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[START OF TRANSCRIPT]

Emily: Hi, I'm Emily Ladau.

Kyle: I'm Kyle Khachadurian.

E: You're listening to another episode of The Accessible Stall.

K: What are we going to talk about today Emily?

E: We're going to talk about mobility.

K: What?

E: How you move around this world?

K: I don't know what you're talking about. Please explain it further.

E: I think you do. You speak difficult.

K: Yes.

E: Okay. So, we are going to talk about the various ways that disabled and non-disabled people navigate the world and that is by foot that is in wheelchairs, I'm scooters.

K: I wouldn't make this list. You're bound to forget someone.

E: In car, wheel or chairs. Well, no, I think making a list is almost going to prove a point that I wanted to make pretty early on, which is that there is no one right way to get around the world. There's just not.

K: That is true. That's true.

E: There are people who navigate the world by using their hands, by literally walking on their hands because they don't have lower limbs or people who scoot around. The list is just endless. I think we need to get out of the way right away that there is a right or wrong way to move.

K: Yes, there's not.

E: The reason that we wanted to talk about this particular issue is because Kyle and I were talking about it before we started recording and realized it would make a pretty good podcast episode, the ways in which there is a hierarchy of mobility.

K: Right, or at least perceived.

E: Yes, perceived hierarchy, but I would argue that there is a hierarchy in so far as how the world treats you.

K: Well, yes. It's pretty objective that since most people walk that if you walk, then you'll have the least amount of accessibility issues in terms of the physical world.

E: Yes, but then that comes down to this superiority complex that I think some people who walk have, and I know I'm probably going to get myself in trouble for saying that, but I really believe that there is a certain contingency that believes that walking is the only way to go and a lot of times it ends up being parents who have it drilled into their head by doctors and things like that, that their child must walk.

K: I was one of those.

E: So, tell me about this because I was also one of those and I veered off the course.

K: Well, I like walking. Let me just start by saying that, I don't think there's anything wrong with not walking but as it's what I've grown up with, I tend to prefer it because that's what I know best. But, yes I was one of those kids. I was born three months premature and my CPA... my parents, I remember they always used to tell me that all they cared about was that I was alive and that I had all of my mental capacity as much as a baby could have at the time like, there was nothing wrong up there. That's all they cared about. They didn't care about how I moved or didn't move, but...

E: I feel like there's issues with that in and of itself, but anyway.

K: They were young parents, they were my age, they were our age when they had me, in a world where this was before the ADA.

E: In a world.

K: In a world.

E: Kyle does it so much better.

K: In a world, where there's no ADA, one disabled persons search for parking turns into something entirely off top. Okay.

E: This is why I cannot drink water while we're talking.

K: No, but seriously. I'm not saying that that's a right way to think I'm just saying if you add context, it sort of makes a lot more sense but anyway. As I grew up, I didn't walk at the age that you're supposed to, which I don't know what it is because for me, it's like later, I think it's around 18 months or two. I started walking when I was like five, and that was after my first surgery without which I either wouldn't be able to walk or walk a lot “worse” than I am now, than I do now. My parents always pushed the idea of walking on me because they didn't know anything about disability. So they're like, “Oh, you know, my kid is not different.” I sort of admire them for that, but as an adult now I can, look back at it and see like, oh yes, of course, their intentions were great. But whether or not they were right in thinking that is, it's no longer relevant because I'm an adult now who does walk, but it's sort of this interesting thought experiment today where, how different would my life be if I were a chair user? I would like to believe it wouldn't be that much different except I'd be complaining about accessibility as much as your average wheelchair user does, rightfully so.

I remember like my dad used to teach me how to walk. I used to walk on his feet and even after surgery, my parents would force me to walk with these giant waist high cast on my legs. I look like Frankenstein's monster, for real. It was pretty funny and so I never but also at the time, I've said this before, I went to school for people with disabilities so at no point did I think that walking was better than a wheelchair, I just thought that it was best for me. I grew up never seen wheelchairs as less than. When parents push walking on their kids when I think they're afraid of our wheelchairs, and I think my parents were but I sure wasn't. I chose walking anyway.

Although, slightly off topic when I was applying for college, I use my like walking is like this huge feat that I did in order to get the admissions office to feel bad for me and let me in and it totally worked everywhere I applied, it was amazing. I swear. Yes, I know, okay sorry I've been talking for a long time and you have words to say but long story short for my personal essay I would write how walking was my first personal achievement because I was born this way and this is the worst like in spoke pornography thing ever. It worked because I need to get into college and you use everything you got and I got that.

E: I totally used my disability for my college essay not that this is...

K: There you go, so you understand.

E: ... at all the point of what we're talking about. Yes, but I talked about this transition from being in a world where there were no disabled people to going to summer camp where there were a ton of disabled people and suddenly realizing that I needed to flap the old wings and become independent. I did some precollege leadership forum thing and then whatever.

K: No, no, I made my disability the entire point it was so bad, it weren't though.

E: I don't even know if I could find my old college essay, but **[0:07:27 inaudible]** here nor there. Back to mobility and how you move around this fine world over here. For me, I definitely had walking shoved down my throat, not by my parents but by medical professionals who gave me the impression that sitting down was bad and that I needed to walk even though it was uncomfortable for me, even though it was unwieldy for me. When I do walk, which I still can do but I do so rarely, it’s maybe five times a year if that now I wear full length braces on my legs, and they're in these heavy metal plastic Velcro affairs. I have to use a walker and I have to push on my upper body to hold myself up and my butt sticks out. I feel like I'm waddling and the whole thing is just not a good look for me.

Also it’s like really uncomfortable and if I fall over, I have to lock both of my leg braces so that my knees stay supported. Basically fall like a tree. I could literally kill myself from walking so I just don't anymore unless it's for physical therapy. Every once in a while, my physical therapist convinces me to put my leg braces on but I transition to using a wheelchair gradually throughout the course of my life and started in third grade, I got my first wheelchair and I think that was really hard for my mom actually because she walked her whole life so she was like, no but it's a sign of my failure as a parent if I let my kids sit down. I also think that was just some bull crud that she was being fed by the man.

K: Parents think weird things for their kids. I don't know, I’m not a parent but I imagine that it would affect your rational thought when it's your kid. Who knows? I don't know.

E: I think that people have this idea that using a wheelchair is giving up.

K: Yes, maybe. I've heard of that I've never seen it but I've heard it enough to it would be stupid for me to deny it. I don't know what my parents’ impetus was to force me to walk. I feel like it was the better choice because the world isn't accessible or as accessible as it could be rather. In so far as that I completely understand and it's because of that, that I try very hard not to lose it, because I don't want to lose it.

I don't have any shame and using a wheelchair, I will use them if the distances are too long like I did in Disney World last year. I have nothing. It's not a pride thing. It's not like I don't want it but I just want to keep this as often as I can as often as I am able to because I know that the world isn’t built for people who use wheelchairs. Now that's nobody's fault, that's no one person's fault, but...

E: No, it's kind of everyone's fault which thereby makes it nobody’s fault.

K: So? That’s still, nobody. No one raindrop feels responsible for the flood. What I think is when people don't build accessible spaces, they don't realize that one day they're going to get old and might need a wheelchair or they might have a kid who needs one, or they might marry someone who needs one. It's very short sighted not to do that no matter what reason you have for not doing it.

E: That is such a good point because I don't expect people's houses to be accessible or things like that, but also I wonder what are they going to do if something does happen, then they scramble to make their house accessible, which is why I think accessibility should be more of a focus and universal design in so far as designing a space that people with mobility equipment can get into and people don't have that kind of forethought ever.

K: You could say it's a money thing, but is it really? It's money that yes and it costs money, but like if you're buying a house or renovating one, it's not money that you don't have. It's just money that you want to spend on a nicer kitchen countertop or something instead of, “Oh, we're going to be 80 someday hopefully, and we might not be able to move as well so therefore we should install like ramps everywhere.”

E: Well, and speaking of monetary concerns, the other concern with using a wheelchair is how expensive it is.

K: Oh, absolutely.

E: Insurance concerns and the battles for durable medical equipment. There's a lot to be said for not having to use a wheelchair.

K: It's expensive to be disabled. It's really expensive to be a disabled wheelchair user in this country. I should say this is America so it might be different in other places with **[0:13:06 crosstalk]** medicine.

E: I feel like it’s everywhere because they're still this market monopoly on wheelchair and technology use, where it's not in high enough demand that they can make it cheap but it...

K: That doesn't make it right.

E: Yes, no.

K: Case in point the epipen debacle going on.

E: Mylan can make generic epipens for half the price. There's no such thing as a generic wheelchair.

K: Half the price, it's $30 versus what they're selling it for **[0:13:42 crosstalk]**.

E: No, I haven’t really been keeping up with the Abby thing controversy.

K: That's a whole philosophical thing, right? When does healthcare become a human right? I think the answer is always and feel free to disagree with me if you want, I'm not talking to you. I'm talking to this listener here that I'm imagining, but I personally believe that at least for mobility, like that is the most basic thing, if you would have picked one thing that isn't language that separates us from our ape cousins, it's like our literal bipedalism. I'm serious. It's our ability to walk and some people can't and we know that. How come we think it's okay to deny a person to do the thing that they can't do in a way that they can do.

Seriously, I don't understand. The way I get around is with my legs. You don't use your legs, you use a chair that has a motor on it. It's the same, it's analogous to it being your legs so without it you can't move like I don't understand. I get things cost money and I get things are expensive and I get yes, low demand not enough demand and they can charge whatever they want because people who need them, need them but you're denying someone the right to move on, what if you couldn't move? What if you couldn't move? It makes me angry.

E: I have like so many points of what I think about this. It's funny because I think the major point that I want to make is obviously I take issue with the fact that like insurance companies are so quick to treat wheelchairs like this unnecessary **[0:15:23 crosstalk]** equipment.

K: This burden, this like, "Oh, yeah you need one of those." Here you take this piece of crap with two rusty wheels and no cushion. What do you need a cushion for?

E: The other thing that I want to touch on that you brought up is that a wheelchair is a person legs because it is my legs and I just wish that people would wrap their heads around that. I must complain about this all the time but I'm going to do it again. I cannot stand the term...

K: That's true...

E: What?

K: That's true you cannot stand I'm sorry, I had to.

E: Oh, but I'm...

K: **[0:15:56 inaudible]** really using.

E: You should really insert the symbol noise there.

K: Oh, you know I'm going to.

E: I get really frustrated when I hear bound to a wheelchair and confined to your wheelchair...

K: Oh boy, here we go.

E: Because I am none of those things. I'm bound by the inaccessibility of the world around me, but I love having people who are like, "Oh yeah, I totally get it. Like your wheelchair is your way of getting around." It's so rare that people actually acknowledge the fact that my wheelchair is essentially a set of legs for me and...

K: I find that... I'm sorry, go ahead, I didn't mean to interrupt you, I just my mind is exploding.

E: I don't know I was going off on a tangent there. Long story short is, I don't like it when people treat wheelchairs like this horrible thing, when in fact, it is quite literally my source of freedom.

K: Let's talk about why that might be. Now, I have no idea and I don't think you do either because you've used one for the better half of your life. That's something that I often wonder because I think of what a world would be like if everything except the perception of wheelchairs or disability as a whole, were just a little bit different, right? Because right now, a disability to an able body person is something that they don't want. Okay, fair enough. I'll give that one to you. I don't agree, because my life is okay and your life is okay and if you're born with them, it's not a death sentence. I'll give you that. It's a scary thought, sure, but you're disabled now. Now, you're disabled. What you got to do, homeboy? How are you going to get around? Okay, so now you don't want to use a wheelchair, fine.

E: It's because the wheelchair is the symbol of disability, both figuratively and literally.

K: Well, I don't like that at all.

E: Okay, but I'm not even talking about the little handicapped access symbol or accessible icon. What I'm talking about is that wheelchair is the most easily recognizable synonymous thing with disability and so it's like frightening for people rather than something that people would see as a source of freedom. I understand that.

K: Yes, no, I understand that, I emphasize with that.

E: I think what’s necessary is a perception change and we never really get that but...

K: I don't know about never man, I really don't. I'd like and maybe that's optimistic I don't know.

E: I just don't think that people will ever be able to separate wheelchair from this notion of suffering. I don't think that able bodied people who are not intimately acquainted with disability will ever be able to see beyond that. I think that for people who have very little knowledge of disability, any form of mobility equipment is inextricably linked with a source of suffering and misery.

K: Why do you think that is? I think that's an interesting question and an interesting point you made.

E: Because it's so medicalized, is probably only one aspect of it but I think that's a big aspect of it. You think of wheelchairs as the thing that gets people around a hospital when they're not well, you think of crutches as something that a person uses because they're literally broken, they broke themselves, their bone needs to heal so they're using the crutches. To most people, it's a symbol of injury or illness and not a symbol of something that is really life sustaining. They think this temporary inconvenience to people rather than something that isn’t actual necessary part of everyday life. Both people like it holds you back, a wheelchair would hold you back, but for me, a wheelchair literally propels me forward.

K: I understand that though. I can understand that point of view, I can understand that a typical able bodied person is probably massively inconvenienced when they break their leg and have to use a wheelchair for a week and then crutches for another six. I get that because your life is different in those seven weeks or however long it takes to heal a broken leg, I don't know, I've never broken my leg, but...

E: Speaking of, oh my goodness, don't tell me that you know what my life is like because...

K: Do people actually do... I have to ask you because I... that's absurd to me. That's actually absurd.

E: People, no people do this all the time. They're like, “I broke my leg ones in seventh grade and I had to use a wheelchair all summer and it was terrible and I didn’t get invited to any of the birthday parties because I couldn't go swimming in the pool because I had a cast on my leg so I know exactly what your entire 25 years of life must be like.”

K: Here's the thing about that, if you're 12 and that happens to you and you think your life is horrible for those three months, I get you, your 12, everything is horrible **[0:21:11 crosstalk]** and those three months are extra horrible.

E: I don’t know maybe I should not have picked formative years.

K: Whatever, don't say you're 25 and you do that. Those three months of your life are horrible. I get it. They are just like you said, for most people a wheelchair and such would hold you back. I get it. Yes, your life is bad for those three months because your life's different now, but then you better and now it's gears into the future, and you look back on that and you don't think ever that it could have been because your life was inconvenienced and not because of the media that you now needed to move by. It's not because you broke your leg, no, no, no breaking your leg is something everyone does. It's because you had to use a wheelchair. That sounds absurd to me but judging by what you are saying...

E: No, I think it shapes how a person perceives things.

K: No, I agree with you, but I'm sitting here like. I think that's nuts. I agree with you that it certainly would but I would sooner suggest... I'm just thinking for myself but wouldn't the unfortunate event be that you broke your leg and not that you had to use a wheelchair because you broke your leg.

E: Yes, but that's not how people think. Then the other thing too is people like to do simulation events a lot, which I hate so much.

K: Oh my god.

E: If you are going to try to use a wheelchair for a day and telling me that you get my life, oh my god go take a long walk.

K: Off a short cliff.

E: Oh my god.

K: I'm conflicted because I really do understand, I hate them. I'm not conflicted with my feelings about them but I do...

E: I think they are well intentioned and sometimes more often than not poorly executed and usually end up with a result not being; gee I get what it's like to be in a wheelchair but man your life sucks.

K: It sucks. Yes, because to them it does. It's different. If- if...

E: Different is always bad.

K: Yes, no, I actually would. If they invented a Larson syndrome exoskeleton thing tomorrow that enabled you to walk more or better than your walker does and you tried it for a day and not for the minimally required three months to get your bone articulation correct like most people do with their wheelchairs, like they roll around for a couple hours, and they don't learn things like how to back into restroom cells or any of that cool stuff. If you did the absolute bare minimum to try something, you'd be like, “Oh, yes, I really, I prefer my wheelchair.” You might end up preferring that anyway, no matter how long you use this metaphorical, mythical exoskeleton, but my point is, if you don't give yourself enough time to learn something, of course, you're going to think it's worse than the thing you're used to, no matter what it is.

E: I think that simulations point to the fact that the world is not designed for people who use mobility equipment.

K: That's why I like them and that's where it stops.

E: The problem is (a), I really don't feel like that's doing enough. I feel like that's the tip of the iceberg, and (b), the lack of access seems to directly translate to feelings of pity. If someone is going to do a simulation, and they're going to encounter a lack of curb cuts or something like that, or a doorway that's too narrow or a bathroom, and they can't get into, I don't want you to come out of that simulation feeling sorry for me. I want you to come out of that simulation being like, “This is bullshit and we're going to fix it.” Then I want you to actually fix it.

K: No, I'll even give them less than that. If you even feel that this is bullshit, because most people don't even get that far.

E: I want you to feel this bullshit without also pitying me.

K: Absolutely. You're right.

E: Because pity accomplishes nothing.

K: I wanted to just say point blank that I think you're right. I feel like most people can see that I was implying that but just so that there's no ambiguity whatsoever. I agree with you. Yeah, simulations are **[0:25:00 crosstalk]**.

E: I hate them so much. I hate them. I hate them. I hate them. I hate them. I hate them.

K: How do you really feel?

E: They're great. Oh my god, they literally just make me want to bash my head against a wall. Is how I feel about simulations, but anyway, now that we know that I'm very impassionate about this particular stance, back to a slightly gentler and topic which is, don't be afraid of mobility equipment. I think that society has painted it as something to fear. I really just wish that people would understand that it's not a big scary thing. I mean, even to the point where when I'm moving through a space people visibly back away from me. I don't think that they think that they're going to catch the wheelchair cooties. What I think is that wheelchairs are just these big old scary things to them.

K: I disagree. I think that they think that you don't know what you're doing.

E: Oh, well, no, that's not even a matter of disagreement. That's just a whole other issue entirely. Because I also think that's true.

K: Which, is even more absurd to me on a on an entirely different plane of thinking.

E: My very favorite thing is when other people tell me how to drive or they complement me on my wheelchair driving. Hey, man, I've been doing this a long time, quiet.

K: You know what the best part is, if you look at the twinkle in their eye when they say that to you, they really think that they're the first person to tell you that.

E: Oh my God, everyone's like, I'm so clever and original. I'm going to make a joke about your wheelchair and how good you are at driving or tell you that you need a license for that thing. Okay, take a number. I've heard it before.

K: Oh my god.

E: I am stuffy in this episode and I’m not even sorry.

K: Imagine if you didn’t need a license for that thing. Oh, that would be…

E: I feel like licenses would be going way too far, but when you get a power wheelchair, I would say for the most part, it's kind of like dropped at your doorstep. You have a couple of fittings and then you're just supposed to figure it out.

K: Having used one for maybe a day to cumulatively across my whole life, yes, they expect too much.

E: I don't think that driving lessons would be all together a bad idea.

K: Yeah, I was joking about the license thing.

E: You would add another layer of complication to the process of getting a wheelchair.

K: Well yes, I agree with you. I'd rather not have them and have everyone have access to them but learn how to use it same way we learn how to use anything.

E: I adjusted relatively quickly. I don't quite know why that is, but to me my power chair was very intuitive. It's to the point where the movement in my hand to operate the joystick is often so slight that except for the fact that the wheelchair is moving, you wouldn't even know that I'm doing anything because I know the sensitivities of my power chair. It really is an extension of my body in the same way that you know if you put pressure on a certain area of your body it might feel a certain way. For me, I know if I put pressure on my wheelchair in a certain way it's going to make a certain movement or jerk me in a certain position.

K: That's very interesting, truly.

E: I also know when people are touching my chair. I mean intuitively like…

K: You can feel the slight weight difference?

E: If you touch my chair and I can't see you I can sense you, because you're touching an extension of my body and I don't mean I have some weird creepy wheelchair sixth sense. I just mean that I am so used to those surroundings around my body space that if something is infiltrating that space, you're invading my personal bubble and I can tell even if I can't see you.

K: That makes sense. I don't know I just feel like we shouldn't see wheelchairs or any other mobility aids as like this, I don't want to say death sentence that's a little too dramatic, but like almost in the way that in the way that you hear people perceive them right?

E: No, I really think that is how people perceive them, like their life is suddenly over.

K: If you are someone that became disabled, like, I can't imagine that. I can only imagine the initial shock of that is the worst thing ever and I'm sure as badly as I think it is, it's 10 times worse because your life is different in a second in a way that you didn't understand. I can't imagine the pure raw emotion that must go through someone's head who's been through that, but for your average Joe or for something like, when is the average person going to use a wheelchair? When they're old. No one wants to get old, no one wants to die.

I get why it's scary. No one wants to become disabled, I get why it's scary, like I just said. What I don't understand and maybe this requires too much thought from like some other person. That's why this doesn't happen, when you see a relatively young person such as yourself using a wheelchair, it's different. Again, maybe it's because I grew up around the sales people. I have this sort of engrained in me, but there's a difference when I see people in wheelchairs like out between somebody who is like our age. I assume that if you're in a wheelchair and you're young, that you're probably more likely born with whatever it is you have so that means to me that you know what you're doing.

E: Or I mean, you kind of had some kind of accident and but again, it’s just…

K: Absolutely. No, but you've had it for so long at that point, no matter what it is, whether you're born with it, or had your accident or whatever at a young age, that you would know what you're doing. If you're young, is what I'm assuming. If you're older, I'm actually more likely to assume that you don't know what you're doing because you might have had a whole able life and this is new to you.

E: Do you mean in terms of like navigating the wheelchair?

K: Yes, not living in general.

E: No what I meant, but yeah.

K: I do strictly mean using whatever mobility--- Let’s call them wheelchairs for now, it’s easier.

E: It does extend to all mobility equipment, though. Yes, that's another thing to you. You make a really good point. I mean, wheelchairs also are associated with getting older or having some kind of malady. Is always interesting when people ask like, what happened to you or what's wrong with you? Or they're like, I'm so sorry you're in a wheelchair like, I'm so sorry you're standing on your legs.

K: Well, that's the thing. That sounds like a sassy come back, but it's really like the exact same thing.

E: It’s the equivalent.

K: Yes.

E: Why are you sorry? You know when you should be sorry?

K: That's what I say to everyone who says they're sorry to me. I asked them why? And like their reactions always like, “Oh, wait, yeah, I don't know. I don't know.”

E: If I didn't have a wheelchair, you should be sorry. You should be sorry for all the people who are fighting battles to get their wheelchair. You should be sorry for the people who end up stuck in bed because of insurance struggles to get the coverage for durable medical equipment. Don't be sorry for me.

K: Yes, that's a huge difference. Actually, I just thought of something. If I may, slightly off topic, completely off topic, the only thing is similar is a mobility aid. I went through several. I went through several when I was a kid. I used the walker and then I used crutches and then use one crunch and they use none. I went through several.

E: One crutch. Two crutch, red crutch, blue crutch?

K: Pretty much and the walker was actually read, funnily enough. I learned that none is best for me in the way that I move that might be true for you. It also might not. I'm willing to accept that there is a stigma around wheelchairs in particular, but if you're somebody in search for your perfect mobility aid, I wouldn't let that sigma prevent you from moving to the best of your ability. That's kind of, I don't want to say said, but if you're somebody who doesn't want to use a wheel chair because…

E: No, I know exactly what you mean. Almost like for vanity or for like you're worried about admitting defeat?

K: Yes, and I understand that that's probably a very big personal struggle. I feel like every disabled person has to do that at some point. I know I did, but it wasn't so much defeat as me going like, yes, this is my life. If you're somebody that doesn't want to use a wheelchair or is afraid to, you like sure, but don't let that stop you from using what could be or could not be your best way of movement, for vanity sake.

E: That is so true. That's such good advice and I definitely had a moment of hesitation getting a power wheelchair because I do still use a manual chair pretty frequently all the time in the house. I used to use a manual chair a lot when I was younger, navigating around middle school, high school, things like that. As things got bigger, essentially my world got bigger. High school with a bigger building than middle school and my college campus was bigger than my high school building. A power wheelchair essentially became a way to preserve my arms and my shoulder joints. I had a moment of feeling like am I admitting bodily defeat or becoming lazy or something like that.

When I first got my power chair, I was in high school and I remember very clearly the first couple of weeks that I brought my chair to school, I switched back and forth between my manual chair and my power chair. People were very quick to make comments about it. Mostly it was like, “Oh my god, that's so cool. “ It was also a lot of like, “Oh, why do you need that? Why are you switching to that?” I was so compelled to constantly explain in a way. It doesn't, it doesn't mean anything different my disability and not progressing. It just means that I got this power. I was so quick.

K: If you're going to explain anything. If you're going to make one point though, to someone that you care about, like your friends. I would say that that's a pretty good one, because they don't know, but that’s it.

E: Sure, everyone kinds of…

K: I understand your frustration.

E: … nosing their way into my business.

K: Absolutely, absolutely.

E: And wanting to know was something more “wrong with me.” Mostly, it was just like, “Wow, that's so cool.” Which, I still get that all the time. Anytime I use any of the features on my power chair, like the elevation or the tilt, which is only a matter of access for me and making my life easier.

K: As opposed to what?

E: When I raise my chair up, or when I lean back.

K: I know what you’re talking about, but I mean, what else would it be?

E: Other people think it's just like, “Oh, you got your wheelchair tricked out. Oh, that's so cool. Oh my god. It's like Pimp My Ride for wheelchairs. Whoa.” I've kind of taken to being like, oh look, here's my party trick. I can raise myself up to your eye level.

K: I mean sure if you.

E: I still explain away my mobility equipment, despite the fact that I am inextricably linked to my mobility equipment.

K: You know what? It's a conversation piece I guess. I don't know that's dumb, but at least you're funny about it. I guess I don't know.

E: Well, that's the thing like…

K: You have to be right?

E: No, I really do. It's a very rehearsed per formative thing. When I first got to my college orientation, we are all sitting and standing in a circle. I was like, “Hi, I'm Emily and let's just address the elephant in the room. I'm sitting on it.” Like, you know. Ha, ha, ha, ha, ha, ha.

K: That has to be exhausting.

E: It's all the time. All the time.

K: You know the best thing about walking is, I never have to do that. I didn't know that up until now. I didn't know there was such a thing as the best thing about walking, but my god, you just help me find it. Oh my god. That's awful. I can't wait to do that to you every time I see you from now on.

E: I feel obligated to make other people comfortable with my disability. The thing is that I'm not uncomfortable, but I am made uncomfortable by other people's discomfort.

K: Can I ask you something?

E: Sure.

K: As a matter of pure curiosity. I know that in a perfect world you shouldn’t have to do that. I understand that, but I imagine that it's easier for everyone if everyone's comfortable. Of course, it's not your responsibility to make them comfortable. As a person with a disability, you probably went through some sort of self-acceptance phase and it probably hit you really hard one day if I'm imagining correctly, as is the case with most of us.

When someone else is uncomfortable around you for whatever reason they might have because of your disability, do you sort of sympathize with that in a way because there was a point in your life where you had to learn to accept yourself? I mean, you can correct me if I'm wrong, but I imagine the answer is, yes, and that's why you might not mind too much when you calm the other person down by making a dumb wheelchair joke.

E: Are you essentially asking me if it bothers me or if I mind it.

K: I imagine it bothers you a little bit, but I what I'm asking really is, not do you mind? But when you do it, I imagine you don't do it to shut people up. Does it bother you that people are uncomfortable around your wheelchair not knowing anything else about you? Knowing that you probably, and correct me if I'm wrong because I don't want to be wrong because if I am it defeats the entire point of what I'm trying to say had to do the same thing to yourself at some point your life, become comfortable with yourself. Knowing that you went through that, does it bother you that when other people do it to you?

E: Huh! That's deep. It bothers me in so far is that I have to do it constantly. For other people, it's an obligation. It's like part of my job to help people and not be so on edge about…

K: Oh, it's not your job to do it. Sorry, go on.

E: No, but that's the thing. It's my personal responsibility. I can leave people floundering and uncomfortable, but what would that accomplish?

K: If anything…? I mean, if you're seriously asking me if it's not a rhetorical question, I think that would make it worse. I think if you change one person's view of disability just by beating them, I think that that's doing something.

E: If I want people to interact with me “normally” then I have to do something to normalize the situation.

K: Okay, that’s fair.

E: It frustrates me, but I don't wholly object to it. The other thing is your question while it's something to think about doesn't totally compute in my head because for me, I never looked in the mirror and had a conversation with myself like, “Well hi Emily. I'm Emily and check out that big old wheelchair you're sitting on.

K: No, I understand that.

E: I go through this constant cycle of working on self-acceptance, but when you meet someone, you have about five seconds to get past that initial stage of, do I accept this person or not? It's up to me to immediately make sure that that happens. Or if it's not a context where I need to make a wheelchair joke, it ends up being a context where I immediately have to speak up and sort of prove that my presence is about more than just the wheelchair. I have to prove that I am there to engage and communicate in a certain context and not that I'm just a person who's plopped down and being decorative.

K: You're not the token disabled person

E: I guess, but sometimes the jokes that I make are to cover up my own embarrassment with myself. Because my chair is so big, as aware of my surroundings I am, sometimes the surroundings are just not meant for me and I'll hit something. I've like pulled entire racks of clothing. I've pulled desks in college classrooms. I’ve knocked a bunch of stuff over. Now my customary joke is “Oh, I was just rearranging the furniture” and everyone's like, “Hahaha” but really…

K: Yes, you're embarrassed and they have to deal with it now and it's just a bad situation all around. Yes, no, that's a perfectly good answ-- I didn't really expect you to go deep into it. I actually really appreciate it because I did not know. Walking, am I right?

E: Wheelchair… Am I right?

K: Yes. No, but I mean, really, like, it's just how we get around man. Not much more to it.

E: Yes, I think it's good to talk about how you do things, though and to acknowledge the complexity of it, while at the same time also realizing, and this is my takeaway.

K: Okay, we're doing… Yes.

E: Yes, this is my takeaway. Acknowledge the complexity of different modes of mobility and know that there is no one right or wrong way to be mobile, but at the same time also don't take it so seriously.

K: That's a very good point. I’m glad you said that because we don't.

E: In so far as we had a long conversation about it I guess we do, but this is not going to keep me up.

K: This has a purpose. Every day in life like, you don't care about your wheelchair like that.

E: No, not at all.

K: I bet you barely even notice it in that sense.

E: You don't think about it just the same way you don't really think about getting up and walking around.

K: That's exactly what I'm saying.

E: When I do talk about it, is when something isn't accessible to me, but in surroundings in which nothing is off limits to me in regards to structural accessibility, I don't think about it at all. Why are you thinking about it? Stop thinking about it.

K: That's a very good question. If we just don't think about it, it'll go away. Disability is a nutshell. No, no, go for the love of God.

E: Oh goodness. What's your takeaway?

K: Walking is weird man. Ever think about what it really is? Now, just get around the way that feels most comfortable to you and don't let anyone tell you that one way is better than the other.

E: Yes.

K: If that's walking, then it's walking and if it's not, it's not.

E: I was going to say we either put one limb in front of the other, we put one wheel in front of the other, but the wheels move in tandem. So that didn't really work, the way I intended.

K: That's okay.

E: But that's okay. Anyway, I'm Emily.

K: I don't know why we can never end that episode. Why is that? I mean, I'm Kyle. Why? We always we end so strong, and then we say goodbye, and then this happens. I don't get it.

E: Because we don't take ourselves too seriously.

K: That's a good point. I don't even know what I'm doing. Okay, good...

E: Wait. Let's try this again. I'm Emily.

K: I'm Kyle, I think.

E: I hope that's who I'm talking to.

K: Wouldn't it be weird if I was someone else.

E: Oh, gosh. Whoa! Okay, this is getting too deep. Thanks for listening.

[END OF TRANSCRIPT]