

Pigeonhole Episode 21

[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.]

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, what kind of biscuit is this?

JESS: (biscuit) Well, (biscuit) it is a British biscuit, 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.

When you say "biscuit," do you see a biscuit?

JESS: No, no, no (biscuit). My thoughts are totally (biscuit) biscuit-free. (biscuit) None of the things that I tic are things that I'm consciously thinking about at all. 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], which are the tics, the vocal tics (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) (biscuit) (cats!)

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

JESS: [laughs]

CHERYL: It's so delightful. Like, I just stim out on [laughing] your tics.

JESS: (biscuit) Well, I suppose for that bit, they're really useful because, I mean they're obviously very changeable, (biscuit) [thump] but they are like, they are relatively consistent.

Sometimes people can become really focused (biscuit) [thump] on that outward expression, the tics as the outward expression of, (biscuit) of my neurodiversity and (biscuit) 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 can be really wearing.

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

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. 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.

As a creative person [thump], (biscuit) using tics as a way of accessing spontaneous [thump] creativity is definitely part of my practice. 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) and told me not doing something creative with them would be wasteful. He talked about being quite envious of some of the ideas that my tics generated, and I didn't get it at all. I found it really hard to talk about my tics at that point. 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. (biscuit) [thump] (hedgehog)

[plucky guitar music break plays through the next paragraph]

So, people always ask me about, why biscuit? I'm often asked (biscuit) 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. 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 the, [chuckles] made society more inclusive and cured ableism than changing my body. [thump] (biscuit) People wanna focus on my body, not on the systems that enable me to live. (biscuit) [thump] (cats) (sausage)...(da da da!!)

Disabled people viewed as burdens and consumers

Lots of the great things about my life are dependent on decisions of other people. So, I am not [thump] 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.

You know, I'm very lucky that I have a package of support that meets my requirements at the moment. And actually, for a long time, I had support in work but not support at home. So, 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're like, "Ah, why do you need an extra 15 minutes to get washed at the weekend?" It's like, well, you know, that's because I might wanna wash my hair or condition it. (biscuit)

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. 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, that's something that's very confronting to people, often to medical professionals.

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

How Jess got into performing

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, 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. In that moment, I promised myself that I would never set foot in another theater again. 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), 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 on 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) 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 (biscuit) [thump] because 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] (biscuit) (hedgehog) (cats!)

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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