

The Accessible Stall Podcast

Episode 65: Disability Sucks (Sometimes)

E: Hi I'm Emily Ladau

K: And I'm Kyle Khachadurian

E: And you're listening to another episode of *The Accessible Stall*

K: Emily we've got some business to take care of!

E: What's that?

K: We have to tell these people how they can support our show!

E: So there are a couple ways that they can do that!

K: You can go to our Patreon page at www.patreon.com/theaccessiblestall and just one dollar a month guarantees that all of our episodes from here on out are transcribed! Or...

E: You can rate us on iTunes, whoo!

K: Or like us on Facebook, or follow us on Twitter! Or, if you really like us you can do all of those things!

E: But Patreon is probably the most important because all of the money goes to making *The Accessible Stall*, accessible!

K: Plus our transcriber needs to eat, so yeah

E: Yeah

K: Anyway, what are we gonna talk about today, Emily?

E: Disability really sucks sometimes

K: Oh my God, I'm so glad you said that because I've been having a horrible CP week and it's just so much. And we always try to be positive on this show and sometimes...

E: Do we?

K: Well we try to be real. And this is real.

E: You know, I feel like I exist in this weird balance where I don't want to act like my life is sad or difficult because I don't want people to pity me or think that I'm inspiring for getting out of bed in the morning, but then I get mad when people don't realize how difficult things can be for me and so I exist in the in between of this. And so basically I've just decided to not complain to anybody about how much disability can actually suck.

K: Unless they get it. Because I do the same thing unless I know that they're ether okay or they have a disability themselves, like then I complain a lot.

E: LIke we complain to each other all the time, like Kyle messaged me the other day and he was like, "I really just want you to know that my butt hurts."

K: It really did hurt, it was bad. And it had no reason for it at all. I get in a similar situation like if I'm on a bus and I'm struggling, and somebody notices it and someone gets up. It almost never happens so when it does I take it. But then , immediately as soon as my butt hits the seat I'm like, "Wait a minute! You saw me! You're not supposed to see me! You're supposed to treat me like everyone else, you wouldn't have gotten up for anyone else." And it's like, it's so weird because on the one hand, I wanna get angry at that, but on the other hand it's like, "No, I needed the seat though!"

E: Yeah, I don't need people to give up their seats for me, and it's not like I'm riding The Struggle Bus.

K: I mean, you carry your seat around with you.

E: I do. But for me Disability sucks more because I'm constantly in pain, and I'm constantly running into access issues, and people are constantly making annoying comments, so when you add up all of those things it's kind of a shit show.

K: It's kinda like, it is a bit of miracle that you got out of bed in the morning isn't it? You don't want anyone else to know that, you just wanna do it

E: Well part of that is because I'm not a morning person...

K: Well yeah, but you know what I mean. You don't want to be called inspiring but if you knew the night she had, you would think, "Wow that actually is inspiring!"

E: Yeah that's real. Because I actually sometimes wake up in more pain than I go to sleep in.

K: Oh my God, I hate that, me too man!

E: And then you have to get up and face you're whole day. But I want people to be like, "Wow, you're doing amazing!" But I also don't ever want them to comment on how amazing I'm doing, ever.

K: Yes. it's just one of those things that you want them to think, but never say.

E: It's such a double standard that we have, right?

K: Does that make us hypocritical? I mean, I feel like it literally does

E: Absolutely!

K: I feel like it literally does, yeah. But I mean I feel like also anyone disabled who's listening to this, which I believe is most of you, totally understand what we're saying.

E: Okay, here's a perfect example. When people try to...I was gonna say when people try to empathize with me, but not even. When I try to act like I can empathize with other people. So they'll be like, "Oh my God I woke up this morning and I just had this horrible tension in my neck and I must've slept wrong!" And I'm talking about people who don't have disabilities. And I'm just like, "You slept wrong? My existence is wrong! I was born wrong!"

K: My dad has like a knee problem, lik a mild old guy knee problem that every old guy has. And he was climbing up the stairs and he goes "Oh my knee hurts so f*cking bad!" And I was like, "Oh, you have one bad knee? Tat must be nice!"

E: *(Laughing)* But, see the thing is that unless it's someone who is really close to me, I don't say anything.

K: Yeah

E: Sometimes even medical professions will try to my pain levels and it's like, No! Or just some random person...Okay it's everybody! Everybody! Everybody who does not have a disability who is like, "Oh my God, my back hurts!" And I just wanna be like, "No it doesn't! You don't know pain!"

K: *(Intensely)* "You merely adopted pain and I was born in it!"

(Emily giggles)

K: That's from, *The Dark Knight Rises*. It's a really bad movie but that was a nice line in it. No, but I mean really it's like...And I get it, your pain probably does suck but mine is probably worse. And there's no way I can tell you that or show you that without sounding like a complete ignorant person on his high horse over here but still.

E: No no, it's not ignorant it's just sort of...

K: Holier than thou, sorry.

E: Holier than thou, yeah. Like in my head I always feel like I wanna outdo the other person, but I'm like gritting my teeth and smiling and nodding and being like, (*through gritted teeth*) "Uh huh, I understand. You must really be having a difficult time."

K: It's like those people who either intentionally or unintentionally one up you when you tell them a story? It's like, "Oh you know, when I had my wisdom teeth removed it really hurt because they forgot to put the anesthetic on!" And then it's like, "Oh yeah? Well the removed all four of mine at once with nothing but a rusty pair of pliers and it also hurt!" It's like, "Okay but can I say my thing?"

E: Yeah but I don't want to complain! That's the flip side of it, because if I complain it's a sign of weakness..

K: Oh no it's not, I love complaining!

E: No! To people who don't get it, it is!

K: Aah why would complain to them though?

(*Emily laughs*)

K: No I hear you, I hear you.

E: This is a double edge sword!

K: Absolutely. Everything we do on this show is a double edge sword. But it's such a weird, I don't want to call it a balance because I can't do that. But it is though! Cause I mean, I really have days where it's just like, I wake up and I look at the ceiling and I just go, "Ah f*ck!" And it's like, my parents do that and my sister does that, you do that, everyone on Earth does that, but their not doing it because of why I'm doing it! (*laughs*). Like, their not. But everyone with CP who does that, is though! And it's like I want you to know but I also don't want to like put that on you. I don't want you to know at the same time. Cause like, what if it's so bad and I don't even know that because this is the only thing that I have ever known?

E: It's not even a matter of not wanting to put it on people, it's just that I tend to always put up some kind of front about it, and I guess by talking about the fact that I'm putting up a front about it, I'm taking down that front, but then I'm going right back to doing it tomorrow.

K: I mean, look this is for educational purposes only, this is not a real peek behind the iron curtain of Emily's

E: Nobody knows anything about my life.

K: Except that you like the color turquoise and you like chai lattes

E: Both correct

K: And you have an affinity for peacocks

E: I can really be summed up pretty easily

K: I'm just reading your Twitter bio

E: I know!

K: But I mean, it's so weird because we've touched on this a little bit in other episodes here and there and where we've touched on it is basically where....the intersection of our advocacy and the rest of the world. Because obviously like as Professional Disabled People™ everyone else thinks that you must represent the entire embodiment of Disabled humankind. And obviously that's not true, but everyone who's not disabled seems to think that about every disabled person. And so part of the pressure that it puts on you is that you have to be at your best all the time. And we did touch on that in our mental health episode but we never really like dove into why, and this is a big part of why. Because sometimes we don't really wanna smile and nod, you know?

E: I never want to smile and nod, but that's my default function is smiling and nodding. I will smile at you and nod at you, and I will...act like I'm okay even though I'm not.

K: Yeah

E: Over and over and over again.

K I think that's a bit universal which is good because anyone who's not disabled who's listening to this will certainly understand that. What's a good analogy for someone who's not disabled to understand what we're saying? Imagine a cashier asks you, "Oh how's your day going?" And your day like really sucks. And instead of just saying, "Okay good," you actually decide to tell them how your day is, and then they immediately stop listening. It's like that, except all around you.

E: "How are you?" is a really difficult question for me because I don't usually want to answer it. And I thought about it a lot in college because my campus was relatively small so I would

always see people that I knew and you would always stop and you'd be like, "Hey how are you?" Or even if I was just passing by people and we didn't stop it would always end up being, "Hey how are you?" "Good how are you?" "Good!"

K: In that respect I feel like "How are you?" is just like the next thing you say after "Hello."
Neither of you care.

E: Yeah. But then that's a standard experience whether or not you have a disability. But the thing is when it comes to having a disability, my answer is probably different than you answer.

K: Yeah and I worry even now that we're saying this that we're coming off as like miserable all the time, Which is sort of like the exact point that we're trying to argue against is that we're not miserable all the time, but we are sometimes. It's just that when we are, we really, really are. I just wanna make that clear, it's not all bad it's just that when it is, it's pretty bad, it's really bad.

E: But sometimes it's also just normal.

K: And that's the thing, you know? That's why I have a problem with like the, "Oh you now, you're life's not so bad, but I wouldn't wanna be like you!" That's why I have problems with people like that. It's like, "Well first of all that's rude, and secondly, you don't know that!" You don't even have the faintest idea of what being like me would be, you just think you do because you see how I walk. Like, you know...But it's, I don't know, I don't like complaining. Even though I just said I did. It's one of those things that only feels good when you do it, and then when you're done it's like, "Did I need to do that?"

E: So what do we do about this? Because we can talk til we're blue in the face about the constant facades that we put up and the fact that we want people to somehow understand that having a disability sucks sometimes but we don't want them to be the ones acting like it sucks...What do we do? I mean, we exist in a complete conundrum if we can't come up with how to respond to it.

K: Well I mean, I think part of the answer is just to start talking about it, I mean, even in the Disability Community sort of in disability circles.... Unless you're in a space or in a subcommunity so to speak, of people who are talking about how Disability sucks, or if that's like the discussion of the day. Um, we even tend to hide it from each other due to that constant need to always put up a...I mean, you called it a facade but...I mean I guess so, yeah a facade...

E: That's what it is

K: A facade of how you're supposed to be. And within the groups where everyone is sort of understood to be I don't want to say a safe space because that's like really overused but really, when you're in one that you know to be good and you know that no one's really gonna judge what you're saying, there's that relief of you finally getting that stuff off your chest, but you know

it's very quickly like "Okay, now I'm done, now I have to go back out into the world" and you gotta stuff it back in there. But it's like on the one hand, we shouldn't have to, and on the other hand that's not unique to disability either and I would find it very annoying if the whole world sort of honestly answered the question, "How are you?" all the time.

E: Right because none of us want to hear the answer sometimes

K: Yeah! And so in that respect I don't know if there is anything to do? But I don't think the right thing to do is shy away from talking about it...at least not amongst each other.

E: Is there an added layer in the world that we currently live in? Because I feel like lately the conversations that I have with people instead of being the usual, "How are you?" " Oh, good how are you?" now it's like, "Oh you know, the News blah blah blah everything's so sad, I'm miserable."

K: I think the News, now that you mention that I think the News is a really good analogy. An able-bodied person, unless they become disabled later in life will never understand what it's like to be us. But I think the way the News makes them feel is not exactly one to one, but a decent way to sort of understand how a disability feels on a bad day. Where it's like, it's not really ruining your day, you just wish it wasn't there.

E: That is a good analogy. I hadn't thought about that.

K: Yeah, this just came to me while we were talking. But I mean, I don't know I don't talk to other people about the news unless it's you.

E: Nobody?

K: No

E: Is that just because I always need to complain about it? (*chuckles*)

K: Yes. But I mean, so do I, that's not "Emily complains a lot" that's, "We gotta get this out!"

E: Although she does

K: I mean, I didn't want to be the one to say it but...Part of living a privileged life is that although the news bums me out, it doesn't ruin my day. But I understand that for a lot of people it does, and I also feel like not watching it is...I don't want to say irresponsible because there are plenty of good reasons not to watch the news, especially if it's for your own good, but like it's less bad at least knowing what's going on than not if you can help it.

E: It all comes back to the News

K: I mean...ehh. Look, if the News wasn't the News people would find other reasons to feel bad. But I think the point we're trying to make is that we have an added layer on it that you might not, which is a Disability that we can't just turn off like the News.

E: As much as we may want to

K: And not to get into a debate about whether we would fix or cure our disabilities, but there are definitely days where it's bad. And then there are definitely days where it's like, "Dude do I really need to have this? Like can I just for like, ten minutes? Can I just feel what it's like to walk straight once?" You know?

E: I would be so lost though.

K: Yeah I think it's a little bit different with you. I think if, yeah imagine if you just suddenly have the ability to walk? Like, you'd realize it by accident. Like imagine you would just like fall off your bed or something and just get up and freak out like, "Ooooh how did I? Ah what? OH MY GOD!"

(Both laugh)

K: And then sit back down and be like, "I don't know what to do!"

E: That was a reenactment of Emily walking

K: Yeah. I don't think if my CP disappeared tomorrow, I honestly don't know how long it would take me to realize unless I was having a bad pain day before it went away. Like I'd probably look down and go, "Huh. That's a little weird, I'm walking pretty good today!"

E: I think you'd realize pretty quickly...

K: Ahh... I think you're right. I take that back, I would have to right? There's no way. There is no way.

E: Well, because this is all we know.

K: Yeah. In the same way you notice a new mark on your face or something like that, like you know yourself.

E: And so, in knowing yourself...this is getting too existential for me. Can't do it.

K: Go on...

E: No. I was gonna say in knowing yourself...I don't even know what I was gonna say. Ah, it was too existential for me. That was it. That was a warning bell, it was like, "Emily, stop this right now."

K: Do you find it uncomfortable to admit that Disability sucks sometimes? To yourself...

E: Yeah because...

K: Just to yourself

E: Yes, because I spend my whole life trying to tell people otherwise so...am I a hypocrite?

K: No. I don't think that makes you a hypocrite because you're not telling people it never sucks, you're just telling people it doesn't suck.

E: But I often feel like a hypocrite because...Okay, here's a perfect example: I was once doing a BBC Radio interview, and I never publicized it and proceeded to let it bury itself on the internet. Look for it if you must, about that movie *Me Before You*, and they were trying to get me to explain what it was that I found so problematic about the movie and book before it. And so I think I summed up by saying, "We just want people to know that it's not so bad on the other side."

K: I think that's reasonable

E: Yeah, but I just, I didn't like how it came out but the point is that...I spend my life trying to convince people that things actually are not that bad. And then, when things actually are that bad, I don't want to admit to it, I don't want to talk about it, I don't want people to know about it, and so it becomes a matter of hypocrisy.

K: (*Sighs*) See, I hear you. I guess I don't feel that way because it's not my job, I haven't made it my life to tell people that it doesn't suck so bad on the other side. I mean I do it through the show but I don't so it nearly as much as you, so I sort of understand why it might feel that way. But, I will say that if another friend of mine texts me first that they're having a bad day? That's it, that's the floodgates, that's when they open. "Oh, really? How much time do you have?"

E: Right but then it's a culture of always trying to outdo each other. We do that with being busy. "Oh I'm so busy." "Oh my God, I'm so much busier than you!" You know? It's like a constant competition. "My body hurts more than yours does, I'm more disabled than you." I mean, the list goes on.

K: That's just so....That just points out that humans are d*cks in general. I hate the busy thing, it's like...

E: We're competitive...

K: I am busy, but like I am never too busy to do something that I want to do! That's why you do it, you know what I mean? Like, if you really wanna do something, you make time. And if you can't, you wait till you have time and then you do it. I never understood that whole, "Oh I'm so busy" means, "I never wanna see you at all!" That's what that means, "Stop asking me to see you cause I don't want to." That's what that means

E: Yeah, yeah you could translate it like that, but sometimes I do wanna see people and I'm too busy. But this isn't really about business, this is about...

K: But then you schedule it!

E: This is just a general need to outdo each other.

K: I know. That just got me cause it's one of my little pet peeves. But see, like I never wanna outdo you, and I don't think that's because we have different disabilities. And when I talk to someone with CP like me, I don't know if I'm outdoing them so much as comparing notes. I mean you're right, you're right, sure humans do have the need to outdo each other and we do it to each other all the time, like usually in jest. But, if I have a bad CP day I'm like, "Does this ever happen to you? Has this ever happened to you?" like, "You won't believe what happened to me today! Are you having a bad day?"

E: Well that's solidarity. That definitely makes me feel better.

K: That's what it is! And i feel like at least wit you and the people I'm close to with CP, the playing field is a little even so to speak, even though you and I respectively have problems that the other one literally can't even imagine. So I don't really know how to reconcile that with the whole wanting to "outdo the other" thing, but I will say that I do find it like mildly therapeutic in a sense to do that with somebody. And not for nothing, but there is some sort of positive feeling to know someone else goes through what you're going through. But it is this weird large kept secret when you're not in a situation where you can openly speak about the parts of your disability that sucks. It's like we all know it;s true but we can't say it because there's always this social pressure on us that we must be the best we can, 100% of the time.

E: I call it always being, "On"

K: Yeah, you've definitely mentioned it before on what was it? I think our Mental Health episode.

E: And then the "Off" switch goes, I was gonna say the "Off" switch goes on, but you know what I mean. I flipped to the "Off" switch when suddenly I'm around people that I'm comfortable with, but mostly I'm "On" because I want people to think that I'm totally killing it at life and that Disability aint no thing.

K: But I mean...I hear ya, because I'm the exact same way, but the thing is, it is a thing some days. And I hear myself saying this and I hear us doing this episode and it's like, "Well is that really that much different than everyone else's life problem that they're also all not talking about?" And part of me wants to say "No," and also a part of me wants to do that thing where I one- up outdo and be like, "Well, no but you don't have to deal with this! And this, while it might not be better or worse, is certainly more." And I guess that makes me a hypocrite too.

E: I also think about in terms of larger life issues like just that certain things are more difficult for me in general. So like one thing is that I still live at home with my family and a lot of that is because I can't find an accessible place that's super affordable and things like that. And I don't talk about that to people a lot, but it's a reality, and it often makes me feel bad about myself so I sort of exist in a mode of pretending like, "It's fine!"

K: I mean how much of it is pretend?

E: It is fine! It actually is fine. But the thing that becomes not fine is the feeling that if you open up too much, that you will be judged. That you'll be seen as less than, that everything that you have worked so hard for to combat in terms of Disability stigma is going to come back to bite you.

K: I 100% agree with you. Counterpoint: People with Disabilities are seen as less than anyway, so why does it matter? Not saying I agree with that, cause I don't. But we are.

E: It matters to me.

K: I agree with you, I was just messing with you.

E: It's on a personal level!

K: Yeah no, I understand. I was just being facetious. But I guess that's the point! Because if we're gonna be seen as negative anyway, we may as well make the best of it. And so when the cracks in that start to show it's like, "No, no don't look at me!" You know?

E: Well that's when I take myself out of any kind of spotlight. I don't really post about negative things. I remember one time a couple years ago when everything just finally got to me and I posted something about how I am just *tired*. I'm just *tired*. And it like raised alarm bells for a bunch of people in my life and they were like, "Oh my God, are you okay?!" And I was like, "See? So now I'm trying to be honest about how exhausting it is to be disabled and I just freaked out every person close to me within like a thousand bajllion mile radius." You know what I'm saying?

K: I hear you. How much of that do you think is because your facade is just so gosh dang good up until that point that you really...

E: Probably!

K: Yeah, I mean isn't that double edge sword in itself? Because if you never did that then no one would've been worried. I'm not saying you did the wrong thing, but how much of that was your own doing?

E: You just want to have a moment of honesty and just want people to understand that this is hard sometimes. And when you show that vulnerability, I think that's the word that I've been trying to get to this entire time. I'm not good at being vulnerable.

K: In proper *Accessible Stall* form, we are at the end of the episode when we finally have our little lightbulb moment.

E: That's always how it goes isn't it?

K: Yes. We are not good at being vulnerable. And I don't know if that's a pan Disability thing or just a Kyle and Emily thing but I do know-

E: No, I definitely think that's a Disability thing because while I complain about being bad at being vulnerable, in the same breath I also like have other people talk to me about how they struggle with being vulnerable too. Like Disabled people always talk about how difficult it is to be vulnerable to the outside world and we can only do it with each other!

K: I have a friend who has CP like me and that's sort of what we talk about most. Well, no it's not, but when we talk about CP is what we talk about most is the idea of vulnerability and how you sort of by having this, and by having a life where you have to deal with it everyday you sort of fight your whole life to have some sort of, not self control, but some kind of ownership of you in your body when it's taken away from you by force by like a doctor or by choice if you decide to go out in the weather, like in the snow and you slip? And it sort of reminds you that it's still there and it kind of shocks you back into the world...Where it's like, you don't wanna forget, like you know who you are, no one forgets who they are in that respect but it's just like, "Oh, CP you're still here. Right! Of course you are" You know? And I know that's at least true for me cause I don't think about my CP ever unless I fall that day.

E: It's like how you don't think about your mortality until your confronted with it?

K: Oh yeah, it's exactly the same, yes. Man, we make good points at the end of episodes Emily!

E: You know what, because it takes us thirty plus minutes to talk out what is even going on in our heads. I think that's really how we function.

K: I mean, we don't wanna lecture people except for when we wanna lecture people, and I think part of it

(Emily laughs)

K: ...Is that they get to come on this magical journey with us to what I would say is a good point! Do you have any Final Takeaways?

E: Yeah, I think we needed to rename the podcast. Instead of *The Accessible Stall*, *Journey to a Point*

K: *Journey to a Point*. And the subtitle is like, *Just listen to the Last Five Minutes!*

(Emily giggles)

E: No, but really though because it seems like that's the only time we really accomplish anything.

K: It's true. My final takeaway is, if your disability sucks we wanna know about it! So let us know about it and tell us your story, and tell us what you think!

E: My final takeaway is kinda cheesy but it's just that you're not alone in the feeling vulnerable and the feeling like you cannot be vulnerable.

K: Yeah, you're not. In fact, it's funny because I would imagine that lots of people with disabilities feel like they are, and the irony is that everyone who is disabled feels that way. I don't wanna say everyone but like...there's not a disabled person that I know that doesn't feel that way.

E: Yeah, I mean we can't speak for everyone but also can we sorta kinda speak for everyone generally that we all have these feelings?

K: I think as humans we all have this feelings, but like specific to Disability, I truly do not know a single disabled person that doesn't feel like what we're describing.

E: So my final takeaway is that as per usual when we're trying to sort out our emotions on something, yes this conversation was a little bit all over the place but it's an important one to be having. And sometimes sorting out our feelings for things this complex as this requires that you don't take a linear path to figure out what you're thinking. I mean, I know we always say there's a lot to unpack here but, that's because it's true.

K: Yes. And with that, tha is another episode of *The Accessible Stall*.

E: Thanks so much for listening

K: And might we say you look good today

E: Very good today

K: Goodnight everybody

E: Goodnight