I'm curious how you were able to create a nonprofit in the midst of autistic burnout.

Mel Houser: So I think, like, to answer that question, it requires, like, rewinding and capturing the emotional intensity of, like, [00:02:00] PDA fear. It's not just PDA rage. I feel like I talk about PDA rage, like, a lot. Like, rage is, like, an emotion that I feel on the regular, so I, like, name it and refer to it a lot. But fear is not an emotion that I mean, like, is anybody comfortable with fear? I don't know, but, like, I'm not. And so, like, I remember ... I mean, it's not, like, a cohesive movie that I watch in my head a lot, but, like, I have snapshots of it, of, like, the desperation of, like, what it is to be a PDA who is trapped in the corner, like, the caged animal in the corner.

It's not, like, a subtle phenomenon. And I don't ... I actually haven't ... I hadn't had that experience before because in general, as a PDAer, , I get the hell out of environments that are unsafe. I cut off so many relationships, like, "Oh, you? You're unsafe." , I've had relative privilege ... I mean, of, like, all my layers of privilege, that's one of my layers of privilege that I have in general been able to leave [00:03:00] relationships and leave environments that are unsafe for me.

It doesn't ... I don't do it immediately, and, like, it might take me a while to realize that, like, a job is unsafe or a relationship's unsafe or, or whatever. But, like, in this instance, this was, this is purely unambiguously dangerous for me and my family. And I have tried through the usual channels to advocate for myself and to, like, name my truth.

Elizabeth Carney: What you just described reminds me of something that Amy Noyes has said to me, and I think about it all the time now, which is, they said, "I need to do things that allow me to stay in choice."

Mel Houser: Ooh.

Elizabeth Carney: And I, and I really like that, and I really have tried to kind of, like, incorporate that into my thinking and framing of things because that is the difference between my nervous system being safe and my nervous [00:04:00] system feeling like it's in threat because I, it, the choices can be bad, but as long as I still get to make them.

Mel Houser: Yes. Yeah. Yes. So, like, the story of All Brains Belong is the story of not being in choice.

Amy Noyes: Mm.

Mel Houser: And that, for me, was the most unsafe I have ever felt.

Elizabeth Carney: Say more about that.

Mel Houser: It's COVID. And we, as a pool of five doctors, the three doctors who were under 70 years old decided we would cover the hospital, and we would have the two older doctors over 70, not be in the call pool.

So we were three people covering our patients in the hospital. So it was 24-hour, seven-day straight call. Yeah. We decided that it'd be better to do that because we thought we were all gonna get COVID, and we thought that the-

Elizabeth Carney: Oh, yeah. ...

Mel Houser: thing that could happen is for us to get COVID and then have [00:05:00] someone have to do extra call.

So we're gonna take seven days straight and then have two weeks of clinic. If we get COVID, we're gonna present in week two during clinic, not in hospital call.

Elizabeth Carney: Yeah. Wow.

Mel Houser: And we will hopefully recovered by the time it's time to go back and do it again. So we did that and we didn't know. We didn't know how long it was gonna last.

Elizabeth Carney: Yeah.

Mel Houser: All of a sudden, it's been, like, a year and a half, and we're, like, still doing that.

Elizabeth Carney: Oh, yeah.

Mel Houser: So I'd be, like, getting called at 2:00 in the morning and I'd have to go into the hospital and, like, admit a sick patient and, like, think I'm gonna get COVID. I would love to capture ... And it's interesting, like, in the book-

Amy Noyes: mm-hmm.

Mel Houser: I feel disingenuous not telling this story because it feels like you can't really get it if you don't know the story.

Amy Noyes: Yeah.

Mel Houser: And, like, the core of the story is that when I advocated to say, "It's not safe for me to be awake twenty four seven for a week at a time, I was told not only you're not fulfilling your [00:06:00] contract, but I was given a letter we are concerned about your psychiatric health."

Amy Noyes: Wow.

Mel Houser: That's the moment. That's the PDA-

Amy Noyes: Wow.

Mel Houser: ... Rage and fear. So it's not- Yeah. ... I'm afraid of getting COVID and it's not-

Amy Noyes: Wow.

Mel Houser: ... I'm afraid of get- of whatever. I have to figure out some way of telling that because the intensity of that is what says-

Amy Noyes: mm-hmm. ...

Mel Houser: I don't care that I'm in burnout.

I need out.

Amy Noyes: Yeah.

Mel Houser: This isn't safe for me. The expectations on me are so incompatible with not just living the li- the life I want to live, but it's, like, incompatible with, like, surviving.

Amy Noyes: Mm.

Mel Houser: Be able to tell me, you know, you need to, you know, you're gonna cover the hospital indefinitely 24 hours, seven days straight for the-

Amy Noyes: Yeah.

Mel Houser: basically indefinitely, and I don't care that you ran your car off the road, and I don't care that you're flipping your lid at your family, and I don't [00:07:00] care that you're telling me you don't like it, and you, I don't care how you feel. Oh, by the way, you have to, or you don't have a job anymore. That's what they said.

Amy Noyes: Well, and just knowing you, as much as I know you, as my physician, as, you know, in community and, like, in your leadership style, to, that is, like, so tearing at the core value of basically, like, of who you are incredible.

Mel Houser: You see, like, tearfulness. It's, like, the intention of it all. Yeah.

Amy Noyes: That's what, that's what I'm want- that's the part of the curiosity. And I mean, that, that's what was, that's why the question came to me because I knew so many pieces of the story. And I also know in terms
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of how protective you are of the practice and All Brains Belong, like, I knew that, like, there was some protective piece of, like, what you're doing.

So I knew, but I think for me, what is astonishing is the sort of rising of the Phoenix or something, you know, like, [00:08:00] out of the burning of the ashes of burning all of that down, saying, "No, I know that not only do I need my needs met as a physician, but I know there's patients, I know my patients, and I know my patients are not getting the care they need."

Mel Houser: What I was gonna say is, like, I felt like at that time, I was able to provide medical care in, like- Yeah. ... the way that was, like, the, the way that was expected. Like, I was able to provide medical care in a way that, like, the patients got what they need from me.

Amy Noyes: Mm-hmm.

Mel Houser: But I could see, I could, like, forecast that, like, this is not sustainable.

This, like, I don't ever want to be in a place where I can't provide medical care because I, I really thought I was gonna die.

Amy Noyes: Yeah.

Mel Houser: Like, I really don't.

Amy Noyes: That's the part for about the, the question is sort of, like, because I know what it feels like. I thought I was gonna die too, in that, that big, the big burnout, because, like, probably you could map out all the little, you know, like, the big burnouts at the time, but this, but to [00:09:00] me, if, like, the autism diagnosis and, like, that kind of burnout is the burnout of, like, I have to change something or I'm gonna die.

Mel Houser: I'm just gonna die.

Amy Noyes: Mm-hmm.

Mel Houser: I don't know the mechanism, but, like, this, this, I just know that this is not, this- Self-sustainable. ... not sustainable. I'm like, what does it mean to, like, not be sustainable? I just, like, I don't know, I thought I'd have a heart attack or stroke. I, like, thought that that was gonna be happening and I was definitely gonna get COVID.

I need to not die. I need to not bring COVID home to my baby.

Amy Noyes: Mm-hmm.

Mel Houser: That was my truth and then, like, the deep shame of, like, I hope they don't find me out that, like, I care more about not dying.

Amy Noyes: What, your story to me is just so representative of how, um, prior to, like, burnout, prior to this, like, your story is representing, um, how much PDA is a protector is, is such a deep protection.

Mel Houser: Yes. I deeply feel that because it's, um, you know, I think there's, like, levels of bur- like, there's a burnout experience and then there's the PDA rage fear [00:10:00] involuntary limbic response to activate. I didn't start all brains belong in dorsal vagal shutdown. I was in activation because I had to be. And when I was in dorsal vagal shutdown, I was not starting all brains belong.

When I was first threatened by my employer, I was in dorsal vagal shutdown, and I lost the ability to speak and brush my teeth and leave my chair and all of that. And, like, I've told that story.

Amy Noyes: Mm-hmm.

Mel Houser: But , I think it's difficult to appreciate how I got there without the backstory.

Amy Noyes: Yes. I agree.

Mel Houser: I can literally count on one hand the number of times I've been in true dorsal vagal shutdown.

Amy Noyes: Mm-hmm.

Mel Houser: It's, it's an experience that I think my PDA keeps me out of a lot of the time because I don't tolerate it. I don't tolerate it. It feels terrible.

I'll, like, be in it for a day or two and then I'll pattern match it and be like, "Oh, no, not that again."

Amy Noyes: Yeah.

Mel Houser: And, like, anyway, I, I think that that experience is probably relatable [00:11:00] to other people.

Amy Noyes: Mm-hmm.

Mel Houser: But, like, I go right to activation. I live in sympathetic activation. I live here.

Amy Noyes: Yeah.

Mel Houser: I live here. Yeah. So, so to tell the story of, like, how'd you start All Brains Belong while you were, like, so dysregulated, it's because I live in sympathetic activation.

Amy Noyes: Yeah. Oh, yeah. Yeah. That makes a lot of sense.

Mel Houser: I may as well start a nonprofit.

Sympathetic

Mkazas: overdrive. Yeah. And, and navigating that.

And we all know, like, finally there's words that, you know, and all the special different methods of limbic system retraining that are out there and all of the, like, coherent things that are finally being talked about and, and, like, um, you know, how to fix ourselves, right? Like, there's, there's these, all these new ways to fix ourselves.

Mel Houser: I have such a limbic response to that stuff. I don't wanna retrain my nervous system. My nervous system is, like, what keeps me alive.

Mkazas: It's like, how do you [00:12:00] navigate your own limbic system and, like, you know, sympathetic isn't always bad and parasympathetic isn't always bad. Like, they're really important places to be-

Mel Houser: Yeah.

Mkazas: and cultivate safety inside of, and we've been taught to not trust them.

Mel Houser: When I notice my nervous system, I have trained myself to assume that my sympathetic nervous system is not reacting to me. It's reacting to my environment, so sometimes that becomes a clue that something is unsafe-

Mkazas: Right.

Mel Houser: ... Even before I cognitively know.

Mkazas: Right.

Mel Houser: A lot of times I know already, you know, like, Medicaid, you're unsafe. Cognitively, I know that, but, like, if I get going about it, I [00:13:00] don't ... I get, I notice that I'm, like, I'm doing the fight thing, I'm emailing, I'm talking, I'm telling the story, I'm doing the thing, I'm writing letters, and then I crash.

Oh, I have an energy disorder. I can't spend my energy this way. It's not because my sympathetic nervous system did the wrong thing. Right. It's that I don't feel ... I I don't feel my internal body signals the way that other people do. And so I overshoot and I overspend energy.

How do I manage that? Like, I just know it's a thing. Try to do better next time, try to sort of, like, have an awareness of, like, oh, you can't talk about Medicaid for an hour. You can only talk about Medicaid for 45 minutes or or whatever. Can't talk about Medicaid all day. Also ... I sort of tolerate sympathetic overactivation.

I don't tolerate dorsal vagal [00:14:00] shutdown. I don't tolerate that feeling of, like, numbness, dissociation, crashing. I don't, I don't tolerate that feeling. I hate it. I find it so just, I don't have any skills in it. I just, I, I, I hate it. So when I'm in sympathetic overdrive, I'm like, great, I can do something with this.

So I, like, try to be in a state of agency all the time, which is counteractive, like, pacing and, you know, all of that. So at least I, like, try to be laying flat while I'm act- like, while I'm doing stuff to cope with my sympathetic overdrive. I think maybe that's another thing I do.

Mkazas: Yeah. I mean, that ... It sounds like on a certain level, you're saying, like, you know, being in that sympathetic state is, is your body telling you, "We need to put some energy here because this thing is really important."

Mel Houser: Yeah.

Mkazas: And sometimes it's, like, a thing you want to put energy in, um, and other times it's a thing that you have to put energy in and you know it's gonna make you crash. Yeah. And you don't really have a [00:15:00] choice, but you have to do it. And then other times, you can be like, you know, "Getting into this state is gonna give me energy to get to the next part of my day."

Mel Houser: Yeah. Yeah.

Mkazas: Energy for because I'm not gonna have energy for. So if I jack myself up now, then I'm gonna be able to get through it, and then I'll be able to calm down and maybe not trash as hard.

Mel Houser: Yes, I agree. The other thing is I still have collected clues after the crash. I am able to reflect and be like, "Actually, these are not all the same, so I'm gonna pick and choose."

Like, I don't go to school, like, patient school meetings anymore, because my heart rate's 200, because my autonomic nervous system says that everything to do with that situation is unsafe. It actually doesn't help my patient. It just hurts my health and my ability to care for other patients and my family and myself, so I don't go.

Elizabeth Carney: I feel like Brain Club, in a microcosm, is kind of, is a lot like that [00:16:00] because I feel like it's a continuous discovery of, like, "Oh, right, this thing doesn't work for me. I need to let go of it and turn towards this thing does work for me and I can go towards this thing." And it seems to happen both, like, naturally and instinctually and, and it all has to kind of do with remembering what you're getting back in touch with your gut and what your gut is telling you.

Mel Houser: Yes. That is, like, I think for me, like, the biggest thing of whatever this journey of the past three and a half years has been or four years, four years since my autism diagnosis, yeah, that was four years last month. So it's gotta be ... I mean, it has not been all or nothing, but, like, the practice of when I have some intentional top-down cognitive awareness-

Elizabeth Carney: Mm.

Mel Houser: it's like, "Oh, I'm gonna work on intuition. Oh, that [00:17:00] means I have to actually go with my gut every time, over, over, and over again." And, like, I am going to, "Oh, uh, that doesn't, I don't know. I don't trust it. I'm, so I gotta ask 50,000 people and get their consultation on, like, whether I should do the thing that is safe for me and avoid the thing that is unsafe for me.

And I'm like, now, like, my, I first go with my gut and then, like, you know, I actually probably need to do some problem solving. I'll reach out for help. But because I am so, um, what's the word? I'm so used to, or I'm so, like, acclimated to sympathetic activation or sympathetic overdrive, I can do stuff in this place.

Amy Noyes: The thing that is occurring to me was, like, w- I wonder in that dorsal vagal shutdown, there's silence. So you're, like, in t- t- total opposite movement than the [00:18:00] sympathetic. And I'm wondering in that, if it actually forced rest for you and then in that the inspiration, like, the energy could come-

Mel Houser: No.

Amy Noyes: ... Because... no? Okay.

Mel Houser: That happens a lot. I just knew I didn't tolerate this state and I, I had ... In many ways, I mean, the other thing that's important about this is that I got my autism diagnosis during that dorsal vagal shutdown. So I got my autism about diagnosis in that week.

Amy Noyes: Yeah. Okay.

Mel Houser: So, like, dorsal vagal shutdown, I don't tolerate this. I don't know why my body doesn't move and I don't ... Now I have this, like, you know, the way, the way that people describe, you know, like the eureka moment and the kaleido-

Amy Noyes: Yeah. .

Mel Houser: .. Scope and the rainbow and the, you know, like, you know, so that happens. Yeah. And then I'm like, "Well, this is not sustainable. I have to have a job. I have student loans and a mortgage and a baby and, like, I gotta do something." And, like, PDA in the background of, [00:19:00] like, I'm gonna shut you down now

because you're com- you know, it's the computer blue screen of death, that's what dorsoleg shutdown is, I think.

Amy Noyes: Yeah.

Mel Houser: So PDA shuts, you know, I'm gonna shut you down because you're s- you're feeling so unsafe in a way that, like, not

I mean, I wouldn't say that, like, not a lot of nervous systems would feel unsafe in this situation. I think that probably most nervous systems would feel unsafe in this situation. Yeah. Um, but, so I'm not like, "Oh, this was a disproportionate response." I also don't care if it was a disproportionate response because it was my response.

Amy Noyes: Yeah.

Mel Houser: The PDA shut down. And then I think your point about, like, you know, I needed to rest. It didn't feel like rest. It felt like the computer's gonna catch on fire. It's like the surge protector.

Amy Noyes: Yeah.

Mel Houser: The surge protector is what I think dorsal vagal shutdown is for me. Mm-hmm. So surge protector goes, the circuit blows, I'm shut down, and then, like, in the background, I have to, like, my ADHD, and, like, I don't necessarily think that it's helpful to, like, parse out, like, this is my autism, this is--

Amy Noyes: Yeah.

Mel Houser: But, like, instance, this is my ADHD that is rapidly IDA all the time in a way that is-

Amy Noyes: [00:20:00] Yeah.

Mel Houser: ... Generally distracting to me and, like, generally, I don't, at that time, I, like, didn't have, like, a place for it, but, like, that's the part of me that saved my life. Yeah. Yeah. And then I could, you know, the autistic make a list and follow it thing, like, I could do that.

I just had to, like, have the idea first of, like-

Amy Noyes: Yeah.

Mel Houser: .

.. Needs to happen. This needs to happen. And the other thing that was important about that is I -- there were, like, different components that needed to be met. So one is I need to, like, pay my student loans and my mortgage, two is that I knew I've never run a practice and I never wanted to run a practice, but I, like, kinda knew kinda what the components were.

So I didn't have to, like ... When you say, like, had you do this in burnout, I wasn't, like, starting from complete scratch. Like, I, I'd had some training in practice management.

Amy Noyes: Okay.

Mel Houser: I, like, knew that, like, if you bill insurance, you could, like, probably figure out how much the insurance pays you, and, like, you could look it up [00:21:00] on their website. I kinda, like, knew that that was maybe a thing. I've never done it before, but, like-

Amy Noyes: What I wanna just reiterate was, you know, it's interesting because, like, I might have my experience of the burnout and the, like, what I might call, like, a still small voice because mine, my ADHD wasn't forward at the time because I was still so much in sympathetic.

But that's what I was wondering was, like, in the midst of this, like, dorsal shutdown, I didn't know that that had gotten to that point, but I knew there was this, you know, leaving your job and coming in to s- to then say, "I'm gonna start this. " But I think what's so amazing, I think, to think about people at Brain Club and think about that story and think about that, um, the way in which we could doubt ourselves in the midst of what the world is telling us. Like, "I'm worried, Mel, I'm worried about you." I'm, like, this, like, outside, like, instead of listening to you, instead of hearing you, instead of trusting you, and have been able to help me pull out that, that voice [00:22:00] that was chattering to me that I didn't have the confidence to listen to.

Mel Houser: Yeah.

Amy Noyes: And there's something, it's extraordinary about the way that you were able to shift into what you knew, so that you know I, you know, I'm a good doctor, you, I know I can do this, and that chattering came forward, you were able to listen to it. And I just wonder how many people might have that chatter that can't listen to it because of the way the world has treated them.

Mel Houser: Absolutely. And I feel like I have to name another layer of privilege because of the nature of the kind of job that I happen to have, that I happen to have, which of course is, like, on the basis of, like, so, so I'm white, I went to college. Yes, I have, you know, half, I have a half a million dollars in student loans, but, like, I went to college, so, like, already, I am more likely to have access to medical school than other people.

Amy Noyes: Yeah.

Mel Houser: , So I, because of the nature of the job that I, and a career I end up, I, it's hard to say choosing because I, because I, this [00:23:00] honored privilege that got me here, but, like, because of the nature of the job that I have- mm-hmm. ... my job is the kind of thing that insurance companies pay for. Yeah. But, like, already, I didn't have to do the un- the little voice that says you can't do it.

I didn't really ... I mean, I had that voice. I always have that voice, but, like-

Amy Noyes: Yeah.

Mel Houser: ... I don't care about it because I have a thing that I could bill an insurance company for because of what my job is. If my job were something else- Yeah. ... It would not have happened so quickly. Also, I have a v- I have an intolerance for delayed gratification.

So most people who start a small business, , it's the long game, right? Like, think about how long it has taken, right? So, like, all the things, right? So me, I took two weeks off from work. I took FMLA and I started a nonprofit.

Amy Noyes: Yeah, that's what I'm saying.

Mel Houser: Because I had to.

Amy Noyes: Yeah.

Mel Houser: I have two weeks.

You know, I also had the privilege of being able to save. I kinda calculated, not me calculated because I discalculia, but, like, I asked my husband, like, how many weeks can I go without working? And, you know, I could, I could go a few months, so it was very [00:24:00] urgent.

Amy Noyes: Last question. What role does patient autonomy play in your model of care and how do you support informed co- collaborative decision-making with your patients?

Mel Houser: Oh my gosh, I love that so much. I would say, like, rewinding, patient autonomy has ... I'm not even sure, like, how it all began. I don't remember, but patient autonomy, maybe that's just as a PDA, or I didn't ever make that connection before. Patient autonomy has been, like, the most important thing to me, like, through all my training and, and beyond.

And when I saw it being violated, I would rage and I would rage at individuals who didn't even know they were doing it. They were just, like, doing system stuff, like, "Oh, you know, we're gonna, like, take it to the, to surgery, sign this form." Like, oh my God, they have no idea what you're about to do. They have no idea.

Amy Noyes: Yeah.

Mel Houser: So I'd, like, see stuff like that. Or I'd be like, "Well, you know, here's your pill. Go and take it. " And, and I'd see that [00:25:00] and be like, "They don't know what it is, let alone what do they wanna take it? " Like, I would f- I would rage as, like, a little first-year medical student. I would rage about this all the time.

And when you, like, look at my blog from medical school, it's, like, raging about the violation of patient autonomy. That's what the blog's about. So I'd say that that's, like, a, a, a, a premise or a preface to your, to my answer to your question. So, so historically, even though I think that there are a lot, like, I have a certification in motivational interviewing.

I think by and large, motivational interviewing is not neuro-inclusive, at least in the way that it is mostly delivered in that, you know, reliance on open-ended questions, for example, maybe that's just the one part. Reliance on open-ended questions and the glorification of open-ended questions, I think, it doesn't reach all brains.

But my motivational interviewing training was essentially a respect for patient autonomy. So if you truly believe in patient autonomy, you are not [00:26:00] attached to the outcome of behavioral change. You are not attached to the outcome of, for example, does someone quit smoking. All you are attached to is whether you showed up as a clinician and engaged and engaged in the, in the relationship, essentially.

Amy Noyes: Mm-hmm.

Mel Houser: And I was like, "Oh my gosh, that's amazing." So that was really helpful as I did my certification during residency. So I did it in training, which was very helpful because that, that wasn't always the messaging being given-

Amy Noyes: Yeah.

Mel Houser: ... Of that you're not attached to the outcome. And, like, what is that that's, that's, like, PDA sweet spot of, like, energetically I'm in the room with you and I don't care whether you change your behavior.

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I'm not trying to control you.

Amy Noyes: Right.

Mel Houser: I just wanna engage in the relationship and, like, make some reflective comments and not ask open-ended questions, but, like, skip that part and, and do the declarative language stuff of, like, you know, sounds like you don't really [00:27:00] wanna stop eating gluten. And if somebody else-

If somebody stops eating gluten, I don't care.

Amy Noyes: Mm-hmm.

Mel Houser: I mean, I want, I mean, I think I'm, I'm, I'm attached to the outcome of you having a good life, but, like, if you don't wanna stop eating gluten, there's probably some good reasons for that. Like, legitimately, I'm not gaining you. I'm not tricking you.

Amy Noyes: Mm-hmm.

Mel Houser: I literally don't care if you stop eating gluten.

Amy Noyes: Mm-hmm.

Mel Houser: So, like, that distinction of I'm attached to you having a good life, I am not attached to you following what comes out of my mouth.

Amy Noyes: Yeah.

Mel Houser: Like, that is an important distinction to me that I have always felt and that I, you know, I think is, like, very much a part of this.

And it's like, when people, like, they wanna be taught what to do for PDA, it's like, you have to get to that place. Mm-hmm. And nur- like, people who are ... I don't know. I, I think when people are not PDAers themselves, they don't really actually understand that. Yeah. They do have, like, I can be in a room with someone, including with a patient.

And a patient's trying to get me to change my behavior, I can feel that in an email-

Amy Noyes: mm-hmm.

Mel Houser: ... And it feels unsafe. Mm-hmm. And, you [00:28:00] know, I get it. I get why you're trying to get me to change my behavior, but, like, my, my limbic system actually regards this email is unsafe.

Amy Noyes: Yeah.

'Cause I mean, I just had an appointment with Sierra and I just said, we're making some decisions around my health.

And I said, "I think we need to make this one decision because I know that I'm not gonna ... Like, I have ARFID and I'm in constant pain. So I know I can't make the other changes, so I think we're gonna do the, make this decision based on I know I'm not gonna be able to change my behavior." And it was just like, that makes so much sense, right?

And so I think what's interesting to me being a patient, and I'm curious, like, what you'll say about this is I feel so informed. I feel like even if you care if I stop eating gluten or not or, you know, whatever, the thing is, is that regardless of the choice I'm making, you will give me the information.

It's almost like you'll strew the information or you'll, like, you know ... And so maybe I'm not making that decision today, but all of a sudden in six months, I can just [00:29:00] notice I'm making, I'm ma- I'm changing that decision, but not because you told me, but because I made the connection for myself.

Mel Houser: That's so interesting that you say that.

That's so interesting. I feel like the difference between a strew and what I think I'm doing, and, like, maybe it's not perceived this way, but I'm not gaming you.

Amy Noyes: Yeah.

Mel Houser: I'm not strewing. I don't know what ... I didn't talk to Sierra. I have no idea what you talked about, but, it's not ... sometimes I strew. I strew a lot of things. When I strewed to Zachary, I'm like, "You know, it might rain. There's a coat in the car."

Amy Noyes: That's true. Mm-hmm.

Mel Houser: I'm hoping they wear the ... Like, I am attached. I actually legitimately want them to wear their raincoat.

Amy Noyes: Mm-hmm.

Mel Houser: What I'm mostly doing is informing is, like, I wanna, I want you to know everything-

Amy Noyes: Yeah.

Mel Houser: I know about a thing, otherwise I don't feel like I'm engaging in a complete informed consent discussion. I actually get, I used to [00:30:00] get, like, negative reviews on, when I was a medical student, because supervising residents would be like, "Why are you taking so long to, consent the patient?" Consent is not a verb that describes what I am doing.

Amy Noyes: Mm-hmm.

Mel Houser: I am, it's ... Attempting to elicit consent, I am seeking to provide information for a patient to provide consent.

Amy Noyes: Mm-hmm.

Mel Houser: I am not consenting the patient.

Amy Noyes: Mm-hmm.

Mel Houser: And that is a cultural clash that I have-

Amy Noyes: Yeah.

Mel Houser: ... felt. And so-

Amy Noyes: Yeah. ...

Mel Houser: sometimes people are, like, sometimes, if I don't have foot on the gas, which is rare, but, like, if I don't have foot on the gas, I might be like, "How much information do you want about this?"

But, like, mostly I forget to do that and I info dump because, you know, I do that, like, that is a thing that I do. And so some of informing is, like, I'm info dumping and I don't realize I'm doing it. Oops, sorry, now you're overwhelmed. So, like, I have to also monitor that, but I'm not sure. I feel like I'm-

Amy Noyes: The [00:31:00] interesting thing for me, and what, maybe why I use the word strew, because it doesn't, I don't necessarily feel like you are strew.

Like, I don't, if that implies, like, you're trying to get me to change, I might feel like maybe it's strewing to me that, because it's just information coming. So maybe that's just more of, like, what ... Yeah, maybe it's just sort of, like, my perception, because normally the patient, normally the doctor's just like, "Take this medication," doesn't give you information.

Then you're having to go home and Google, like, why am I taking this medication? Then you're on, like, I know why I'm on every single one of my medications. And there's been times where I haven't been able to take my medications, but I can come to you and say, "I have a PDA response to taking my medications," you know, and then I get to figure it out.

It's like, I, oh, I shift my big pills to the night because I can't take them in the morning because I feel ... You know what I mean? Like, I start shifting it around, but it's partly because I know the importance. And then if I look at the pills, I know which ones to take. If I have to take one pill, I know what one of your pills-

Mel Houser: Prioritize because you know what they are.

Amy Noyes: Because I know what they are. And so for me, I think in my [00:32:00] PDA response to self-care for whatever those things, it might feel like, "Oh, I'm strewing the information you've given me. " Yeah. Not that you're doing that.

Mel Houser: Oh, that's interesting.

Amy Noyes: In order to get myself to ... Yeah, so that's the experience I have is it feels like, oh, this isn't the, a demand.

This is like, okay, well, we just know if you don't take your guanfacine, you're gonna lose speech in three, in five days- Right. ... because we've had, I've had that experience

Mel Houser: Right. So- Matter of fact, it's neutral language. Yeah. It's neutral- It's neutral. There is no energy. It's like, yeah, it sound- Yeah. You know, I like remember last year that, um, you know, when you stopped taking your guanfacine five days later, you lost the ability to speak, you know?

Amy Noyes: Yeah. And you can remind me in that because it's a rel- it feels more of like a connection relationally than it does, like, you're this authority figure powering over me.

Mel Houser: Yes.

Amy Noyes: And so, yeah, anyway, I just, I, I just feel like you're collaborative decision making with patients because I s- I've not, I've not just witnessed it with myself, I wish, witnessed it with other people., I'm just so, so [00:33:00] curious about that.

Mel Houser: Yeah, it's interesting. Like, I think that maybe when something I'm, like, working on or thinking about because Sierra, because now Sierra and I do a lot of groups together, and so it's, like, cool that, like, I think Sierra's amazing and I'm so grateful that, you know, she's my child's clinician.

Anyway, but it, and it's cool to also see different styles, like, energetically, Sierra comes from the same place as me, but her, um, her style of doing it is differently and I think that Sierra, one of the places that Sierra does a much better job than I do, I think, is, um, when people are overwhelmed, I am an all or nothing patient autonomy flag waiver, and I tend to say, "Here are some options I can think about.

Here are, like, the two or three options that I, I might choose in your [00:34:00] situation. Which are you leaning toward? And we can talk about it. " Sierra asks another layer, "Do you, do you wanna decide? Do you want me to decide? Do you want us to decide together?"

Which is like, "Huh, that's so interesting." We're just like, "That would never even occurred to me. "

Amy Noyes: So I think what I think about in terms of, like, medicine or, you know, the diagnoses or any of those kinds of things is so important, even if they are technically disorders. What I'm saying to you is that when you and Sierra treat, and anyone at All Brains Belong doesn't treat me as a disorder for having those things.

And I think that is fundamentally the difference between traditional healthcare and when you go to a traditional healthcare, it's like, what did you do to cause the, like, the energy of it? And, you know, it's like, go lose weight and exercise and then come back and talk to me. That's how I always was, like, if I got my hands dirty as a little kid, it's like, "Go get really dirty and then come back and talk to me.

Like, you're too sensitive, you're too this, you're too..." [00:35:00] And when you come here and you can actually be honest about what your experience is because you know you're not gonna be seen as a disorder, you're not gonna be pathologized is, that to me is radical.

Mel Houser: Thank you again to Amy Noyes, Elizabeth Carney, and Mkazas, not only for this interview, but for the past two years as community moderators and stewards of the Brain Club program. Join us in two weeks for our next episode, part two of this interview, where we talk about ABB's systems for gathering feedback, making decisions, shifting power, and supporting staff and patients to thrive

If you wanna keep exploring with us, you can join our Live Brain Club events most Tuesdays at 6:00 PM Eastern. You can also dig into our free digital resource library with all the recordings from the past four years at allbrainsbelong.org.

You're not alone, and we're glad you're here. See you next time.