

The Accessible Stall: Episode 002: Help

TRANSCRIPT

Emily: Hi I'm Emily Ladau.

Kyle: And I'm Kyle Khachadurian.

Emily: And you're listening to The Accessible Stall. So what are we gonna talk about today, Kyle?

Kyle: I think today we should focus on instances of unwanted help.

Emily: Oh boy, I can go on and on about that topic.

Kyle: I think everyone with a disability can, it's a fairly ubiquitous thing in our world.

Emily: So, we should probably decide what we mean by unwanted help.

Kyle: Yeah, unwanted help is sort of like imagine if you will--you see an elderly person walking across the street--and in the stereotypical format, the way it should go is: you ask them if they want help to cross the street, they say yes, and then you help them. *Now* imagine if the elderly person says "no", or "maybe not today" and you insist on helping them anyway because you think that you know that the elderly person needs more help than they're letting on, and they're just saying "no" for their pride, or something. that is sort of what people with disabilities go through on a fairly frequent basis.

Emily: So I guess a comparison would be if I was pushing my wheelchair across the street and someone said "hey, you look like you might need some help, can I help you out?" And I say "no thank you!" or I say "yes please!" and they go either on their merry way, or they help me cross the street. Alternatively, I've had people come up behind me and grab my wheelchair from the back unexpectedly sometimes and start jolting me forward, without my permission, and claim that it's because they're trying to help.

Kyle: Yeah and I guess the main focus of this episode isn't that help is bad because it isn't. Most of the time, help is exactly what it is, but the point of this is that we tend to know when we need help more than you do. And sometimes, the reasons that we say no to unwanted help isn't because we're too prideful, it's because your idea of help may actually be doing more harm than good.

Emily: And sometimes it's a little bit embarrassing too. because people will throw themselves at you and automatically offer help without assuming that you might be totally fine figuring things out on your own, like our little adventure in the movie theater a couple weeks ago

Kyle: Yes, you should tell that story.

Emily: Yeah so Kyle and I and our friend Meg went to go see a movie and we were minding your own business, waiting on the line, and out of nowhere--literally out of nowhere--a movie theater worker comes up behind me and says [emphatically] "come with me I'm going to show you where to go!" and we were just like "where did he come from, and why is he yelling in front of everyone?" And then when I said "oh, I'm good I'm going to wait here with my friends thank you", he said [emphatically] "ok, I was just trying to help" and backed off with this sort of offended puppy dog look on his face and so it raised a question in my mind "should I be feeling guilty for rejecting an offer of help, or should I feel like I said no because I didn't need it and that's that."

Kyle: It's one of those weird social situations right? Because the other person in this scenario really thought they were doing you a favor and they probably were on some level, and it puts the pressure on you because when you say no for whatever reason you have to say no, to them it makes you look like the bad guy. And it's just bad all around because now you've left a sour taste in his mouth, he's probably never going to offer help again, and everyone walks away slightly worse off. And it could have easily been avoided if the person just came up to you guys and asked you if you needed help.

Emily: I will counter that with sometimes I'm literally just sitting there doing nothing, and some will approach me and say "do you need help?", but I won't be making any indication that I'm in any sort of distress, sometimes I'm just sitting there playing around on my phone, or just staring off into space waiting for someone, but I think "wheelchair" almost calls out "help me, help me!" and I struggle because I don't want people to think that I'm ungrateful or that I find them unkind, because I know that someone who's trying to help me is not a malicious person, but I also don't want to automatically appear helpless or just be somebody's good deed for the day, you know?

Kyle: Yeah it's a fine line. I feel like for the most part, when you refuse help some people just shrug their shoulders and go about their day, but there's always a small percentage of people that they almost get offended--no--they DO get offended, they get legitimately offended, you know "how dare this poor disabled person refuse the help of me?" and I'm not a fan. I don't even understand it. I feel like as a person if somebody says they don't need my help it's probably for a good reason.

Emily: Have you ever had a situation similar to mine? Because I know that our disabilities present themselves differently so for me the wheelchair is a very visible symbol, but for you I don't think people pick up on it quite as quickly that you have a disability.

Kyle: You know it's funny, they don't. But, what does happen is when they see it they're more than happy to help if I'm having a particularly bad day--and I don't know what it is, right? Because I don't notice it-- but I know that it's not completely invisible and I know that if somebody sees it every single time they've been more than willing to offer real, actually help then I actually did need, so I can't say that that's a bad thing. but, what I will say is that there have been-- and I can't think of specifics, but I'm sure that this scenario has happened in my life,

where for example, I'm leaning on a closed door and somebody will open it thinking that that's what I'm trying to do and it will totally throw me off balance and then I will fall and hurt myself. That would be the closest thing that I have to be analogous to what you said. even then though-- and this is the screwed up part-- because even then, in the case where I've injured myself, I can see completely what they were trying to do and I can see the goodness in their heart and it makes me feel bad. on the other hand though, I've also had situations where I've tripped and fallen on the street and people have literally walked right over me, and as much as you think that makes me angry, it really doesn't because I don't know if I would help somebody who just tripped, but I can't. I don't do it because I can't, I don't do it because I'm a mean person, but in my head everyone who stepped over me isn't mean either, they're just in a hurry or couldn't do it for whatever reason either and so I guess what I'm saying is that it's definitely more difficult when the situation presents itself that they're usually right, which is the opposite of you, and I get that, but I guess that's the trade-off of not sitting down in some way or another.

Emily: It's funny because sometimes if someone ignore the fact that I clearly appear to need help Kama then I get frustrated, or someone sees me approaching a door and doesn't bother to hold it for me or lets it close on me, then I say "oh really nice, you just let the the door slam on the girl in the wheelchair", but then sometimes I think to myself about the people who literally run all the way in front of me it cut me off just so they can grab the door for me and I'm like "oh man this person is trying to give me all the special treatment just because I'm in a wheelchair, leave me alone I can open my own door", so sometimes in my own head that people can't win for losing with me.

Kyle: Yeah, but in that particular case of opening doors, I don't know about you, but I hold doors open for everyone and I can honestly say that it's not an act of chivalry or feeling bad for the disabled person, it's just because I was raised in a world where holding the door open for somebody behind you or even in front of you in some cases is the right thing to do. if they are immediately behind you, you hold the door open you let them go first. If they're a little farther, you pulled the door open and they come in after you. It's just what I do. Whether or not you're sitting down, or a woman, or any other weird rule to that situation does not apply. 100% is not relevant to me. I actually will get really annoyed when somebody doesn't hold the door open for me, because most people I know would, I think it's rude, I think it's right up there with somebody not saying "excuse me", or "please" or "thank you", it's a matter of manners more than anything else.

Emily: Dude I'm going to argue with you for a second because you let doors close on me all the time.

Kyle: Yes, but that's because I hate you. [laughter] No, it's because I don't know whether or not you "have it", and that's a strange wheelchair situation. Because you don't hold the door open with your hands like everybody else, you hold the door open with the machine that you're attached to, and that's fine, but it's hard to gauge whether or not you're fully in, and I'm not 100% at guessing when that is yet, and sometimes the doors get heavier on the way in, unfortunately.

Emily: Likely excuse. No, I understand what you're saying. I think about it, and I think you know me, so it's a lot different and I'm also willing to yell after you that you should be nicer and hold

the door for me but I'm not going to say that to a complete stranger. But sometimes, I'll be out in public with more than one person who has a visible disability, and then nobody will bother to hold the door for us or help us and at that point, I just think "really? C'mon, an act of kindness wouldn't kill you at this point."and so, I'm trying to find a balance in my head between being grateful for help but not rejecting help but understanding why people offer to help, it's just this big jumble in my head.

Kyle: I don't think there's a fine line between those two things though. I think that most of the time, the situation can honestly be remedied by asked me if you need help, I understand that a door is a weird situation because it's just a thing that either you do or don't do, but in other situations if you can just ask the person if they need help then the situation will resolve itself. Because either you do and you're going to tell the person how to help you and the person that will, ideally just, say "oh ok" and walk away.

Emily: Yeah that's another thing,when you ask someone, it opens up the opportunity for them to explain what they need so that you can actually be helpful, and that's huge because sometimes for example: when I'm traveling on an airplane and the people who help me get on the plane if I'm not with my family, it seems to be quite the circus production. And they sometimes without even asking me will grab me off of the aisle chat that they use to help me get into the plane, it'll really hurt. So I've taken to saying before anyone grabs me "this is what I need, this is how I need you to help me" or "don't touch me there" or "don't grab me here" and I feel like I have to be very firm because a lot of times not disabled people treat me as though they know better what will be most helpful for me.

Kyle: Yep. Has there ever been a case where they've been right? has there ever been a case where they did in fact know better than you? That you misread their intention, and ended up doing something that you didn't realize that they were trying to do and it ended up being better?

Emily: I can honestly say nothing that I can think of. and I don't want to tell her I'm just full of myself, or think that I am the all-knowing power, but I also just know what's going to hurt what my body can do and my body cannot do, so I guess I'm also able to very firmly able to speak up for myself. but, there's a whole other set of issues, let's say somebody uses an assistive device for communication, or someone has a speech impediment and they're trying to verbalize the assistance that they need but people are patient enough to sit there take a minute and listen to what that person is trying to convey.

Kyle: I mean that's just basic disability etiquette, and that should actually be another episode [Emily interjects: Stay tuned!] but I agree. especially in cases where you're communicating with somebody who's nonverbal or at least a verbal in a way that isn't through their mouth. I've never seen somebody run out of patience quicker than when dealing with somebody like that unfortunately. Generally speaking, what they'll do is they'll speak to the nearest person that looks like they can speak, which is just awful. It is the worst thing ever.

Emily: yeah so unwanted help ties into a big phrase disabled people will throw around and people may not understand what it means but "presuming competence".

Kyle: Oh yeah you should probably tell everybody what that means first.

Emily: Yeah well, it's funny because the words standing alone, I mean anyone would I think catch on to the meaning of it but in regard to disability, it means [emphatically] not assuming someone is incapable of thinking for themselves, or advocating for themselves, or doing something for themselves, and let that person take charge and show you what they can and cannot do. so often, that seems to be a foreign concept to people. even when dealing with someone who is able to clearly verbalize what they need, it's like the wheelchair suddenly throws everything off.

Kyle: I need to give these people a little bit of a bone though, I mean sometimes, it's their first time. And, that's ok. If that's the case for you then nobody is going to dislike you or feel ungrateful for the help that you tried to give, and ended up not. Generally, at least for me, if I receive some form of unwanted help, I can see through it enough to know that the person honestly tried. In my case more often than not what happens if it doesn't do any good. in Emily's case it sounds like the worst thing that can happen is it does harm. For me it's a zero-sum, but for her it's a net loss, so it's a little different I suppose.

Emily: Well what if you were walking down the stairs? Or down a ramp, and someone tried to help you? Would that be useful or would it throw you off balance?

Kyle: It depends entirely on what's going on. If I'm running down the stairs I do need help, but there's nothing anyone can do to help me. I used to have a co-worker, that once she knew about this little thing that I sometimes need, that she would just do it. and the first time she did it Kama it was before I explicitly said that I needed it, so she just sort of picked it up in passing, which is great I suppose. But at the same time I didn't explicitly say it so I didn't know how to feel about it but I couldn't really be too mad because she was absolutely right. what she did was she noticed that there was a large step for talking like a 4-inch step between the step and the ground, and she hopped off of it and gave me a shoulder to lean on, which I didn't need. I didn't need that, that's a gap that I can cross without any issue whatsoever, but it helps if I have a shoulder. It makes it that much more easy [sic]. And I remember just being sort of confused, like "oh how did you know I needed that?" and what she said was that she just assumed that it would make sense that I would need that, and I really--I don't want to say I wanted to be upset about it because that sounds like I'm being pretentious, but I wanted to feel like "oh, this is somebody assuming I needed help when I might not have", but in reality what it was was someone who was around me enough to know little intricacies of my disability without having to ask me--although I would have been happy to talk about them, by just picking up little things that she's noticed about me. And I think that that's great. I don't like assumption, I don't mind presumption. When you have a reason to do what you're doing, rather than blindly following this idea of "help"--if your help is catered to that specific person rather than "somebody in a wheelchair, they must need help", I think you'll go farther. I mean I think asking is the best way to go, but I think if you're too shy to ask, but not too shy to help, the best thing you can do is sort of survey the situation a little bit and see what makes sense from a purely common sense perspective, because sometimes you might be right.

Emily: Or maybe a little bit more instinctual. Which I think sometimes comes with having any sort of relationship with a person.

Kyle: Yeah but I mean you can also just put yourself--if they switched places, if the person trying to help you was sitting in your wheelchair and you were trying to help them--what would they want you to do? This is what the person doesn't tend to think about, but if you ask them to--I mean if you're asking them to you're asking for a thought exercise so you wouldn't actually do that, but if you could get them to that point where they would consider "what would the situation be like were they the ones sitting down", I feel like more often than not, they'd be like "oh! Yeah! That was ridiculous of me, I should have done this."

Emily: So a little bit of "put yourself in their shoes for a second", and try to figure out how you might respond if the help was thrust upon you in that way?

Kyle: Yeah, but that's not even wheelchair or disability specific, if you see somebody struggling with a lot of heavy groceries and you wanna help them, what's the best way to do it? Probably the best way to do it is to first ask them if they need and then hold one of their bags, or if it's a big bag hold underneath one side or something, it doesn't have to be about disability, and yet somehow, when you are disabled and visibly disabled, because it doesn't happen to *me* so often, it's just a giant "help me" flag that you can't get rid of. And it doesn't come from a place of being ungrateful, it generally stems from a place of pure frustration *because* we realize you're so helpful, without *being* helpful, or rather that because we realize that your intent is *so good* and so well placed, but your execution of that intent is so off.

Emily: I'm also thinking as you're talking about the different types of help, and you're talking about the intent and execution, but sometimes people are helpful under the guise of condescension. Or condescending under the guise of helpfulness rather

Kyle: Which is it? Because I'd say that both of those things are true

Emily: I think both of them exist. But I think that what I'm getting at right now is condescending under the guise of helpfulness. So, I'll get into an elevator and I have literally had people say "the buttons right there sweetie" and I'm like "I-I see that, thank you so much, really appreciate that".

Kyle: I've learned to laugh at that. Because what can you do? That person to me is too far gone. If that person's idea of a good deed is helping somebody in a wheelchair press a button, they're never gonna sit there and learn why what they did was sort of screwy. They're just not. They're going to go home and think about you once over dinner and then never again and that's that, and just like you you're going to tell the story on the podcast and you're never going to think about it again. Until it comes up again.

Emily: I probably think about it more than the average person because I'm always encountering situations where I'm navigating the waters of help. but at the same time, I think you're right I have to laugh it off and have to let it roll off my shoulders and just sort of write a few people off as a lost cause, but hope that maybe they'll think about what they did.

Kyle: this is going to be someone of an unpopular opinion, but I will say even in that case I get it, I'd never do it because I know better and I think everyone should know better, but I understand that not everyone does know better and I understand that even in a case like that, they really thought they were helping. Was it condescending? Absolutely. was it wrong? Absolutely. Did they think they were doing the right thing? Yeah. And that's the worst part. I would honestly rather somebody be outwardly condescending and tell me that they hate me, or something like that [Emily laughs]

Emily: I don't think that's condescending, that's just rude!

Kyle: Well whatever! I'd rather have somebody be overtly condescending for disability related reasons than hide it under the guise of help. But I think that when they hide it under the guise of help though, they don't really realize what they're doing is condescending. And I'm not so cynical as to not know that, but then the problem becomes, where do you start? It's such a weird thing because it's weird for everybody, right? They think they're doing the right thing, you know they're doing something good but for all the wrong reasons... you know--I was in a McDonald's once with my friend who has no arms and somebody took time out of their day to show us how to open a door. And, yeah I mean, great, but what he failed to realize is we were already in the McDonald's, we know how doors work.

Emily: I realize the people listening can't see my face, but boy did my jaw just drop to the floor [Emily laughs]

Kyle: It's true! And what do you do? What we did was we screws with him. Like "oh thank you so much! We really appreciated it!" [Emily laughs] ...which is the exact wrong thing to do if you're actually trying to teach somebody something. But in a case like that, what else is there to do? I ask as an open question, because you have to have fun sometimes not everything has to be a teachable moment.

Emily: that's a really good point, because...

Kyle: Sorry, I don't mean to interrupt you

Emily: No that's ok!

Kyle: but to amend myself, I think as disabled people we should take advantage of our teachable moments, which is also somewhat of an unpopular opinion, but not everything has to be, such as how to use a door.

Emily: no, I think that unwanted help or wanted help and teachable moments really do go together because a lot of times I want to explain why what someone's doing is maybe not the best thing, or maybe they can go about it a little bit differently, but then I end up realizing that the moment has passed, I was a little bit too shell-shocked to even go about having a teachable moment. So I wish that I could be better at doing it on the spot, but sometimes the only thing that I can do is go with it because I'm just so stressed by it.

Kyle: But also because you have stuff to do.

Emily: Right? Exactly, you're going somewhere.

Kyle: There's no definitive--like, somebody walks out of that situation with their pride wounded. Sometimes you need that, sometimes you need to have your pride bruised a little bit to learn something, but I will never say that help is bad. I will never say that unwanted help is bad, because unwanted help is still help. The bad comes from the lack of knowledge based on how to help, or the insistence that your way is the way to help and the only way to help and the definitive way to solve whatever conundrum I find myself in. Genuine help is always appreciated, and that's not a disability issue either, everyone loves help sometimes.

Emily: Yeah I'll give a perfect example that's completely not at all disability related but just shows how sometimes unwanted or unrequested help can actually be a good thing. I was in a home improvement store with my family last weekend and my dad was carrying a really heavy box, and all of a sudden we passed by this couple that had a wagon but there were only a few things in the front of the wagon, so out of nowhere the woman looks at my dad and says "you clearly need this more than I do, here.", and starts taking the box out of his hands and putting it in her cart, and then taking her stuff out of the cart, and basically relinquishing it to my dad, and was it requested? No. Was my dad totally fine carrying the box? Yes. Does he have any sort of disability or indication that he was struggling? No. But, it was this, I guess random act of kindness that was actually really appreciated and actually restored my faith in humanity and then my mom and dad and I had a lovely little chat with them and we all went on our merry way and felt good about everything. So, that's a perfect example of how sometimes unrequested or unwanted help can go perfectly well.

Kyle: It all just comes back to assessing the situation and asking. You know? "Hey, need a hand?" would do more than just giving one. Because what am I supposed to do with it, you don't know me. But if you give me the chance to explain why I might need your help, then you can do a better job at helping me. If you wanna help so bad, then you'd take the extra 30 seconds of your life to learn what the best way it is for you to do that.

Emily: I totally agree.

Kyle: And when you ask if we need it, then it lets us decide, and it isn't "oh ok, I'm in a wheelchair and you're in my life now because you think I need help". It lets us decide whether or not the help is wanted or even necessary, sometimes it might not be. Sometimes it just looks like we're struggling because... I mean... we know how we look. [Emily laughs] No, it's true. We know that, to the general public, people with disabilities look like trainwrecks, I mean... this is a secret that we try to keep. But some of us are [both laugh] willing to admit it and I guess that's sort of where this comes from because, I dunno... just ask man... just ask.

Emily: I think one of the best examples of how to go about asking in the right way, is I was at the movies with, the guy I'm dating and he and I relatively, you know, just starting out in a new relationship and so he's sort of getting used to my needs as someone who has a disability and he does not have a disability, and I was getting up from the movie theater seat at the end of the

movie and it's a bit of a high jump from the theater seat to my wheelchair seat, but I do it all the time so I'm used to it, but he doesn't know that. So he just said "can I do anything to help?" and I said "no, I'm good!" and then he just stepped back and let me do my thing, went on talking, didn't insist that he had to help me and I just thought that was the perfect example of what to do in a situation where you're not sure if help is required.

Kyle: Yeah. [both laugh] That about covers it.

Emily: Is it safe maybe to leave it at an example of what *to* do, rather than what *not* to do?

Kyle: Absolutely, because you can talk about what not to do for days. There's so many ways to do it wrong, but the only way to do it right is actually the easiest way too... if you think about it, it's just to ask.

Emily: Yeah.

Kyle: But, you know, help is always appreciated, we don't mean to sound ungrateful. If there's one thing we want to make clear it's that it's not the help we don't enjoy, it's the assumption that we need it and it's the assumption that we need it *that* particular way at *that* particular time in *that particular capacity* from *you*.

Emily: Well, let me ask you this. Do you feel like there's ever a time where you would want to sit there and explain everything? Would you be willing to sit there and explain your needs to every person who ever asks you? Would it get more annoying to you if people ask you constantly "how can I help?" or "do you need help?"

Kyle: No, no.

Emily: So you'd always rather be asked?

Kyle: Mhm. But if you know me then you know how to help. If you don't, you would ask me. If you're a stranger and you ask me how can you help or if I need help... if you ask me *if* I need help, my answer if it's yes, it's gonna be immediately followed with what you can do. That's just a thing I do. That doesn't bother me at all, because if you're asking me, then that means that you wanna do it. [laughs] So I'm willing to take a sentence to help myself help you help me. [Emily laughs]

Emily: If you followed all that.

Kyle: Yes it could get annoying but it doesn't happen to me often enough where that *would* get annoying. I understand maybe for you, people would see a wheelchair and assume that you're incompetent and can't do anything except breathe and even that's probably a miracle to them [Emily laughs], so explaining your every need to them I can understand can get completely tedious, but for me I'm always willing to explain myself, because it's really not that much. It's usually "hey, can you stand in front of me?" "Hey giant man on the subway, do you mind if I

lean on you? All the poles are taken." And that's another thing too, I'm not ashamed to ask for help. Ever.

Emily: You know what, I know we said we were gonna conclude it but I think really quickly I think that's the best note to end it on, is it is not a source of shame if someone disabled asks for help. That's not something to be ashamed of. It is okay to be interdependent. It's not dependant, it's interdependent.

Kyle: I think that doing the helping, if that happens, generally get it for the most part. If they say no, I would assume if somebody says no to a request for help, it's more that they're busy doing something else than they're a bad person. Maybe that's cynical of me, but I would assume most people usually are willing to help unless they really can't, and if they really can't you probably don't want *their* help anyway.

Emily: Yeah, so I think we should wrap it up on the positive note of "it is okay to ask for help, it is okay to offer help, consider the ways in which you offer help and be willing to work it out, to take the extra second and make sure that you're not making any assumptions about the person who you're offering to help." And I think on that note, we can wrap up the podcast.

Kyle: Sounds good to me. Next time, we're gonna talk about sex.

Emily: [laughs] So stay tuned! Because that should be interesting. Or maybe we'll talk about something else. Kyle wants to talk about sex and disability. [laughs]

Kyle: Or dragons, I don't know. Alright, see you guys.

Emily: So on that note, we will catch you next time, bye!