### **Transformation**

Age 27
Assigned Sex Female
Pronouns They/Them
Gender Identity Non-binary
Race American

#### What is your gender identity? Please describe

I experience gender as this thing that is not really a part of me, but that is part of the game that I have to play in order to be - you exchange certain things for certain things. Femininity is generally exchanged for safety. You make yourself non-threatening; palatable. You make yourself pleasing, and the reward is there's not violence. And, alternately, when there already is violence present, masculinity can be a response of protection and of making space and establishing boundaries and maintaining those boundaries.

I understand gender, I think, as more of a survival context tool. Something like code-switching, in the way that we understand that. It's something that allows me to navigate the world safely, but when I am in a space where I feel most connected to myself and I feel most authentic, I don't feel that either of those are true. It doesn't feel that I'm statically within either of them, and I don't experience my gender as womanhood being a threat to me. I'm not offended when people accidentally perceive me as a woman. I keep my long hair for a reason; I can't afford to not have it. I'm not a great driver and when I have short hair I get pulled over and given tickets relentlessly. I had short hair for 6 months and I got 7 tickets that amounted to over 700 dollars over little things, like "Oh you made a left turn when you weren't supposed to". I couldn't see the sign, but that doesn't matter. Or, "You were 7 miles over the speed limit" and I'm like, really? You can get pulled over for going under 10 mph over the speed limit?

So, this is the other thing I understand about gender. Femininity is associated with innocence. When there is a question of guilt, I absolutely have to appear feminine. If I

am less feminine than another person in the room, or I'm not feminine enough, or am in some way dissonant in that I'm not playing woman well enough, there are consequences for that. I get a ticket, or it escalates and he asks me to get out of the car, or somebody takes something I say as aggressive when I was just being honest or up-front about something.

I feel like gender has always been something that was really confusing for me and I wasn't even really concerned with being authentic, I was just concerned about being safe and figuring out how to adapt to the situation in such a way that I would maintain the advantage and the upper hand, which meant coming into a space, immediately assessing the situation - who experiences what. And you can tell, certain types of men respond to different types of things. Same thing with women. When you walk into a space, depending on who they believe themselves to be, there are certain ways they expect to be treated and you have to be guessing and perceiving and guessing what that all looks like constantly and it's so stressful. So, I think I find the best spaces are spaces where gender isn't something that we're questioning anymore. I'm not asking what your gender is, I'm asking what your pronouns are and I'm treating you the same as everyone else in the room. And trying to maintain that level of breaking people's associations, too. "I identify as a woman therefore I deserve to have the door held open for me, therefore I deserve a ma'am after you hand my change to me." or the opposite "You should thank you for holding the door open for you because I served you as I'm supposed to", or whatever.

It's this constant gamified aspect of society, just like the classism, right? Just like you don't want to wear shirts with holes in them or people are going to respond to you differently. If I walk into CVS wearing my pajamas they're looking at me like I'm going to be stuffing things into my pockets; very different if I wear a pants suit. It's the same situation for me; I don't feel like any of it is inauthentic or authentic. It's a matter of, did I do it because I was trying to survive? Was it coming from a piece of me that's a survival piece or is it coming from a piece of me that's genuinely present and creative? Because, you can't be creative and be defensive. You can only do one thing: you can be yourself or you can be worried about being on the offense.

So, I think that's how I understand my true gender identity. When I don't have to survive, when I don't have to fight, when I don't have to flee, when I don't have to be

afraid, what are my options? How do I want to exist, how do I want to feel and how do I want to be perceived and treated? I think it's really important for me to have the ability to fluctuate and to have people respond to me in that way and just mirror back that change; that I'm not invisible. I don't have a dress on today, I'm wearing slacks and a bowtie. 'Today, I am sir! Sorry, catch me tomorrow and you might find a different-' to just have people be responsive and care about how you're showing up and to witness you in a genuine way.

For me, being non-binary, a lot of people experience it as, "Oh, it's so much work for me to relate to you, to be responsive to the way you're changing, to the way your presentation is changing" But, it's not really that hard, because you notice it enough to be uncomfortable... When I grow out my mustache and I show up and I'm wearing something that's totally opposite from the last time this person saw me, they notice it, because they become uncomfortable. So, if you could just notice it and change the pronouns appropriately, that's a step above. That's going beyond to say, 'I see you, I hear you'.

Which is no different than someone that you care about in your community saying "Hey, I have trauma around text messages. I really want to be in community and conversation with you guys, but sometimes when I get bombarded with text messages, it actually gives me a lot of anxiety. Could we maybe do a group video call instead or do both? That would make me feel better" And then, if you actually care about the person, you would make the change and it wouldn't be a big deal. It might be a bit inconvenient, but you care about that person being able to show up fully, and they're telling you it's a source of trauma for them, so of course you do it.

But for some reason, gender is this thing people don't want to budge for and don't want to admit that it's been traumatic for this person for their whole life. Do you know what it's like to be dressed up in bows and lace and paraded around? It feels like being a zoo animal and it's horrible. These are gendered experiences. Pageantry doesn't affect boys in the same way, that's not a social paradigm we force them into. We make them do a pageantry in terms of sports; it's different, like Gladiators, it's not the same thing. They're both traumatic, the force, the lack of choice is what makes it traumatic.

So, I've had a love/hate relationship with gender. I still don't know if I love it - I don't know if it can be a tool of liberation. You being able to show up as you are and maybe today you are feeling feminine and that's real and to be able to switch your pronouns to speak to that and to name this part of you that's suddenly alive is this beautiful power, but at the same time, the way that it currently operates is to keep people in their place. It's really unfortunate, because when you allow people to be expansive, really almost everyone desires it.

I just started reading this book by Mia Birdsong called *How We Show Up*, and she's talking about, who are the most disenfranchised, who are the most disconnected people? It's actually the people in power. It's actually straight white men that are the most embarrassed about lacking community, and not knowing how to be connected. Like, yeah, they have friends, and they have family, but they feel like they don't even know them, or that their friends and family know nothing about them and are strangers. How do we get there?

Well, your gender became this power construct where you were unable to have a full spectrum of emotions, which means you can't have a full spectrum of preferences, or decision making ability, or autonomy in your own life. You think you're free, because you've earned success, when really, you've just caged yourself in a particular way, and you're so angry that when you see somebody else, like me, who is not successful in the same way... Like, I'm on food stamps, right? It's not successful in the same way. But, you know, I'm working on intergenerational trauma, I am healing a chronically ill body, I'm doing community work and setting my community up for success going forward, and trying to lift all of us together, instead of worrying about how I can pay my rent. And ultimately, I feel a lot more connected.

And it's true. Before the quarantine, I was hosting, like, cuddle parties and things. It would always be the White man, after class, would wait till everybody else would leave, and they'd be like, 'I've never experienced anything like that before'. Like, I don't want to down-talk any of the stuff I've done, as if I didn't do somatic research and read all these books and do all this practice – I did – but also, this is just playing. I'm like an adult camp counselor. I'm just trying to get people back to a place where they can access their inner child, where they can access this creative space. Where they don't feel like they need to make a grab for power, and that they can just exist. That's

not anything crazy, but they don't have access to that, because they're so worried about maintaining power and control. Like, bro, put on a dress and some lipstick, it'll feel good. Dance to Beyoncé a little bit and relax. You'll still be able to be a dad after.

I think there's that fear. I see that fear when I'm in conversation with my dad. When 'they' became the word of the year, he was like, 'Can you believe these trans-es? You're not one of them, are you?' And it's funny, because they are very progressive, and they're like, 'No, we love the gays'. And I'm like, 'Okay, hold on. Yeah, actually being neither a man nor woman is also being trans, because you're not occupying a traditional space. So being none is still another. So yes, sorry, I am also in that group, and now you're forced to expand your empathy and compassion to them as well'.

#### Were you able to have that conversation with your dad?

Um, it was a long conversation that happened in small bursts over a really long period of time, but I do feel like they're coming to a point where they understand it. That doesn't mean that they don't slip up. They won't use my chosen name, they still use my birth name. And that's fine, when I took a new name, I wasn't like, 'This name is dead, I never want to be this person again'. I just sort of saw it as, this is what I was given, and I sort of started here, and then I augmented. I said, 'You named part of me, but you missed something. It just wasn't all the way there, and I just added a little something around that'. But, I don't feel that it's cancelling that out in any way. I don't feel ashamed of having grown up and participated in the rites of passage for women, and that kind of thing.

I feel hopeful. My son gets it and to me, that's my primary concern. We got time to fix the past generation. He is growing up fast and he is very pale, so I need to make sure that we got all our ducks in a row and he knows how to use the privilege that he has. He knows where it's at and what's going on and what choices are available to him. I never shamed him when he wanted to dress up in a My Little Pony dress that he used to love and a little sunbonnet that he used to put on when he was little. I'd be playing Shania Twain, and he'd be running around in this outfit. The smile on his face, it's just pure joy. And at no point is he like, 'Oh, I want to be a girl', or like, 'I don't want to be a boy anymore'. He's just like, 'I know that I can express myself and choose and have

autonomy in that, and that it wouldn't take away from who I am'. You know? So that was really my only goal.

#### How old is your son?

He's 10. He's in fifth grade. It's crazy, they grow up fast. Well, and sharing an office with your 10 year old is so weird. He switched schools and now it's online. I'm here, and he's like, over there, and we're both on our headphones. I like it, because I get to overhear. When I hear something fishy, I'm like, 'Don't say anything, but that part that she said, that's -----'. You know, like, 'That's fine, but we're not celebrating Columbus Day. So don't put that outfit on. You can tell your friends. He wasn't a cool dude, so we're not doing that'. You know, little things like that. And not that we didn't talk about these things before, but it's another thing to be able to, in real time, be like a commentator and give context to the education that's going on. So yeah, that's a really unusual opportunity. It's definitely tiring and it's definitely difficult to do the scheduling, because I also work for myself and from home. I wouldn't mind if he could go back at least a little bit, because I think he misses it. He needs to play with kids face to face, but I do like having that involvement, so it's not bad.

## So, we sort of covered this, but if we could get a little more in depth about what femininity and masculinity mean to you; what those terms actually embody for you?

I experience them as flavors of the same energy. Depending on where the sources are, it determines the action that I take. I feel very feminine when I'm in a space of being receptive, like when I'm receiving or being affectionate or caretaking. My love language is very tactile; I like to do acts of service, especially around food. Feeding and making sure that everyone drinks enough water and has taken their medicine and their vitamins and has all the tea they need and all that sort of thing. That feels like a very feminine space for me, especially because I became a mother before I was even an adult. I got pregnant on my 16th birthday.

I thought I wasn't able to have kids. Medical malpractice; they lied to me and told me that I only had one ovary. It turns out it was fine. How? I have no idea. There are so many weird things that have gone on with my body. So yeah, I sort of had to separate what is feminine from what is womanhood. When I separated that, it was

because I used to be very resistant to femininity. I mean, I biologically don't produce almost any female hormones. I have PCLS and a couple other conditions that essentially means my body composition is largely androgens. So, I sort of fall on the intersex spectrum from a hormonal perspective. Everything isn't all the way switched on to one side or the other, which is actually really common. We're actually about as common as redheads, so you probably know somebody that's on the intersex spectrum and they didn't even know it. You can go your whole life not knowing it until you try to get pregnant and realize that there's fertility issues, or something is in the wrong place.

So yeah, I think I exist in this space where my presentation fluctuates as my hormones fluctuate. Like, I'm currently menstruating. Anytime I'm menstruating, it feels like a very primal space, like a very private feminine space where I feel like femininity is something that I have to be very selective about, because there's a greater capacity for vulnerability there than in masculinity. That's how I experienced that at least; it comes naturally in the space when you're receptive, and it's sort of open and porous. As a result, I think I resisted that, because I didn't feel comfortable being masculine enough to balance myself out until much later in life.

There's all these weird, micro-aggressive traumas of just living and failing to defend yourself when something happens and when people are associating you with taking advantage, because they see you as innocent. So, the same exact coin that I cashed in for safety also has a price attached to it. The other flipside of that is, they're more likely to try something, right? Like, yeah, they're gonna do what I'm asking with less resistance, but they also might try to get something at the end, or might try to push my boundaries in another way.

It's taken me a long time to understand that it is not a weakness, and I now understand how much of a strength it really is to be able to know when to switch it on and when to be receptive. Because really, the femininity is sort of this glue that holds me together. In my relational sense, it's the part of me that forgives. When there is a reason I should be mad, like, they did mess up and I want to hold a grudge, because the masculine part of me is like, 'Boundaries; we're not letting this happen again, they need to learn a lesson,' but then the other part of me is like, 'But they're not

disposable. How can we learn a lesson?' So, there's sort of this constant dialogue going on.

Depending on where I'm at hormonally, I might have more or less of one voice or another. I experienced masculinity as very structural. My masculine self wants to make the home safe. So, what does my feminine self-need; my feminine self needs to make sure that it can do all of the self-care stuff, which means my business has got to be in order. I can't take time off to relax if I'm not up to date on my projects. So, I think my masculinity comes out very much like my Virgo rising. It feels like that has a masculine element to it, where it loves scheduling and loves looking ahead and being like, my bills will be paid, so I don't have to worry about it, I can do all my spells and rituals and my manifesting and not have the stress. I experienced them as these polarizing forces that balance me out; where the truth of me in any given situation is somewhere between them.

How much or how little I get is fluctuating and my responses to them, I think, are very different as well. Like, I love a balanced masculine. When there's a balanced masculine in the room, I will instantly find them and I'm like, 'Yes, I'm here to be your beta, I will do your bidding. How do we organize these plebes?' I get very into the moment and I'm like, 'What do we need to do? Let's delegate and task orient'. I get very into business mode, whereas I find that I rely more on my feminine self when chaos happens; something unsuspected. If someone has a trauma response, and I need to adapt, I need to change the programming to be able to respond to them or something I had planned that I thought was perfect, the structure that I outlined, well, it's not working for the group of students I have and I need to improv it. That's where my feminine expression feels like it can really thrive is where the masculinity created this container. It had a guess, it doesn't always get everything right, but when it doesn't get everything right, it's still okay, because feminine me is really malleable takes the shape of what it's in, sort of like mycelium space where you're swimming around with everything and it feels very much like shadow and light and that interplay between these two forces.

The meta-emotions are also really interesting to me; how you feel about femininity affects how you experience it, how you embody it, and how you access it, or if you access it, and think about masculinity. It's so interesting to see the way that those

things play out and the way that a fear or distaste or discomfort with one will throw you so far in the other direction. It's super-duper interesting. I'm very fascinated by it.

It seems like you're really in tune with your own body and your own brain in terms of maintaining and recognizing what's happening. Did you have any role model for exploring this? Or was it just through your own research and your own intuition recognizing it within yourself?

I think I knew this was something that was, like, a dirty secret for a really long time. I would approach it, I would get close to it, and then I would call it something else. I would get close to it, and I would be like, 'Oh, I'm a lesbian, okay, that's what it is'. Or, I get close to it and be like, 'Oh, I'm just butch?' 'Oh, I just like this color palette'. I kept sort of wanting to call it something else, so I was not actively living a full expression.

It wasn't until I started making friends that I didn't have to do work to be seen around... That it didn't matter if I wore the trousers and the hat and grew my moustache out. If I saw a certain friend who's also trans, they just use the right pronouns. They just say, 'They are looking really handsome today'. They just use the right words, they find little ways to give you these kernels of experiencing euphoria in the way that you want to with your gender. That makes you feel brave enough to ask other people that care about you to do it, too.

It's something that I think has to start - at least for me, because of the fear and the layers of repression that I had built up around it. You know, I say I'm American, but it's first generation Italians, so they had very particular ideas about what women were supposed to be and do. Not super. So, I think I was really hungry for a role model of just somebody who experienced gender in a way that was liberating, and not repressive. I grew up watching Xena Warrior Princess and Tomb Raider. Those were as close as I could get, because they felt like these characters that were occupying the liminal space between femininity and masculinity that I wanted, even if they weren't naming it.

Then, I started coming across poets like Andrea Gibson, who is not trans, but is a butch lesbian, and was presenting in a different way, and was sort of giving me permission visually. It's mostly other non-binary and gender fluid artists and friends, more so than celebrities, I think. But the writers, and experiencing the poetry and the

writing from the perspective of non-binary and other enby's, was the representation that made the biggest impact on me, because it was the interior monologue validation that I needed. Like, oh, I really am not making this up.

That's the feedback you get a lot of times. It's like, it's such an inconvenience. 'Would it kill you to just keep this to yourself? Like, really, you can't just hide this for your entire life? You really can't do that?' And you know, getting to a place where other people are like, 'I don't want to do that, this actually is unbearable. This actually is making me want to not exist at all'. Like it actually is worth the risk. And it was it was those stories that really made me feel like, 'Oh, this is worth doing, even though it is a scary thing and that people are gonna question if it's real, and they might not understand, and that people that I love may never understand' and 'Can I still be loved by them and still receive that love and find a way?'

Like, my best friend is straight as a whistle. As hetero as they come. We grew up together, though, so it's like... You can't get a 15 year friendship back, doesn't matter that we have nothing in common now. I don't mean nothing, but our hobbies and things are so different, and for a long time, they were like, 'I don't really get it' and when my family got into fights, they didn't always pick my side. And then, they just started doing little things like, they went to this dispensary – they're a medical marijuana patient – and they got this sticker that said, 'they/them', and they were like, 'Oh, they had these stickers in the dispensary, so I just grabbed one'. Little things like that, where it's like, yeah, they don't always remember to use the right pronouns, but in that moment, they thought they knew that this would bring me joy, so they gave it to me.

Or like, my other best friend for years and years and years – also very straight – was like, 'What are things that we can do to make you feel more seen with me? I want to give you those experiences too, even though I'm not in that'. And I was like, 'I don't know, maybe we could shave together'. So, we would shave our beards together. I would do his and he would do mine, and we'd have our little husband moment. It didn't make him less attracted to me. He's still straight, and is attracted to me, and doesn't identify in a different way. Just because I'm not a woman, and he knows that on the Kinsey scale that means that he's somewhere, but it doesn't disrupt his life, right? I think those are the most profound role models for me; when my straight

friends make that little bit of extra effort to just be like, 'How can I make you feel safe? How can I make sure you can show up and feel like you're here all the way?'

## Sort of along those lines - and this question was specifically about appearance, but I'd like to open it up and make it more general. Have you felt pressured to change the way that you present by family or friends?

Only my entire life. I used to get horribly shamed in middle school through high school - there was a little bit in college, but I shut that ---- down. By then I had a voice. But yeah, my mother was a hairstylist. I was this already traumatized kid: I'm super hairy, I'm brown, I'm in this entirely White, blonde school. I'm really nerdy, I'm getting bullied, I have no friends. She just wants to make it easier for me to connect, so she starts very early on in my life with the hair removal, waxing me. She works for salons, so it's accessible. And we're shrinking, and we're waxing, and I'm constantly covered in nicks and cuts and burns. And I have EDS, we didn't know that at the time, it was undiagnosed, so every time I would get waxed, my skin would come off. All of it, all of the skin would come off, and it would just be giant burns on my face. It's a miracle that I'm not covered in scars all over my mouth and my eyes. I should be, but somehow the skin healed and it's not terrible. It's just paper thin, so it would just come off and leave these scabs. By the time the scabs fell off, the hair had grown back. It was just this crazy violent system where every week, going through hours and hours and hours of pain and trying different things: lightening my hair, lightening my skin, trying to just stop people from being nasty, and really struggling to figure that out.

It didn't get any better. I mean, high school was just as bad. I went to an all-girls Catholic school, so it was a little worse, maybe, because then the slut shaming comes in as well and anything that happens to you is always your fault. And, there's also the homophobia in there and so many layers to this absolute craziness. I wasn't allowed to wear pants – all I wanted in the winter. At my all-girls school, you could wear slacks only for like this two month period of time. Me with EDS, poor circulation, I got icicle toes, I'm always cold, and I don't want these skirts. The boys are flipping my skirt up and sexually harassing me, I'm getting molested everywhere. I'm like, can I just cover my body, please? If it's so horrible for my knees to be out, because my socks might be too short and I might turn into a ----, can I just put some pants on?

And that was, of course, a big deal. They didn't want you to do that, either, because you couldn't be too masculine. It's just constant nonsense.

I went to college, and I got out of college, and I was like, I'm going to do it. I'm going to work for a corporation – put my glasses on and put on the collared shirt, and I'm trying to do it. And it was just constant, you know, everything. Like, I don't own bras, it's really uncomfortable for me to wear a bra that has any kind of tightness. Again, because of the condition I have, it's super uncomfortable and can even cause abrasions. Skin comes off sometimes for no reason. I got hives the other day covering my arms all the way up both arms for, like, three days. No reason, just cuz random things are always happening, and I'm just trying to respond to them; put the little fires out that sprout, so that I can function on a daily basis.

But when you're in an office, you're sitting where everyone can see you in this cubicle. My stretching is considered sexually suggestive. I'm like, dude, first of all, if this is sexually suggestive to you, you've got something going on. It's not my problem. I'm also just working, I'm trying to do my best job, stop sexualizing my body, right? Like, this kind of crazy ---- wouldn't happen if I was a dude. Like, my one co-worker at the time went to the gym, and on his lunch break, he'd be like, 'Alright, I'm just gonna go take a quick jog around the block, I'm going to come back, I'm gonna do my stretching in the break room'. But, he's a guy, and so that was fine. But, if I were to go outside and do yoga and come back in, that was not okay. It was this weird double standard, where if it was aggressive and masculine, it was fine. If it was feminine, it wasn't fine.

But then, if I came in and I wasn't dressing femininely, then that was a problem also. I just didn't feel like I had any freedom; on where I moved, or how I acted, or what I did. If I wanted any respect, I had to deal with, you know, Jeff's weird Boomer comments about how my marketing efforts are, 'A little bit like wh--ing out'. I worked for a staffing firm at the time. So, it was like something like, 'Pouring out our personal lives for internet clout' or something, just because I was like, 'People on social media get really engaged when you share things that are genuine and authentic. So I was thinking we could start with some personal stories from within our company, and sort of go from there. We can feature a new person every week, just sort of show that we have expertise on staff'. And if I want my social media campaign to be picked up, I

got to be like, 'Good one, Jeff!' instead of being like, 'I'm so uncomfortable. Can you not casually reference me like that? Because I know that you don't think whores are a good thing. It would be one thing if I thought that you believe whores were just a valid job like everybody else, but I know that you don't, and so it made me very uncomfortable'. But, you can't say those things.

It's like that at every single job. I'm not kidding you. I tell people this all the time: I became an artist and an entrepreneur out of necessity. This isn't something I wanted, I really wanted to just get a day job, and then just do my art under the table secretly, because I didn't even want to show anybody anything like this for me, I'll just hide it forever. Every single place I ever worked, I was sexually abused and harassed. Either it was verbal, or it was physical. I mean, years of it, and it didn't matter if I went to the manager, didn't matter if I went to the owner. It didn't matter who I went to, because ultimately, it came back on me. Even if in the moment they tried to pretend like they were on my side, ultimately, it came back on me. I was like, I shouldn't have said anything, I should have just put up with it. I should have just dealt with it. And as a result, people treat me with hostility, and then I'm forced to quit because it's unbearable. This has happened many times, like every single time.

And if it's not that, then it's white men hiring me for things and agreeing that they're gonna pay me a certain rate, and then trying to undermine and undercut and go back on what they said. When I was doing freelance work, it was a lot of that sort of thing. Like, we want you to do this. I get it done, I deliver it, and I'm like, okay, you promised me X amount of hours, like, where's that payment? You're asking me to do more work, and you didn't even pay me for the last stuff that I did? You know, so it's a lot of weird things like that.

Since I've started my own companies and sort of removed myself from needing to receive or be anyone else's employee, the power dynamic has shifted. I don't know if the chicken came before the egg, right? I don't know if people suddenly respect me because I just am more in my power and so I set better boundaries, because now I'm my own boss and I don't have to worry about if so-and-so does something inappropriate. If you do something inappropriate, you're not a client anymore. That's it. It's one warning, 'Hey, did you know you just-' or, 'Hey, I know you weren't thinking about it, but you just-' For example, let's say I've got a photoshoot, and the

photographer just reaches over and he brushes my neck to move my hair away. 'Hey, I noticed that you just crossed the physical boundary. If you need to move something, please let me know and I'll move it myself. If I can't do it, ask me, and I'll let you do it after I verbally consent to that. But, it's totally not cool for you to just reach in and touch me unannounced. So, if that happens again, we're done, the shoot's over. Just letting you know'. And if that were to happen again, I get to leave, I don't have to worry about it. I don't have to take my voice up an octave and be like, 'Well, it just makes me really uncomfortable when that happens, and I don't want you to take it personally, you know, I really like you, but-' I don't have to do all that.

I don't like beating around the bush, I don't have to do all that fake playing into who somebody wants me to be, and as a result, the people I'm doing business with are suddenly so much more respectful. It happened this year actually, the big shift. Even though I've been out as a 'them' for, like, four years, I haven't been as adamant as I am now, like, 'No, you really do need to just take this little extra step to do better'. And all of a sudden, people are respecting boundaries on all fronts and I'm feeling like I finally found a way out of having to change my appearance, or having to play those respectability politics of having to, like, earn something by covering my tattoos and pretending that I believe something I don't.

It would even happen racially. Like, I would be in a boardroom meeting or something, and someone might just make a passing comment that's sort of white supremacist-y, and they just expect that, because the whole room is vaguely white, and I'm like the only racially ambiguous persons - they look at me as, like, the gauge if it's okay or not. And a lot of times, I was not in a position to say anything, previously. Now I am! I'm like, 'Cut that ---- out, what are you doing? You're embarrassing yourself', like, 'Hey, your racism is showing'. And it's not even a problem [to speak up], and people are being accountable this whole new way. Is that because suddenly I'm living my gender identity in this way that's more honest and not taking bullshit? I don't know. Is it because people are suddenly taking the idea of gender as a flexible thing that people can self-determine seriously? Maybe? I'm okay with any of it, though. I don't need to know why, it can be mysterious.

So, we've talked a bit about how people in business situations have undermined you. Have you had specifically positive, affirming experiences, aside from just

# coming into your own as the person in power? Have you had experiences in a business setting where you feel like the people you've been working with have done specific things that were really affirming to you or empowering to you?

Yeah, I think this is as much about gender as it is about trauma awareness and being trauma-informed. One of the collaborators that comes to mind right away is ----, who I performed with earlier in January. She is a musician and an art director, producer, musician, dancer, pornographer; does all this really incredible stuff, interdisciplinary in all these amazing ways. She wanted me to do this project called erotic dance. And I charge, because I am very sacred about who I allow into my erotic energy - which is not a shame on anybody who is able to access that quickly and easily and charges less for it, it's just something that I worked on for 24 years, gruelingly, to get my body back and to get into sensation and to find what is truly erotic to me, to heal sexually. So, I am extremely selective about who I allow into that space and who I want to create with that energy. It is not about who throws the largest sum of money at me, it's really not. And I had a lot of really strict boundaries around that, around how I wanted to be perceived, how I wanted things to go; what was or wasn't okay, what would make me feel safe. And even though it really was a lot to ask for a first time collaboration, she rose to the occasion and didn't make me feel bad about any of it. Like, did not ask me to apologize, didn't make me feel like it was an inconvenience, was like, 'You are worth the work, and I'm going to do this for you'.

This is what you need to show up, and she has a lot of experience. So, it's really easy for her to just get dropped into that headspace and just get into that central body and begin dancing. For me, we had to do a lot of vocal work warmups, we had to do a lot of practicing out almost different characters, like different levels of energy, with each other. We had to do all of these things to get to a place where I could really access that from a genuine space, because I was like, I'm not going to perform, I want this to be genuine if I'm going to do it. She went through the extra steps to make that accessible to me, and that was the most profound example that comes to mind.

Sometimes, it's just as simple as - when someone hires me for a shoot and they say, when I ask them, 'Is there something that you want me to bring?', because I know the default is that they probably want me to show up with makeup and be feminine. So,

when someone just gives me the option to be not that, and to be like, 'Bring whatever you want, I don't care' or, 'How are you feeling today? How do you want to show up?' Or giving me some kind of choice, like, 'I have these three outfits, which one of them feels the most you, or which one do you feel is the best balance of masculinity and femininity?' Or when people specifically source me for concepts and problem solving and projects that revolve around that identity specifically? Like, 'I saw some casting call for for projects around gender, and I know you love that stuff'. I love that.

That is something that's super easy, because, you know, maybe you wanted to hire me for a bridal thing, but you could throw me in a suit for the last nine minutes and take a couple snapshots of that, too. Maybe that's not what you wanted to pay me for, but you know that that would make my freaking day, and that we can sneak those into the editorial somewhere, right? Little things like that. This goes for any time you're working with somebody, but really just trying to be intentional about who you choose and why you choose them. Like, try to consider all aspects of their identity when you're asking them to be involved in something, and giving them opportunities to flex that muscle, if it's something they enjoy.

# Circling back to your racial identity, you said you just say 'American'. Do you want to talk a little bit more about why you choose to say American, or if you want to talk about your background at all?

So, I say that because I am perceived in this very amorphous way. My racial identity, functionally, is context dependent, because the way that people respond to me changes so much based on – if you saw me surrounded by one side of my family, you might think one thing, but if you see me surrounded by the other side of my family, think another thing, and neither of them would be correct. It's sort of this weird thing that happens where people get fascinated because I look like something that isn't there, like, 'I can't place you, and because I can't place you immediately on looking at you, I want to know what box to put you in'. So, when people ask me, I say American, because I don't want you to be able to come at me with preconceived notions about what it means to be this or that, or whatever. Culturally, everything is so weird. Like, my dad's side of the family are immigrants from the center of Italy, and when I went there to get our family records and do some digging on our family history and figure out like, okay, we're Italian, but like, are we? We only lived there for,

like, 150 years. Before that, we were in the Middle East, and we were Jewish. They only came to Italy and converted because the taxes were really high for Jews in Italy. All this religious trauma you could have saved me seriously would have been worth the taxes...

And then my mom has, again, mostly Italian and other random American immigrant mixes. There's some Portuguese, some Thai, but I wasn't raised in that way. I was raised with my mom making hot dogs and beans and my dad making homemade Tagliatelle. I had this sort of traditional Italian – but not Italian American, because they were actually immigrants – and then this weird other mix of just so many generations of people trying to become American, that's all that it really felt like it was. All of these generations on my mom's side of people that were like, 'We're nothing but Boston, we're nothing but Philly, we're nothing but where we are right now in this moment'. So, I think it's important to be honest that the way that I'm perceiving the world is very much an American perspective, especially because I've done extensive traveling. When people ask me what I am, that's the most valuable marker to tell them in pretty much 99% of the situations, right? If they need to know what language to speak to me in, or whatever. Any other answer wouldn't serve you.

Aside from that, it's just a weird, sort of inappropriate, probing, invasive, exoticizing, gross question to ask somebody because I'm like, at the end of the day, you're asking me that because you want to fetishize me, 90% of the time. I don't really get that question from people of color so much. They just sort of don't care, or aren't really as interested. Or maybe I'm just brown enough to be safe. I don't know, it's like a very strange thing.

Also, I think because in the summer, I'm so dark, like, I'm so dark. There have been so many situations where people have accused me of not being part of my family on my mom's side, because my mom dyes her hair blonde and my brother is blonde. So, I look like somebody else, so I've had a lot of situations – like, my brother's friend asking, 'Who is that person sunbathing on your lawn?' and my brother's like, 'It's my sister', he's like, 'You have a Black sister? How could she be your sister? That's not real'. And I'm like, you met me in the winter before. It's just silly things where, depending on the time of the year, and where I am, I could be perceived in one way or another.

Sometimes, I go through TSA, and everything's fine. Sometimes it takes me forever. I gotta take everything out of the bag. They gotta pat me down extra hard, and they got to look at all of the things, and they got to make it a big deal that I bring medicine through. Like, I'm traveling, I'm not a drug mule. And other times, it's not a big deal. So, it's such a weird thing that totally changes based off of who it is that's perceiving me, and how they grew up, and where they're from, and how old they are. And also what I'm wearing, and how feminine I am or how masculine I am. Did I let my facial hair grow out? Did I let my leg hair grow out today? Do I have my hair up or down? Like, there's so many weird variables, that I feel like the real question when people ask you, 'What is your racial identity?' Is, really, they're either asking you to commiserate in some kind of racist, nonsense, or they're like, 'I want to fetishize you for being other'. Which, usually the people that are doing that will ask me if I'm Oriental. Rather than being like, 'What are you?' they'll be like, 'Are you oriental?'

Ultimately, I don't really know how much it even matters, because I can say I'm Italian, but when you go to Italy, they are – as much as the people who left Italy – going through a cultural crisis, where they want to divest themselves, even of their language. There's this weird thing going on where all of the people of my generation have left. There's only young kids and old people and they pretty much only want to speak English and adopt American culture. You go there, and you're like, 'Where are they? Where are the songs in Italian? And it's so hard to find them. It's so hard to find spaces where there's actual maintaining of culture. So at this point, I'm like, what else could I say, other than American, that would even make sense?

#### Do you still have family in Italy? And that's how you are aware of this cultural shift?

Yeah, we still have the houses. They moved here, but they kept all their stuff there, so we go back every now and then, and I still have family that lives there. I speak Italian – it's kind of a useless skill, because they don't even speak it there, but I enjoy reading poetry. Old poems, obviously, because no one's writing new poems in Italian. It's sort of like a cultural death that's happening over there, and it's really sad. But, I think globally, we're in need of a Renaissance. I would like to see us expand the ways that we define ourselves, because even one generation away from now, things will be so mixed. Also, we need to get better language; more words for how to describe a perspective, or how to describe where someone's coming from.

Yeah, and not immediately recoil from the idea of adding words to our language, or changing our language. It seems like a lot of people are really hesitant to do that, because they think it's somehow less valid because it's new, but language is constantly transforming.

Right, and that's how it stays relevant, that's how it stays useful. Language really is utility. It's art, but it's utility, and if it doesn't function to adequately describe our experience and adequately connect us to a point where we can understand each other, then we have to invent new things. I'm super interested to see what that'll look like, I love how nuanced things have gotten in the gender world. Even a year before now, I don't think I heard the term enby being used all the time. Now, it's just this casual thing that people are tossing around. We're doing it, we're doing the work.

I think people just need to be less – like, don't be embarrassed if something is new to you. It was new to me. Even though it's true in my body, it was still new language to me. I don't feel ashamed of not knowing that I was non-binary 10 years ago. I'm not punching that version of me like, 'Oh, you should have known'. So yeah, I think we just give ourselves a little bit more permission and let it be messy. It's okay. I mean, in the end, it's gonna be so worth it. Any way that we can communicate more effectively and actually connect with each other and understand each other more fully. Not pigeon-hole each other and not make assumptions. Like, even when you ask for a racial identity, there's so much weighted assumption that comes with that, even if I just say Italian American. You know, thinking one thing, and that is not the thing. You know, it's like they're totally different flavors, but we don't yet have that language to get to that level of nuance.

So, I definitely think we can. I'm already seeing it, like the fact that you asked me to do this interview, and I'm looking at the questions, and just based off of those questions, I can see that we're pursuing a new lexicon. We're pursuing a new understanding and a new paradigm. And you're not the only one doing it; we're all participating in this work together, and it's happening. So, it's like, wow, isn't it so much? And also, oh, I don't have to do too much. Like, it is so much, and yet, I'm just doing just enough. And that's good, because everyone is doing it with me. It's a movement, and you're a part of that movement, and it feels really good.

It feels good to be connected in that way. Even before we got on, learning about your project and experiencing your pieces, and even just reading through those questions. I feel connected and united under that. You know, that flag of possibility of like, we're hungry, and we're hungry in this direction.

### Do you do anything to alter your natural appearance? tattoos, piercings, hair dye, makeup, etc? And if so, why?

Yeah, I no longer dye my hair. I do henna, which just brightens it and I do that because I like sort of the shiny-ness of it. It's just like getting a little polish, but it's my natural hair color, it doesn't change my hair color. I don't like to do things where I feel like I'm changing how I look too much because I had to do that for so long, and spend so much energy that I feel like I need to get a lot of that energy back that I wasted on appearances.

So yeah, tattoos are probably the biggest way. I sort of use tattoos as a way of memorializing epiphanies. Like, if life is a series of epiphanies, I use tattoos as a way of memorializing when I feel like I have embodied something and I want to carry it with me. It's almost like if you were in jail and you were marking on the wall as each day passes, checking off, but in a more positive way. Like, counting my spoils if I'm a dragon and I'm collecting treasure, I sort of want to imprint it onto me.

I think it also gives me a way of feeling the community in me and on me in a way that's permanent and held. And that doesn't mean that every single artist that I got a tattoo by I fell in love with or would am still friends with, but each one of them has had a really big impact on my life for different reasons and in different ways. The tattooing experience itself is – there's so much of a ritual and it has the capacity to be a sacred healing space, so all of the people that I've shared that with, I've really learned a lot from and felt like yeah, like I just wanted to claim that and give it presence on my body. I think tattooing is also a way of getting ownership and autonomy over something that was sort of used without my permission, really, and beyond my control.

I don't like makeup a whole lot. I like makeup where I'm like, 'I'm gonna be the moon. I'm gonna make myself a piece of the moon'. Or like, 'I'm gonna be a chameleon, and I'm gonna be really weird'. I don't like makeup where I have to play femininely. I like

makeup in a sense of painting color on the face. When I'm photographing someone's body, I like doing full body makeup, or I'll take a fine mica powder and I'll go along all of the highlights, just to put a little bit of pearly mystery into the portrait. But, in my everyday life, I really don't really don't do anything.

You'll notice it looks like I have mascara on right now, but I don't. I actually got it done with a salon eyelash extension promotion. I did a before and after and I got paid for that, which I don't mind. Like, voluntarily, let me put on my fake eyelashes or whatever. Just because, there's a lot of trauma around that; of going to work without makeup on and being told that you look sick, and like there's something wrong with you, or being sent home to go put on makeup. It's humiliating. That was really not good for me. So yeah, I already am sort of nerdy and I just want to be comfortable. I don't want to be like, wearing all these weird things, it's just so uncomfortable. So, the things I do to change my body are really based around pursuing pleasure and pursuing sensation in a meaningful way. I like the ritual of the henna; I like the ritual of tattooing and the way that you have to take care of yourself so tenderly for weeks afterward, and the way that sort of impacts your day-to-day life and how it does sort of forge these bonds in yourself with parts of yourself. Every once in a while I paint my nails, but I think I just enjoy the ritual of it, then I don't actually want to ever have them seen. Like, I could never get a pedicure or anything like that.

Somebody bought me a gift card to go get my nails and my feet done, like, four years ago. I gave it back to them last year, because I tried to go, and I had a panic attack. I was like, I hate this so much. I can't even put myself through it. It's the way that it's coded as being a woman's thing. I think if I saw more men getting their nails done – and actually, I work with a trans man who really inspires me, and he always has like some fine nails on that are really fancy. I have some texture sensitivities, I could never deal with having on nails, that would freak me out, but aesthetically the way that he is like, 'I don't care, these are my boy nails and I love them'. I adore that and it gives me so much joy and I really admire him for his courage. And appreciate it, too, because I might one day want to be able to, and I don't right now, but I might one day. It would be nice to be able to feel like I could do that without it being something that was going to get me clocked or ruin my ability to be perceived as who I am.

### Have you felt pressured to change your appearance by media, such as social media, but also like more mainstream media, movies, commercials, that kind of thing? Does that really affect you much?

It did - growing up, it was extremely toxic. I would wear things that I just didn't even like and that made me feel exposed. I would do it, and I would feel sad. It feels like selling out a little bit. I think that's what it is. It feels like, 'Oh, my God, this is so far from who I really am', and so performative. I just wish that the cover of Harry Styles in a dress came out when I was, like, 12. That changed my life. If I was like, 'Oh, boys can wear dresses', I probably would have dressed the same as I did, I just would have not felt so horrible about it.

I forgot what university it was... they did a study: if you and I experienced the same amount of stress, but I perceive it as a good thing for my health, and you perceive it as a bad thing for your health, you'll die way before me. Right? Because, it's the context around your experience that matters more than the actual experience. The same thing goes for gender expression. If I had had representation of, like, it's okay to present however you want, in fact, it's okay to be all over the map and just be figuring it out, and you don't owe anybody an explanation, it would have totally changed the game. I think it would have alleviated so much of the isolation, the lack of community, the way that my mental health was really impacted. I think a lot of things would not have escalated; I don't think my depression would have escalated to self-harm in the same way, because it came from specifically loading around not being able to be what I was supposed to.

I just felt like whatever it was that people had expected me to come out as, I utterly failed, and I just couldn't figure out how to get back to whatever it was that I was supposed to be doing. You know, the American dream of, you know, Tommy and Sue. Like, I'm trying to do it, I couldn't figure it out. And I think an example of an alternative, or just permission, visually, is Steven Universe, the cartoon. If I had that when I was a kid instead of the Rugrats... No, I love the Rugrats, I mean, in addition to. I feel like, you know, so many things would have been a no-brainer. So much stress and agony would have just been curiosity and joy. I think we waste a lot of energy with all of this baggage. Our kids actually do a lot better without it. I think we would do a lot better without it, too.

#### It sounds like you've done a lot of work to not pass on that baggage to your son.

I'm trying. That's my responsibility as a parent, I owe every human being on this planet. We got into this because mothers were sort of taken off the role - that's what I witnessed in my family, at least. My dad formed some poor personality traits, because of the whole, 'men are the princes of the family, and they can do nothing wrong. And you know, if he cheats on you, it's to be expected' and like, no, hold on, no, no, no, he's responsible for his actions, and he's responsible for his emotions and like, no. These types of accountability, I think they truly start in the places where we learn language. We learn language from our mothers, in the family, in the home. So I was like, I really wanted to figure it out, because the alternative was, I think I would have continued to hate men and you can't raise a healthy man hating men. So, I tell people all the time, they're like, 'Oh, do you know do you regret having a kid young?' and like, 'He raised me, I had to grow up for him'. I probably would have just done some drugs and, I don't know, made some bad art and not really gave a ----. And you know, I'm having all these weird health problems. I probably would have been so busy with that, I would have been like, no, I'm not even gonna try. But, he put the bar higher; to be better for him. So yeah, I'm always grateful and I think he's gonna be a cool kid. He takes good photos already. I've been giving him disposable cameras over the years. Kids take really good photos. Kids are really amazing.

### Do you mind talking a little bit more about the chronic illnesses that you've dealt with, and how that sort of influenced your relationship with your physical form?

Yeah, so I think it's hard to speak to everything that's going on, because there's so much complexity. But basically, the conditions that I have fall into this weird, gray space called Dysautonomia. I'm just gonna read you the definition, because there's a lot of different things that I have that all sort of fall under this thing. It's a condition in which the autonomic nervous system doesn't work properly. So, that means that the functioning of the heart, bladder, intestines, sweat glands, and blood vessels; all of that is affected. So, it's sort of this systemic thing that affects everything about me, including how I perceive the world, how my brain works, what I need, my rhythms and cycles, all of these things. And it shows up in a lot of really weird, little things that seem to other people like they don't matter. Like, if I have pants that are too tight, it's

not just uncomfortable, it causes pain that will just continue to escalate until I take them off. And if I don't relieve the pressure, my body will start reacting to it.

So, for example, let's say I have something on and I start to feel itchy. My skin doesn't like this sweater, right? It probably has some kind of fake material, like a polyester, in it. I react to everything. I couldn't even use a scented laundry detergent. And now, it's freaking out. I've got probably a couple of minutes between me getting hives or not if I don't take this sweater off. So, I started kind of explaining to people like, my body bullies me around. It really does. If I listen, if I'm able to hear when something is happening, like, 'Oh, my lips are a little bit chapped, I must be dehydrated, I need to start drinking water now, before I try to go do something, because I'm more likely to pass out and have a seizure when I'm dehydrated'. Things can escalate really fast and become a big deal when I'm not listening.

Our society is set up to be like, 'You do what I say, you jump when I say jump. You do what capitalism needs you to do, or else', without taking into account that that's not always viable. So, for example, one of the other conditions that I have is called Ehlers-Danlos Syndrome, I'm hyper-mobile type. So, that means - you have three things that hold you together; you have bones, you have muscles, and you have ligaments, tissues, and tendons. I only have bones and muscles, my ligaments and tendons... basically, might as well be bubble gum. I mean, yours are like a rubber band; you pull them and they snap back into place. That's what it's supposed to do. Well, mine just stretches. They don't go back. You could put it back, but it's already stretched out. And then the further you go, you can bring it back but it's never going back. Whereas for other people, it sort of has this resiliency.

And so that affects everything, right? Why was my skin coming off when I was waxing? Well, that's why I have super-duper thin skin. I get abrasions from the silliest shit, I could wipe myself after peeing and take off some skin, just because it'll just stick to me for no reason. So, imagine navigating anything, right? I'm trying to navigate what they tell you sex is supposed to be like when my skin falls to paper. Oh, and no one teaches you about getting consent from your body, or, oh, I don't know, actual arousal, or any other basic sex-ed stuff.

So, I think it just exacerbated all of the ways in which I felt like I was failing at this thing. It would be like, 'Well, why can't you sit for five hours straight, you should be able to'. Well, for my body, if I sit or stand for 30 minutes, I'm already in pain. Like, I'm switching my feet around and moving things around all the time. A lot of times, when I'm in Zoom meetings, you can't see it, but I got all my physical therapy gear right in front of me. I'll be in a Zoom meeting and I'm doing my exercises, because that's what I have to do in order to function. Because, if I were to sit here completely still, and - God forbid - if I was on an actual chair; you have no idea how many pillows are here, I have like four pillows, making this chair comfy. But it's little things like that.

Capitalism tells you that you shouldn't give a shit about your comfort. You shouldn't need a squishy chair, or whatever, but I do need it, or I'm in so much pain I can't focus. It's not that I'm choosing not to focus on what I'm doing, I literally cannot focus because the sensations are so loud inside of my head. You know, it's little things like that. Like, I have to be super careful about what I eat. I react to any kind of preservatives, any kind of alcohol can have a lot. I can't really have canned goods. I can't have any kind of dairy. Gluten hurts me. Pork, beef, so many things.

But what I will say is, I understand queerness as resistance. I understand queerness as deciding that the way that I am is worth convincing other people that it's okay; it's worth that. And I think I understand my disability and my chronic conditions in the same way. I understand it as a point of resistance, I understand it as my body making my boundaries stronger. And yeah, it makes it stronger by using consequences, and it's not real to anybody else but me, I'm the only one that gets punished. I don't cook as well when I'm sick, maybe, but like, I'm the only one that's directly punished. And yet, at the same time, these symptoms and having to adapt in this way has forced me to resist. The nine-to-five wasn't probably ever gonna work for me, even if I wasn't being abused and having crazy symptoms as a result of that stress.

I don't know, though, would I have left if I didn't get sick from the amount of stress that I was under? I might have put up with it because of my financial fears, or my fear of inadequacy, or my fear of failure – let my perfectionism drive me into the ground. But, I can't because my body breaks down. I think in a lot of ways that has become a gift, because I am usually the person in my group and all of my co-working spaces who

has the awareness to check in and be like, 'Hey, okay, we've been here for an hour, do we want to do a stretch? You want to do a little shake? I'm feeling like I'm having some lower back pressure. How are you feeling?' You know, I'm sort of the weakest link, but that's not a bad thing. I'm the one that now gets to sort of use that sensitivity to be like, 'Oh, we need movement. Okay, nutrition is needed. We're lacking in movement', or, 'I haven't seen you drink anything and we've been on this meeting for three hours', or you know, whatever it is.

It's sort of like my ability to tune into exactly specifically what it is that I need, because there's 1,000 things that can go wrong in my body and there's 1,000 different ways the dominoes can go off and get ----- up and start this chain reaction of disaster that may or may not land me a week in bed. If I don't play my cards right, I could lose up to one, two weeks, maybe a month.

I got a real bad kidney infection in November that I wasn't able to catch because it blended in with all of my symptoms. I lost three weeks. Plus, for one week, it was a whole week of learning how to just walk around the house, and shower, and eat again. It was like three weeks until I was back to being functional again. So, it makes you pace yourself differently. It makes me move and prioritize things differently, and it forced me to recognize that my needs were non-negotiable. I don't know if I would have gotten to that point without it. I really value having a disabled body for that reason. And also, ultimately, we're all going to end up being disabled in one way or another and the sooner that we can figure out how to partner with our bodies, to make longevity whatever it can be, and also know how to ask for help when things start to fail, the better off we are.

Ultimately, it also taught me that people love contributing. Like when I was in the hospital, I was so devastated having to tell my team. It was right around when we're supposed to send this big newsletter out and I'm the marketing person, I was supposed to be doing it. But I didn't even have to ask for someone to pick up the slack, they were like, 'Don't even worry about it. I already finished it, I sent a test to so and so it's already done. You rest. We love you, we're praying for you, you're doing great, you're doing what you need to do right now'. And then when I came back, they were like, 'Okay, we've been working, we're really tired. If you could take some of this

that would be great'. And I was like, 'Yeah, all I'm doing is sitting at home, give it to me' and I was able to be responsive.

The individualist system doesn't allow for [supporting each other]. If you have to work 40 hours a week, no matter what you do, no matter what you get done, then you don't really want to help each other out. You don't really see your success as being interconnected. I think creating alternative ways of relating to each other, alternative ways of working, all of that – and just accessibility is so huge, because there's actually been a lot of people all along that had been suffering with mental health or physical health issues that just have never asked for help, or never felt like they could afford it. All of a sudden, we're in this space where people are recognizing that, with quarantine, they might as well deal with their issues. So, I felt really lucky. I feel like my disability has been training me for this moment and sort of preparing me for this.

I think that we have a lot to learn from the neurodiverse and the physically diverse community. The ways in which they form thriving mechanisms, not even just survival mechanisms, but the way in which they are able to make meaning in life. They are skills that we need. Right now, I'm actually reading a book called *Disability Visibility*. It's an audio book of all different disabled writers and poets sharing some of their experiences and stories and like, Oh my gosh, we're entering the age of the cyborg, and we need to start seriously paying attention and listening to the people who have been augmenting their reality for forever, who have needed this for forever. All of a sudden, tele-doc appointments are accessible. I have friends who are paraplegics who are like, 'We've been literally waiting our entire lives for this'. Nobody made that accessible until now when a bunch of regular people couldn't drive to the doctor's or needed to work remotely.

### Think of all the people who are physically disabled who could have been working remotely this whole time.

Yeah. What we've thought of as ability is completely shifting and changing, which I think is of huge value. All of a sudden, we have just cracked open this egg of like, the world could have looked like this and been this inclusive and been intentionally inclusive the whole time. So, let's rally and fix that a little bit and then we'll be good to go.

I also feel sort of blessed to be in a space where I actually learned how to partner with my disability before it was too late. This is a degenerative condition, and if I - let's say I never got pregnant. I had just qualified for the Junior Olympics, to be on the equestrian team, I would have been training 8 to 10 horses a day, riding from 4am until 2pm. I probably would have been in a wheelchair within 4 years. With that level of activity and repetitive stress injury potential, and I wasn't even aware that my body was fragile. They were prescribing me Vyvanse and Adderall, so I couldn't even hear any of my body signals. I couldn't hear when my blood sugar was low, couldn't hear when I was dehydrated, I was just all action. If I didn't have that crisis that little bit of chaos... I thought I was making a choice like, I'm gonna give this up and become a mother. If I didn't give that up, I would have given up my mobility all for a couple of years of doing this thing I love. It wouldn't have been worth it. I feel like I was very lucky to stumble on this hand of cards.

#### How did you figure out that you had that chronic illness?

It was an entire lifetime of doctor after doctor after doctor, 'What's going on? We can't find anything. We don't know', colonoscopy after colonoscopy. 'We don't know. Everything's bleeding. We don't know what's happening. We don't know where it's coming from'. Just, doctors not having any answers. I was ready to give up, until I met another artist who I met on tour. I was curious about working with them, because there were some similarities in our work – some esthetic crossover, but I didn't realize just how similar it was. And then when we were together, I was watching her move, and I was like, huh, weird, we're super similar. I've never met anybody whose body was similar to mine. Usually, people act like I'm a circus freak. The things that my body does is like, a thing that you show to drunk people to make them laugh. Generally, that was the role that I got any acceptance in – I was a clown, and that was about it. And if I wasn't a court jester, I was in the corner.

So then, she asked me if I had it. She was like, 'Hey, just curious. Do you happen to have this?' I'm like, 'No, no one's ever told me that before'. And then she was like, 'Okay, can I run you this test? There's nine joints to test, let's run you through this test. If you have, like, five out of nine, you should call this guy who's a specialist. It's going to take a couple years to get in with him, but he'll diagnose you'. And I had all nine. She was like, 'Yeah, I knew it. Your body is the same as my body'. It just totally blew

my world, because I could have had four houses with the amount of money I've spent on trying to get the proper medical diagnosis, and to finally have somebody, a regular person just look at me and be like, we have the same body. 'You have what I have'. Oh, great. You just literally blew my world open in 30 seconds. Like, what? So, I got on a list and within a couple years, I had the diagnosis. And then that one right diagnosis led to a couple other right ones, because suddenly the puzzle was making sense. The puzzle pieces were making sense, all of a sudden, we had the proper context

It's funny, because actually 30% of Olympic athletes and dancers and the people that you see that are in peak performance occupations actually have Ehlers Danlos. In the short-term, it's a competitive advantage. Like, let's say I was a swimmer and we're all the same height. Well, even if we're all the same height, your arm can only go up this high. Mine can go way up higher, I get an extra four inches because I can dislocate my shoulder, right? So in the short term, like if I'm throwing balls, yeah, my ability to let this kind of sling is, in short-term sports orientations, really advantageous. It's sort of an adaptation in a short-term sense,

The consequences, long-term, are you have all of this pain, all of this arthritis, all of this joint compression and instability, and specifically cervical instability. And you know, things like your heart muscle atrophy. The most likely way for someone with EDS to die that's super common is that – I think it's the aorta, or one of the distended valves or something – just, like, unplugs. Like, the muscle just atrophies and just lets go. It's not a thing that you can fix, it just happens, and you're dead in 30 seconds; like a brain aneurysm. Yeah, we're all weird.

Short-term, these things, evolutionarily, might have seemed like responses to the stressors of living in this world. I don't know, I sort of imagine it that way, because if you look at the trends of this - the way that this disease is becoming more prevalent - I think that what we're seeing is that Dysautonomia in general is sort of coming from epigenetics of inherited trauma. That's what I'm seeing from the research that I'm doing now. I'm not a clinical psychologist or doing this in medical studies and stuff like that, I'm just reading the information that's available. But, that's what I'm witnessing, because my symptoms are triggered by trauma, more than anything else.

I had a client come for a yoga lesson, and obviously, you need to eat before you come. Well, he fails to tell me he didn't eat all day. So, it's seven o'clock at night, his blood sugar's gone – oh, and he takes blood pressure lowering medication; didn't tell me this either. So, before anything even happens, he just stands up to go get a glass of water. I see on his face, he's gonna pass out, and he's going down. He's six foot, 200 pounds, and I'm trying to grab his body so he doesn't fall on the floor. I don't have insurance, and I'm still working in a pandemic, and I had to catch this person close to his face. All this craziness is happening, and it didn't matter that within a couple of minutes, he was back and he was okay, and everything was over. The trauma response was already going in my body. It didn't matter. I had immense pain, panic attacks, couldn't sleep for several days, and it was just this whole cycle that got triggered. And it's like, okay, yes, that's one instance of trauma, and that wasn't capitalism's fault. Well, it is capitalism's fault that I have to still work during a pandemic, which I wouldn't, as an immunocompromised person, do if I didn't have to pay my rent. But alas, we're here.

It used to be the same thing for the anxiety that I would experience knowing that I had to go into work every day. Or, even that low grade continuous anxiety affecting me in the same way. I used to vomit every single day, multiple times. I would wake myself up vomiting in the morning. Now, that only happens to me when I've had something acutely stressful happen. You know, like the day after that that person fell - I threw up that day, and the next couple days, I was really nauseous. That used to be my everyday, it used to be that every single day. I was bleeding internally, every single day. I had really intense urgency around using the restroom. I used to have really intense anxiety about not being able to feed myself. Sometimes, I'd only be able to eat applesauce. This was the life I lived when I was trying to conform to the structure. And then I was like, wait, what if I restructure my life around my body's needs? And then I'll worry about how to make money after that. Everything changed, like, completely. I wish more people would consider that, because it doesn't have to be so bad that you are bleeding internally for it to matter. Eventually, it'll cause disease; just because it doesn't happen right away doesn't mean that you should ignore it.