

Pigeonhole Episode 22

[bright ambient music]

Introduction

CHORUS OF VOICES: Pigeonholed, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole.

[Transcriber's note: vocal tics will be noted in parenthesis. The motor tic of Jess thumping her chest will be noted in brackets. While the motor tic usually happens during a word, it will be indicated after the word when it happened.]

[low-key lounge music plays during this intro]

CHERYL: Last month's episode was a short interview with Jess Thom of Touretteshero. And there were so many things I edited out for the short episode that Jess had said around Tourette's, about what lots of non-disabled people think about paying attention and showing respect, and about accessibility. I wanted you to have the rest of that conversation. So, this episode is an extended version of last month's episode.

For me, the hardest part in an interview is follow-up questions. OK, [chuckles] I actually often straight-up miss questions that are written on the page right in front of me, questions that I thought of and typed up myself. But if something's not on the page, it's really, really not likely to come out of my mouth. I end up sticking to script a lot of the time or sort of blathering to pass time while I try to retrieve that interesting thing that's now hiding in the far, dusty corners of my mind.

But with Jess, it was different. Although she explains here that her vocal tics aren't about what she's actively thinking about, without planning to, I started to use her tics as jumping off points for conversation. What's the point of ignoring them or of pretending that she doesn't have Tourette's? When I sat with Jess in a downtown Portland hotel to gather her stories, I didn't plan to talk about ableist discos or ableist disability benefits assessments. I had somewhat wondered if I should talk about biscuits and maybe hedgehogs, but I didn't plan to. But in the moment, it turns out that even asking about biscuits opened up a whole world I didn't expect. Which is Jess's signature move.

Biscuits and the creativity of tics

JESS: (hedgehog)

CHERYL: I'll test the volume by—

JESS: (hello)

CHERYL: —asking you to—

JESS: (sausage)

CHERYL: —describe seriously, what kind of biscuit is this?

JESS: (biscuit) Well, (biscuit) it is a British biscuit, so they are very broad, lots of variety. You get a jammie dodger, which is a sort of round biscuit with jam in the center. Pink wafer, which is

a wafery biscuit with cream in the middle. Very dry, bland digestive biscuits. But basically, they're cookies, but usually less exciting. [laughs]

CHERYL: [laughs] OK. Well, the volume's great. I don't know. When you say "biscuit," do you see a biscuit?

JESS: No, no, no (biscuit). My thoughts are totally (biscuit) biscuit-free. (biscuit) [thump] None of the things that I tic are things that I'm consciously thinking about at all. That's why I'm able to have a conversation, I think, because my thoughts are totally, totally clear. So, in my head, I'm just, (biscuit) (cats!) I'm just talking fluently. (biscuit) [thump] But obviously, there's this (biscuit) automatic (biscuit) interruption into my speech [thump], (biscuit) which are the tics, the vocal tics (biscuit).

CHERYL: So, part of my, *my* neurodiversity is that I have a lot of linguistic and sonic stims.

JESS: Yeah (biscuit).

CHERYL: I think a lotta non-disabled people might call your tics distracting—

JESS: (biscuit)

CHERYL: —or interruptions or disruptive. But for me—

JESS: (hedgehog)

CHERYL: —your tics really relax me in this way that I usually don't feel because I'm picturing the things that you're saying.

JESS: Yeah.

CHERYL: And also, the sound of you repeating words is like my stim dream come true.

JESS: [laughs] (biscuit) Yeah, (biscuit) well, I think (biscuit) lots of people edit them out, so (biscuit), at the beginning will hear like every single biscuit (biscuit). And then (biscuit) will get so used to them and familiar with them [thump] (biscuit), the very regular ones, perhaps almost disappear to them. And people say, "Aw, (biscuit) you haven't really, you know, you haven't really ticked very much," or, "You haven't really said 'biscuit' very much." It's like, I have. You've just stopped hearing it. [laughs] (biscuit)

CHERYL: Wow.

JESS: Which is really interesting. And I think often, people think they're gonna find something really disruptive or distracting [thump] (biscuit). In reality, actually, brains are much more flexible than that. (biscuit) [thump] (cats!)

CHERYL: First of all, I could never not notice them. But also, it's so pleasant.

JESS: [laughs]

CHERYL: It's so delightful. And I can't really follow conversations when the topics change too fast.

JESS: Yeah. (hedgehog)

CHERYL: But I just stim out on [laughing] your tics.

JESS: (biscuit) Well, I suppose for that, they're really useful because I mean, they're obviously very changeable, (biscuit) [thump] but they are like, they are relatively consistent. (biscuit) I (biscuit) don't really notice the regular ones (biscuit), but (biscuit), but sometimes, they're really funny and surprising, and [thump] I get quite shocked by things. Very, very occasionally do I get really shocked by something I've said or really (biscuit) embarrassed by something I've said. It's not very often, but it does happen sometimes. [laughing] (hedgehog, cats)

Attention, concentration, and forcing normalcy

[mellow contemporary jazz plays under the next paragraph]

I think (biscuit) Tourette's is definitely a condition where people, I think because it's so complicated and (biscuit) because brains aren't brilliantly understood, (biscuit) sometimes people can become really focused (biscuit) [thump] on that outward expression of the tics as the outward expression of (biscuit), of my neurodiversity. And (biscuit) [thump] will therefore try and say, "Aw, you're ticking loads. Is that because you're angry or stressed or frustrated?" Or, "You're not ticking very much. You must be better." That scrutiny (biscuit) [thump] of people's bodies and their sort of assumptions and preconceptions that go along with that [thump] can be really wearing. It's, you know, they're not necessarily the things that are dangerous in our existence, but they are the things that are exhausting.

I think it can be really tough, particularly for children and young people as they're, you know, who have fluctuating [thump] conditions and who are also going through puberty or managing people's sort of assumptions and preconceptions about young people. I think (biscuit) as a society, we have this idea that focus and concentration looks a particular way (biscuit): that if you're quiet and still, then that's how you give attention. And it's like, if I am quiet and still, I am not focusing on what you're saying. I [thump] am (biscuit), I'm using all my energy and attention (biscuit) to control my body. Actually, if I'm moving around and making noise [thump], I'm much better able to concentrate and take in whatever's happening around me. And I think that's definitely not just related to Tourette's. That spans (biscuit) [thump] a really wide variety of people. But this idea that attention is like you can only focus in this one way and that's the way you have to show respect and concentration and care, all of those things are about trying to normalize different types of experience. Actually, if we just all had a more flexible attitude to what we're expecting and not expected, you know, normative behavior, if we had a wider understanding of what it means to be a human being, (biscuit) then I think we would naturally create better spaces for people whose bodies and minds work [thump] differently. (biscuit)

CHERYL: OK.

JESS: Cream cheese.

CHERYL: So, mm. I love cheese so much.

JESS: [laughs]

CHERYL: I kinda missed it. What kind of cheese did you say?

JESS: Cream cheese.

CHERYL: Oh, I like a more sliceable cheese.

JESS: (biscuit hedgehog)

[upbeat old-timey piano and brass band music plays through the next paragraph]

JESS: We once did a show in London, and we'd been touring our previous show, [Backstage in Biscuit Land](#), [thump], you know, all over the country. [thump] And it's a show that makes space for my tics and gives like [thump], gives them room to be creative and to be really abstract and be really surreal (biscuit). And then we were doing this show in London, and (biscuit) and my tics literally only talked about doorways and cheese for the entire show! With an occasional reference to Alan Hansen, who is a really obscure football commentator from the 1980s. This is a show about creativity, and all I've talked about is cheese and doorways. And I felt, I was really pissed off at Tourette's that day. I was like, my tics have totally abandoned me and just, just left me with doorways and cheese. [laughs]

CHERYL: And Alan Hansen, who, in a previous interview, was in your handbag, I think.

JESS: Yeah. Quite possibly. He does crop up in all sorts of places.

Is Tourette's your improv or writing partner?

CHERYL: Is Tourette's like your improv partner or your writing partner?

JESS: Yeah! It often is. As a creative person, (biscuit) using tics as a way of accessing spontaneous [thump] creativity is definitely some part of my practice. (biscuit) And [thump] I think that stems back to the very first idea that is at the heart of Touretteshero as an organization (biscuit) [thump], which is that to not use tics creatively would be wasteful. So, Matthew, who's the co-founder of Touretteshero, describes my tics as a language generating machine (biscuit) [thump] and told me not doing something creative with them would be wasteful. That idea, that sentence, I was able to hear in a totally different way [thump] (biscuit). We'd had loads of conversations about Tourette's [thump] and that they had nearly always ended in tears. I found it really hard to talk about my tics at that point. And certainly, I know that he'd talked to me about sort of using them creatively, and he talked about being quite envious of some of the ideas that my tics generated. And I didn't get it at all. But then, as soon as he described this idea of a language generating machine [thump], that really captured [thump] my imagination. And I've also been brought up to believe that being wasteful is really bad. So, [thump] (biscuit) the idea that I was wasting this creative energy or resource [thump] stayed with me. And I was slowly able to see that they had value (biscuit) [thump] and that talking about different types of experience had value. And that (biscuit) [thump] feeling upset or sad about (biscuit) [thump] Tourette's was something that I had been conditioned to do rather than actually reflected my experience (biscuit) [thump] (hedgehog).

[plucky guitar music break plays through the next paragraph]

People always ask me about, why biscuit? I'm often asked (biscuit) [thump] if my chest hurts, like when I bang it [thump], which is [thump] you know, I've got a motor tic where I thump my chest hundreds of times, and people are often concerned for me about that. Which is, I understand. People are often really curious about my sleep and how I sleep. People are often curious about whether I would take a magic pill and make my tics go away. I always say that I

would be much more interested in a magic pill that made society more inclusive and cured ableism [chuckles] than changing my body.

Disabled people viewed as burdens and consumers

[thump] (biscuit) But I think there are some other things that probably aren't talked about are things that are maybe some of the darker things around having an impairment and the lack of power that that can bring. [music fades away] And I think [thump] (biscuit), I think I don't get very many opportunities to talk about how precarious my life sometimes feels. [thump] It feels precarious because lots [thump] of the great things about my life are dependent on decisions of other people. So, I am [thump] not disabled by my body, but I would be disabled by a lack of support. And I have great support at the moment, but that always feels like that's something that could be taken away. And I think lots of disabled people who require support, I think, probably feel this precariousness [thump] about that. And there's a certain urgency, I suppose, to some of my [thump] work because I feel like I have to do this now in case some of that is ripped away from me. And I don't think that that is something that much time is given to in lots of more mainstream conversations because [thump] people wanna focus on my body, not on the systems that enable me to live. (biscuit) [thump] (cats) (sausage)...(da da da!!) (disco)

[loungy disco music plays for the next few sentences]

JESS: [laughs]

CHERYL: [chuckles]

JESS: (hedgehog biscuit)

CHERYL: And many discos are probably not wheelchair accessible.

JESS: Yeah. Yeah, yeah. Well, exactly. They (biscuit), there's a great organization in the UK called [Attitude is Everything](#), and they promote [thump] disabled people's access to live music and have been doing incredible work, both around working with venues and festivals to make [thump] sure that disabled people have access to music and dancing as audiences but also as performers. And they have a charter that different venues sign up to. (biscuit) And I went out for a friend's birthday fairly recently and (biscuit) [thump] looked at the venue and could see that they'd got Attitude is Everything Bronze Standard, and all the information looked spot on. And when I arrived, they were really [thump], they knew exactly where I was going. The ramps were quick. They were really friendly [thump]. [quiet disco music and crowds chatting under Jess's voice] They took me straight to the viewing area and was like, "This is the wheelchair viewing area." I was like, "Great. That's amazing. How do I get to the dance floor?" And they were like, "Oh, no. The dance floor's not accessible." And I was like, "What? Wow. I've come out for a night of dancing with a group of 30 other people, and you're saying that the only option I have is to watch from this balcony people dancing?" [disco and chatting fade away]

But I think places often feel uncomfortable with saying, "This is not accessible," and so they don't say anything. And I think that, that is another thing that we really need to tackle: the embarrassment. It's like, if you feel embarrassed about it not being accessible, make it accessible. But if it isn't accessible and you can't change that, or you haven't [thump] changed that yet, you have to make that really clear so that people can make decisions about their wellbeing and what they do. Maybe we would've gone to a club with an accessible dance floor. Maybe we wouldn't. But whatever happens, it's really essential to share that information. And it's not [thump] my responsibility all the time to be checking access. There's an idea that I'm

really interested in that I read an article about, but it was the concept of forced intimacy. The idea of forced intimacy was the idea that disabled people are required to give [thump] really personal information about themselves over and over and again to strangers in order to [thump] access or know whether they can access something.

Particularly, lots of places will say, "Contact us if you have any access requirements" (biscuit). Well, how do I know if I have any access requirements if I don't know what you're already providing? If your building isn't wheelchair accessible, then I have access requirements. I need a ramp, or I need an accessible space. But I don't know whether that's necessary or not if you don't tell me. And so often, the emphasis is [thump] put on disabled people to spill the beans about every aspect of their personal life to get access to something that non-disabled people don't need to do that.

You know, I'm very lucky that I have a package of support that meets my requirements at the moment. I'm aware that I haven't always had that, and I [thump] won't necessarily always have that in the future. So, the support that I need at work comes from a separate pot of funding. And actually, for a long time, I had support in work but not support at home. I was much more independent at work than I was in my leisure time, and I used to dread weekends. And I never used to take any vacation because I didn't have support. What's the point in me taking leave if I'm then just gonna have to sit on my bed for days on end? So, I'm lucky that I now do have support at home, but I have to justify every aspect of that. So, you know, I have an annual review. And fairly recently, I had one, and it was like I was having to justify why I had 45 minutes of support to have dinner, to have my evening meal. And it was like, that's quite a long time for having an evening meal. And it's like, well, it's not [thump] if someone's gonna prepare you something and help you eat it. And then they were like, "Ah, why do you need an extra 15 minutes to get washed at the weekend?" [thump] It's like, well, you know, that's because I might wanna wash my hair or condition it. The idea that you have to just justify every [thump] tiny [thump] part of your intimate life and world is exhausting.

But also, (biscuit) I have lots of privilege within my life as a disabled person. But in those conversations, when my social worker was talking about my "big care package," and she was saying that repeatedly: that language of consumption of resources (biscuit) [thump]. It's really easy to internalize that language and to feel shame, and I [thump] immediately went to felt feeling guilty that I had more support than other people or feeling like I was consuming resources. Even [thump] though actually, the funding that I get then pays other people to provide my support and makes me an employer and goes back into the economy and all these things that, within a capitalist [thump] system are, you know, are how it's been set up. However, the idea (biscuit) that to be a disabled person automatically means consumption of resources and burden is something that I [thump] have to actively fight against in my own mind. [thump] It's just all our systems have that language built into them. Medical systems across the world and doctors across the world are trained with the idea that to be a disabled person is to, you know, is to be a failed person, in their eyes. It's like they're so focused on fixing and curing, if they can't do that [thump], that's something that's very confronting.

[slow, mellow guitar music plays through first few sentences, then fades out]

How Jess got into performing

So, there were like, there were sort of probably four [thump] key things that meant that I made it to the stage. One of those was that I went to see a show by an amazing comedian called Mark Thomas, who was doing a show called [Extreme Rambling](#) (biscuit) at the Tricycle Theatre in London. And it was about him walking the Palestinian separation barrier, and so it was about

segregation. And it was about a subject that I was really interested in. I hadn't been to the theater for ages, [thump] but I really wanted to go. So, we got in touch with Mark. We got in touch with the theater. (biscuit) We met him beforehand. He introduced me to the audience. We did all of this preparation, (biscuit) but despite all of that [thump], [I was still asked to move at the intermission](#) because of the noises I was making. And I was asked to sit in a sound booth at the side of the stage behind glass. And so, we were watching this show about segregation and about separation from this segregated position, and I absolutely sobbed. I felt so humiliated [thump] and upset.

And in that moment, I promised myself that I would never set foot in another theater again because it felt damaging to me. And it felt like I very clearly got the message that this isn't a space for you [thump]. Fortunately, that wasn't a promise that I kept. So, that was a key moment in realizing that the only seat in the house that I knew could, definitely knew that I wouldn't be asked to leave was on the stage. So, occupying that space [thump] and making a show about my experiences accessing live performance felt important. In that moment, it didn't, but that was a key moment on the line, on the journey, on the road to that.

Another key moment was going back to the same theater a year later to see Francesca Martinez's show, [What the Fuck is Normal?](#). It wasn't a perfect experience, but again, it was a negotiated experience, and [thump] what I did see was somebody whose experiences reflected my own and made me feel confident that that was something that I could do (biscuit) and should do. (biscuit) Then, Matthew went to the Edinburgh Fringe Festival. He looked out shows about disability and found that there were very few (biscuit) [thump], and but he did see some work that really, it made him think we should take a show to Edinburgh. And he went in 2013, and we took the show in 2014! So, it was a very quick turnaround.

And the other thing, the other key moment is that I got onstage at a festival, a music festival, with an amazing comedy [thump] songwriter with bipolar disorder called Captain Hotknives who has an incredible mind and [chuckles] makes these hilarious songs and stories. [thump] (biscuit) Never writes down a single lyric. But (biscuit) the first time we met, (biscuit) he was tuning his guitar, and then my tics started going off in sort of surreal tangents. And then he was super quick to turn them around and use them as the starting point for stories. And so, we got onstage together and did that for the first time, and [we've gone on to do lots and lots](#). And we describe it as a master class in spontaneity 'cause neither of our brains are able to do the same thing twice.

(biscuit) And I suppose all of those things came together [thump] to make me feel that I needed to take up space [thump] in cultural venues and that I felt confident to do it. And that that would add (biscuit) [thump] a load of extra stuff to everybody's experience. If the only narratives that you have about disability are from the mainstream press, then you know, (biscuit) [thump] all you've got to draw from are the sort of tragic, overcoming, burdensome stereotypes. And that's not what many disabled people's lives look like. (biscuit) [thump]

[plucky guitar music plays under the next few sentences]

The amazing Stella Young, who's sadly died a couple of years ago, she has done the most brilliant [TED Talk on the concept of Inspiration Porn](#), and I think the line within that that I just was so, just so blown away by and just was like, "Yes! Yes! Yes," was actually when she said, at the very beginning, "I'm here to tell you that you've been lied to about disability, and we've all been lied to about disability. And we've been told that disability is a bad thing and to live with

disability [thump] makes you exceptional. It doesn't. It isn't a bad thing, and to be a disabled person doesn't make you exceptional." (biscuit hedgehog cats!)

I have a really interesting relationship with inspiration as an idea and as a form because, as a disabled [thump] person, my natural inclination is to hate anything to do with inspiration because of how often it's used in relation to disability in really patronizing stereotypes and damaging ways. However, I went to an event a couple of years ago and heard this amazing woman speaking about whistleblowing on a horrific abuse scandal in the UK and how long it had taken her to get that to be heard and how clearly she advocated for young people who were being abused and damaged by people and a system. [thump] I was just listening to her. I thought, I was like, [thump] this is so amazing! And I'm gonna change how I do things, and I'm gonna think about— And then I was like, shit. I've been inspired! (biscuit) [thump] And I realized that I have this really like difficult relationship with the word "inspiration." But actually, to inspire change, to be inspired is like an incredible and beautiful act and is an incredibly humane act [thump]. From that moment on, I was like, I'm gonna really work to try and alter my relationship with inspiration, to reclaim it as a word and as an experience [thump] (biscuit), but to make sure it is only ever being used when it has really inspired action rather than just as like, "At least my life is not like that."

[plucky guitar music plays till the end]

My aim is to inspire people in lots of ways, but not to inspire them because I'm disabled. I want people to change and create a more inclusive society. And I know that humor and art are powerful ways of inspiring and catalyzing that change. (biscuit) (sausage!)

Wrap-up

[upbeat theme music]

CHERYL: Every episode is transcribed. Links, guest info, and transcripts are all at www.whoamitostopit.com, my disability arts blog. I'm Cheryl, and...

TWO VOICES: this is Pigeonhole.

CHERYL: Pigeonhole: Don't sit where society puts you.

Music in the episode

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