Creating a Tourette's-Friendly Practice

with Jess Thom

TRANSCRIPT

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- *Some elements might have been removed (repetition or time-sensitive information, for example)*
- *In some cases, related information might be grouped out of chronological order*
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Steven Bruce

One of the things that we really need to address and that we haven't addressed for some time in our CPD is communication in depth, and also in dealing with people with particular needs. And when they come into our clinic, and I'm joined today by our first superhero, I'm joined by Jess Thom, who is founded website, Touretteshero, you'll have seen pictures of her in her superhero outfit, she has appeared on TEDx talks talking about Tourette's, and also she's a comedian. She has just recorded a radio for comedy series with a number of other disabled comedians, which goes out later this month. And Jess, it's great to have you with us. Should we get a picture of you up in a second? Oh, you that Jess? Thank you. Yes. Right, good. Jess, I've just said that you're you're a comic, you're a comedian. I've noticed on shows you've done in the past, you invite people to actually laugh at you.

Jess Thom

Biscuit!! I don't straightforwardly invite them to laugh at me. And I definitely invite them to laugh with me and enjoy the humour of situations with me. And I think lots of people will understand there's a big difference between and shared laughter and enjoying the sort of humour of a situation or the surreal things forget that I say as tics that are often very funny and can be humorous in the way that the conscious part of me can only dream of. And but there is a difference between that and and laughter that has that is sort of apt someone and it's happening is more mocking. So yes, I would definitely encourage people to laugh if I say funny tics and *Biscuit!* to that they're going to get you they're going to hear the word *Biscuit!* and hedgehog, a lot. And during our discussion and

Biscuit!, I think you've got some biscuits to hand just in case you get peckish, *Sausage, Biscuit! Cat! Tada*! Biscuits but no sausages, and no hedgehogs. *Fuck!* and, and finally, several times a day, my tics intensify. And I completely lose control of my body in speech, which looks seizure like and need similar management. And if that happens to me, don't worry. And it's normal, my support worker, Claire will come and help me, but we would need to stop and I'd come back and join you as soon as I can.

Steven Bruce
Okay, thank you. So, you've told me you told us about your verbal tics, which are you concentrate a lot on biscuits and hedgehogs. But also, as we can see, you've also got physical tics as well, haven't you? How does how does that affect you?

Jess Thom
Biscuit! everyone with Tourette's will have multiple motor tics, so involuntary movements, and at least one vocal tic involuntary noise, and they will have been present for more than a year. And *Biscuit! Sausage! Cat!* and vocal tics and motor tics can both be simple. So they can be simple noises or like sniffing or humming or throat clearing *Biscuit!* or they can be complex words and phrases. Let's get in. Similarly motor tics can be simple shoulder shrugging, blinking *Hedgehog!* movements of the neck or hands, or they can be complex series of movements *Biscuit!*, and my motor tics include banging my chest hundreds of times a day, *Biscuit! cat!* and and tics in my legs that mean that my walking is very wobbly. So I use a wheelchair to get around because it is much safer, more reliable way for me to move this gear.

Steven Bruce
Right? So does that not hurt

Hedgehog! Biscuit! for the first few months, just get my chest bruised really badly. And I was leading to wear dress dressings to protect the skin and the skin but actually am. I've been doing that tic for about 10 years now. And after a few months, I got a nice sort of smooth callus. so smooth lump emerged. So it says my body's adapted. And I think one of the things that's really interesting, and for me as a disabled person, and as someone as a neurodiverse person is learning how adaptable our bodies can be and how adaptable we can be to challenging situations and how other people can can help us with that journey to sort of adapt and accept ourselves as we are *Biscuit! Cat!*

Steven Bruce
Out of curiosity, where where do you put yourself on the spectrum of Tourette in terms of very little affected and very, very much affected?

Jess Thom
again, and I don't really I don't really put myself on that spectrum at all. I don't think severity labels are particularly useful. And I don't think they have a particular value to the person with the tics. And Tourette's is a condition that fluctuates, it goes up and down in the course of someone's life. And

it's getting while I've got lots of tics that stand out and very visible to other people, which many people will say are very disabling tics in terms of the sort of impact they have on my body or my ability. Actually with the right interventions and support. I'm able to be really independent to work full time to do things that I love be very happy. So I think that the me said, actually sometimes people with milder tics or people with coexisting conditions so let's get 80% of people with Tourette's will have coexisting conditions like obsessive compulsive behaviour or attention deficit and hyperactivity, and disorder, ADHD, or OCD *Biscuit!* and and sometimes those coexisting conditions can be more disruptive in someone's life than the tics themselves. So what's visible externally? And isn't always the sort of whole picture of what's going on *Biscuit!?* And, and for me, I'd much rather talk about what somebody will access requirements somebody has what someone needs, rather than a sort of severity level? Because I don't really, I don't think that that adds much, I don't think that that will tell people much about *Biscuit!,* the way that my body or brain works.

Steven Bruce
So I take that point, I suppose that the purpose of the question was, if we see someone with Tourette's in clinic, we'd like you to see people who throw out their arms more often than you do, or have more difficulty communicating you do or are, you are sort of, at the extreme end of that spectrum,

Jess Thom
and tics, so tics are really variable. And it's good, and lots of people will would qualify for Tourette's diagnosis, but not necessarily know that that was the case. So lots of people will maybe, you know, lots of people say, oh, I've never met anyone with Tourette's before. But most people will then be able to tell you that they know someone who blinks a lot or clears their throat all the time. And as soon as you have multiple sort of tics, then you would and that are consistent, and that cover both motor and vocal. And vocal doesn't have to be words sniffing, coughing, throat clearing all vocal tics, and then that would, you would count to have a diagnosis of Tourette Syndrome, lots of people won't have that formal diagnosis. But that doesn't mean they wouldn't need the adjustments and sort of practical support. And that that might be helpful in making them more comfortable in their sort of clinic environment this get, and that isn't element for lots of people with Tourette's, that's a round of positionality. So doing the worst thing in any given situation. So if you are needing to be very still or needing to keep one part of your bodies still, that can that can have a sort of suggestible effect on an opposition or effect to mean that the, that the opposite is more likely to happen. So it's then useful to talk through someone. And the best way of framing expectations like and what you need to do. So how to talk about what you need someone to do, because if you just say don't move to someone with Tourette's is very likely to intensify that whereas if you concentrate on what you need them to do, that might have a more positive outcome will be easier for them to to make their body comply, *Sausage Biscuit!,* but in terms of the sort of my tics are very physical, and I have lots of motor tics and so they're just getting my tics are quite, quite consistent. And, and that they tend to be like a very sort of noticeable level I don't really have to think about when I tell someone that I've got Tourette's because it's you know, it's it's pretty visible and pretty immediate visca there are lots of people who would who do have to think more carefully about when they tell someone that information and I think have trying to have a set

of procedures that gives people opportunities to communicate preference whether that's about how their body works or how their mind works or things that they have their feeling but any opportunities to give people a chance to reveal information and disclose information in positive ways I think would help someone's clinical practice and mean that you will get to get the best information about that person *Biscuit! Cat!*

Steven Bruce
There's a widely held perception isn't Tourette swear a lot but that's not necessarily true.

Jess Thom

And no about 10% of people have called coprolalia which is the technical name for obscene tics. And that's the upset that's the name for obscene vocal tics. corporate practice here is obscene movements and gestures, *Fuck it! Biscuit! Sausage! Cat!*

And then there's, Echolalia and echopraxia, which is an echolalia might be familiar with people to people because it's present in other neurological conditions like autism, where you might repeat somebody's speech, and let's get an echopraxia is repeating someone's movement. Some people with Tourette's also have while we're talking about the alias, some people with Tourette's might also have palilalia which is *Biscuit!* repeating their own sounds. or speech and *Biscuit! Cat!* So I think the perception of Tourette's as the sort of swearing disease is, is, is a big myth. And I think it's a myth that often does get gets in the way of people getting the support they need or being supported well, by by clinicians and by practitioners *Biscuit!*. I think *Biscuit!*. Also swearing like I'm someone who has swearing tics I do have coprolalia *Biscuit!* but I still make up quite a small percentage *Biscuit!* that other things that I say in voluntarily and I think for me certainly *Biscuit!* because there's no intention behind that swearing *Biscuit!* it doesn't sound like Angry swearing *Biscuit* so often people *Biscuit! fuck* don't even hear the words that I you know, swear words as well as because they, they because they don't have that intent, *Biscuit! Sausage! Cat!* but anything I've ever known or experienced has the potential to become a vocal tic *Biscuit!* why certain words turn up and stic around *Biscuit!* is as a mystery and *Hedgehog!* Some people think I'd like trained myself to say biscuit And that's not the case at all, is that's just what my *Biscuit!* is an interruption into my speech *Biscuit!* rather than an interruption into my thoughts. Some people with Tourette's do experience mental tics So, intrusive thoughts are quite common in people with Tourette's *Biscuit! Sausage! Cat*. But for me, my thinking and my thoughts are totally *Biscuit!* free *Biscuit!*, which is why I'm able to have a sort of consistent conversation with you *Biscuit!*. And and most people tend to get used to this sort of verbal interruptions and slowly learn to edit those out *Biscuit! cat*

Steven Bruce
raises so many questions, and we've had a number coming from our audience already. Just Nick has said already he realises that you're great. He says you're very courageous. And it's fabulous that you're doing this do you feel courageous doing this?

Jess Thom

I think I think being yourself this game. And in a world that often expects people to behave in very normative ways. I think anyone who is being their authentic version of themselves in that in situations where they're about as well as barriers, has a degree of courage, it's good. And I also don't feel like I have loads of choice just yet because I want to live active fulfilling independent life *Biscuit!* and talking to people about Tourette's and explaining my condition has become an important tool in making that possible, both for me and other people. So I think that lots of disabled people are courageous, not because they're disabled, but because they experienced barriers in because of the way society is sort of shaped and organised and set up. And so to go out into the world and keep going out into the world, it's good. When you know, you might, you're likely to experience barriers and blocks and assumption. And I think, I think lots of courage within that *Biscuit! Cat!*

Steven Bruce
I infer from that that there will be people with Tourette's who might be very nervous or hesitant to go out and be seen in public if they feel embarrassed by the tic.

Jess Thom
Fuck! Biscuit!. Yeah. And that's, and that's a totally understandable. That's a totally understandable reaction. And I think it's, it's really important when we think about disabling barriers in the world, let's get that there's no judgement on the way that different individuals respond to them. But get I haven't always felt confident facing those barriers. And I haven't always felt confident and able to have conversations like this about my tic. I've learned to do that as a way of *Biscuit!* and making the world work for me, let's get and I'm keen to try and create an environment where other disabled people have to do that less because there's a greater understanding around where what it really means to be a disabled person and how everybody has a shared responsibility and creating a world that is prepared for and thinks about different requirements and different bodies and minds *Biscuit!*. But yes, Tourette's can be quite an isolating condition in lots of ways. It's and that it's an unpredictable condition. So there are challenges of that like with lots of fluctuating conditions. But there's also the unpredictability of other people's reactions to it. And I think that those things combined mean that lots of people with with Tourette's will have understandable and anxieties around being in public spaces or have had traumatic or exclusionary experiences that have damaged their confidence, this guy, and then sometimes this idea that Tourette's is straightforwardly like tics or straightforwardly caused by nervousness. And I don't think that that's a useful way to think about it. Some people with Tourette's will be anxious, this gets some of that anxiety will be well founded, some of that will be because of the way that their brain is set up or the way that their body or mind works, and because they have an anxiety disorder, and *Biscuit!*, but lots of it will also be based on experiences. And some people like I'm not super anxious I'm but let's get but if my tics increase if I'm really excited or really frustrated, or if I hear certain noises, so and there are any sort of heightened emotion can intensify tics, but it's not the cause of it. This get I tech pretty much all the time and having your body scrutinised by other people. And I sort of can't there's often an understandable desire, particularly amongst health care workers and practitioners to try and understand the causes and understand the triggers and like look for patterns. And I think that that is useful to a point if that if the person is sort of on board with that. But it can also be quite

invasive to feel like your body is being scrutinised or used as a sort of gauge of how you're feeling emotionally. So I would be, I would say, it's really important to ask questions and to listen *Biscuit!*, and not assume that just because someone's moving in a certain way, let's get over him in a certain way, or is processing sensory information, this getting a certain way, that that is indicative of you know, feeling a particular emotion *Cat!*

Steven Bruce
Jess you mentioned earlier on about how stress might increase tics in some people. And I had a question about whether emotions affect you. I've also had a question about how you sleep Do you tic when you're asleep?

Jess Thom
Cat? And so to answer the question about emotions, so emotions do impact on tics, but they don't cause tics. And, and so in my experience, if someone's feeling a heightened emotion, they might take more, and also people might take more when they're really relaxed. So this get there's, it's not a straightforwardly linear process, but just like lots of conditions might be influenced or exacerbated by certain emotional states Tech's obviously, are sort of suggestible and sort of vulnerable to that, and *Biscuit!* but, um, but that that's not the sort of root cause of it, *Biscuit!*, sausage cat so *Biscuit!*. And also you can't necessarily and shouldn't necessarily avoid all types of stimulation, it's like I want to feel excited, and risky. And but there's also about having strategies to manage maybe more negative impacts of tics. So I have padded gloves, and that I can wear if that does becomes with my chest banging does become sore. I have cups with lids so that I don't spill hot liquids on myself if I want to have a drink. For me, finding practical solutions detects has been a big part of and thinking creatively around around the situation to mean that I can keep doing what I want to do in the way that I want in the safest way possible. And let's get into and sleep sort of falls into that this gap. And let's get some people taking their sleep. And some people don't get I used to take more in my sleep than I do at the moment. And let's get when I'm very deeply asleep, I don't take but i do i do have some tics in my sleep and they can wake me up and let's get it can also be very difficult to fall asleep. And part of that is because of it because of the tic. Some of that might also be the sort of oppositionality that I mentioned earlier. So when my tics will often increase when I'm really tired or and when I lie down and need to be still they might also intensify because that's the opposite of what I want to be doing at that moment. And I find a weighted blanket really useful for *Biscuit!* giving me a little bit of resistance to help me be still enough to go to sleep *Biscuit!.* And I also use melatonin if I need it. And and I'm really sort of thoughtful about my and try and be really thoughtful about my sort of sleep routine this game. And as someone with Tourette's who's, you know, getting older and this *Cat* and obviously, Tourette's isn't straightforwardly a degenerative condition tics go up and down over the course of someone's life, but it doesn't just get worse. And but there are challenges of ageing with a condition like Tourette's, given that *Biscuit!*, I move around my body goes into quite extreme positions, I obviously move in very repetitive ways. And that has an impact on sort of pain and energy levels, longer term. So I do, and as a sort of long term wheelchair user, I also experience and certain types of chronic pain, because of the way that my body needs to move about. And, and so I think that those things are often not talked about or not planned for. And so it's really been, it's why it's really exciting to

talk to all of you just get because I think that there are opportunities to help prevent injury, or help people live with long term conditions like Tourette's in ways that help maintain their body and mind and well being as well being longer term and reduce pain. So pain also impacts on my sleep. And so I find that so I have a weighted blanket that really helps. I have a positional profiling bed, which means I can sort of move my position and can control my physical position more easily, which is useful given that I don't have lots of control over my body and *Biscuit!* and and I have sort of medication and routine based things that I can do. And if that's particularly difficult.

Steven Bruce
So I'm guessing that you have visited quite a few medical practitioners in your time I don't know whether you've been to see an osteopath, chiropractor or a physio, what are the challenges that we are likely to find in dealing with someone like yourself when they come to us?

Jess Thom
And I think I have I've had lots of different appointments and physio is something that I've benefited from a lot. And particularly, I've also done lots of work in terms of hydrotherapy, because that's a place that I can do movement based exercise sort of safely and in a more controlled way and have less of less chance of injury, and *Biscuit! sausage*. But I think some of the big issues are. The first is really listening to people I think as a wheelchair user, and as someone who has sort of non normative speech patterns and communication, it can take any sort of rushed clinic environment, and weather sort of pressures on time. And then it can be, it can be easy for us to maybe not give people the time to explain their own circumstances and condition in their own words. And *Biscuit!*. I think there's also really the lack of information about conditions like Tourette's that are maybe long term neurodevelopmental or neurological conditions, but maybe not conditions that are and that have, that are sort of life threatening, or, and are ones that people will see or that are really common, where people will be able to see them all the time to x isn't a rare condition. It's estimated to affect about 350,000 people in the UK alone. And but I'm aware that it's not something that people will see in clinics loads. And this get and that individual practitioners might not be working one might only be working with one or two people. And but I suppose my the things that really help is people listening, people being ready to adapt the appointments, then particularly physios have filled like I've the physios I've had have been really good at recognising that *Biscuit!,* I'm not necessarily going to be able to do the exercises in the way that they would usually expect them to be done. So it's about trying to find a way that works for that person's body. And circumstances. And, and that I think that people who will work with bodies and work with muscles and work with joins are often some of the best people at creative problem solving and adapting. And because that's part of what they'll have to do with lots of different types of condition and circumstance *Biscuit!.*

Steven Bruce
That's one of one of the questions that came in earlier on was about about your chest punching just occasionally your arms going the other direction as you did just then and I think people are worried Well, how do we deal with that? If you are on my treatment table, am I likely to get punched in the nose?

Jess Thom
Fuck, There is a risk and there are risks. And that needs to be assessed based on individuals. It has that assessment of risks you need to be careful about because obviously, if you talk a lot about one particular thing, like I'm going to sit on my hands at *Biscuit!,* I'll try and set my hands as we do this. So I don't if we talk a lot about like, you know, hitting yourself in the head or something, let's get it *Biscuit!,* is much more likely to happen. And that's good. So it's good to sort of talk about how we're going to keep people safe like unto us but other things that are there. I should be aware of that might happen suddenly, let's get but also being aware of people's other the sort of sensory environment and sensory landscape and making sure you check in with people about what their preferences *Biscuit!,* are for communication around touch and sound and how things are how information is shared with them. So for example, when I'm very sensitive to gentle touch, so if somebody touches me really in an in a in a very light way and *Biscuit!,* then it can be quite uncomfortable for me I'm often surprised my my reactions are a heightened and that doesn't represent me being genuinely scared that I my body overreacts. And but if someone touches me, and I'm really firm way, and uses sort of deep, consistent pressure or communicates that they're about to touch me, and then that prevents that so but people will be very individual around that. And but I think understanding that some people with Tourette's and other neurological conditions, and will process sensory information differently, or will need different commute will have different communication preferences. And being having that as part of what you what you go through at the start of a as an appointment or start a treatment process with someone so you can establish what they are. I think that's the best way to keep everybody safe and mean that it's a sort of positive experience on both sides *Biscuit!,*

Steven Bruce
Somebody else doing well, they haven't given me their name, but they've also saved a lot of your tics are very repetitive, do you you get anything like repetitive strain as a result of perhaps hitting yourself in the chest every few seconds?

Jess Thom
Yeah, I think I think I had a *Biscuit!,*. I had a physio or, and sort of a doctor, a consultant at some point recently say, but he says but like he suspects that lots of the pain I experiences is a sort of constant, ongoing repetitive strain from bit doing lots of movements in there in exactly the same way *Biscuit!,* and not gently for an you know, for for, you know, for four decades. So that that obviously does that does have an impact, but is obviously also adapt to that in surprising ways. And, and escaped and probably I compensate for that in in in other ways and get used to, you know, you know, that's that's not a surprise to me, it will look quite dramatic if it's, if it's not something that your body does all the time. But for me, that's something that I've cut, you know, I'm accustomed to *Biscuit Sausage! Cat!*

Steven Bruce
The second the second half of that question was, is it okay to ask questions like that of someone with Tourette's?

Yeah, I think absolutely. And I think particularly in a clinical environment, it's really important to ask those questions. And I think it's important to ask them in a way that is specific, respectful, and doesn't make assumptions. So, for example, I wouldn't describe myself as a Tourette suffer, and I wouldn't describe and the tics straightforwardly as a problem that I'm looking to solve, I might be keen to work on and remove some of the pain associated with that or, and be able to do things in a more like certain tasks more successfully, like they're getting to sleep or washing myself, for example, there might be particular things that I would want to work on. But I think it's important not to just assume that the aim would be to make someone quiet and still, and that that would be success, I think, establishing what someone's goals are, and then being really open about and asking them about their of what they need. And, and like, I would expect that to be a sort of ongoing conversation, but get for me, I also give an often give people permission to ask questions, because I would much rather they asked me, and I was able to say that they made an assumption or got information that was unreliable this get, not everyone will and will fit will find that as easy or will feel comfortable doing that. And it is important. And this get that and I you know, there's that there's a labour on energy, like people with Tourette's is not our job to educate people about our condition if we just want to access a service, but I do, but I think it is really important that as part of a service, particularly one that's providing a physical health and treatment or benefit, is that that that takes are thought about within that process. *Biscuit!*

Steven Bruce

I've been puzzling over something you said right at the beginning. You said if I want someone to lie still on my treatment, say well, the worst thing to do is just a lie still. How should we approach that?

Jess Thom

Biscuit! And I think I think that like, it's like I think lies still isn't such a problem. I think if you say don't move it If you said whatever you do keep this bit still. And I often use the example of a ski I took a group of young people go karting once to a go kart track, and they were having the induction *Biscuit!*And the person that was giving them the safety briefing kept telling this 14 year old with Tourette's, to not put his foot on the, on the brake, whatever you do, don't put your foot on the brake. And, and that was then like hit that the young person then got really anxious about put it back doing that thing. And knowing that he he had an automatic oppositional impulse to do that thing. Whereas actually, as soon as we refocused it and concentrated on how he shouldn't be driving and what he should be approaching, he found that much easier. So I think it's about framing of questions. And this guy, and sometimes there'll be things where I just be like, don't have like, Don't tell me the things that I'm not allowed to do or say, because I just, I just would rather not know. And, but you know, that that is about that's about dynamic risk assessment, I think is a really important part of life of Tourette's, let's get the difficulty with that is actually with lots of neurological conditions. And maybe there is a lack of awareness of danger. For me, I've got a really good awareness of danger, and I'm really good at perceiving risk, let's get what I can't do is control my body not to go towards that risk. So if I see something, if there's a hot hob in front of me, or if I see a sort of a sharp knife *Biscuit!* I will know that that's there, and I shouldn't touch it. But then that oppositional impulse will mean that I will reach out and touch it. So actually, that awareness of danger is sometimes the thing that puts me most at risk *Biscuit!*. Tourette's is like quite a complicated, weird condition from that point of view. And it's that it's quite, it's quite a complex thing to unravel and live with. And understand from a sort of lived experience of it, it can be really challenging for family members and for schools and for people are so like supporting and caring and working with someone with Tourette's. And it can be really difficult in clinical environments, particularly where there's pressures on time or resources to actually understand those and complexities and to find solutions.

Steven Bruce
For taking that a little bit further, and your perception of risk, clearly, you're able to analyse what's being said and what's going on. However, if I were to have you in my treatment room, I would be required to give you a warning about the inherent risks of some forms of treatment. And then I'll ask you whether you're happy for me to continue. Is there any danger that you might give me the wrong answer, and I might misinterpret that,

Jess Thom
Biscuit! I think, was getting I think that there is a risk of that, but I think you know, I have mental I have mental capacity, and most people with threats will be able will be able to, to, to take informed consent. And I think if you're in any doubt, I would ask again, whiskey and and let's get most people can quite quickly *Biscuit!*, differentiate chosen speech, *Biscuit!* and tic speech and *Biscuit!* As the person observed, like lots of the movements, forget that I make a very sort of stereotyped and repetitive let's get lots of the noises *Biscuit!* and vocal tics, let's get we'll have have a different pitch. And, and, and have a different intonation to them. So they do seem to sit outside of this get and so chosen speech. So mostly you can differentiate I've find it quite easy to skip listening to other people with Tourette's to be able to differentiate what is their chosen action? And what is a tic, but if you're not sure, it's I would like always ask again, or, or find different alternative ways to communicate. So for example, you know, reading something through or emailing through, there's different ways that there's different ways to do that. If you're not sure. *Biscuit! Cat!*

Steven Bruce
Interesting that you don't like to be referred to as a Tourette's victim or Tourette's sufferer, but you use the word disability more freely than a lot of people might. Rob commented on that earlier on saying that's an interesting perception, but also, as healthcare professionals, if we if we have someone in our treatment room, and we suspect they may have Tourette's, what do we do about it? are they likely to know before we do,

Jess Thom
I'm gonna address the word disabled first, because I think it's a really important point, this guy, and I identify as a disabled person, let's get within the context of something called the social model of disability. So there's when we talk about models of disability, we're talking about the ways and the concepts we use to think about and frame disability and and our bodies and minds and our relationship with them. This gap, and traditionally, the way disability was talked about was using a medical or a charity model and Both those focus on someone being a disabled person *Biscuit!*,

because their body or mind is impaired in some way. They see the impairment as the sole disabling factor in a person's life was good. For me when I say I'm disabled, I'm using the social model, the social model was developed by disabled people decades ago, let's get and it understands that it's normal for bodies and minds to work in different ways, let's get and for some people to have impairments, and or conditions and some people not. So the facts about our body are the facts about our body, that's our impairment, you know, we have an impairment we don't, what is disabling is a failure to consider that diversity of body and mind in the way that we structure and organise society. So Tourette's is my impairment, it affects my mobility. And it affects my communication skills. And I have a chronic health condition, which is also part of my impairments. And that's good, but they're not the things that make me a disabled person. I'm a disabled person, because I expect I have a lived experience of disabling barriers in the world. So if I can't get into a building, because it's surrounded by steps, traditional ways of thinking about disability would say that my wobbly legs were the problem. The social model identifies the steps as the disabling barrier. Let's get the exciting thing about that is that by thinking about a diversity of bodies, let's get whenever we set something up, whether that's just how we lay out our treatment room, or how we communicate information, or get the options we have on our website, if we think about different bodies and minds, we can create less disabling spaces, systems and attitudes, *Biscuit! cats*. So for me, when I say I'm a disabled person, it means that I, I feel proud I can give and receive solidarity, and I can be part of finding solutions to them and making them more inclusive world *Biscuit!* And in the UK, that way of thinking about disability is quite well established, we amongst disabled people. And even though the medical and charity models are more dominant in our society, and that's not saying that medicine is bad, or charity is bad, it's good. But it's saying that when we think about what disabled people and what prevents people participating in the world, often it is the barriers, because of a lack of adjustment and a lack of access. So that things that are preventing public participation, rather than someone's body. And it's, of course, there are things about my impairment that won't be solved by by changing an attitude or changing an environment *Biscuit!*but lots of things, lots of the challenges I experienced day to day can be greatly improved. And by taking that top type of action *Biscuit!* and cat, that was the first part of the question. And I know that in the in the US person first language, so saying, a person with a disability this game is often is the dominant way of doing things. And for me, that doesn't fit with a social model, because a disability isn't with me, it's with the world. And this get and that that in the when we say disabled person, we would describe that as identity first language. So again, language around disability is often changing. It's getting it's something that often people will feel uncomfortable about. And it's, it's about going with what someone's preferences are. And and then when in the UK when you're writing about disabled people. That is that that is the way we most people would encourage that's the sort of standard practice to white disabled person using identity first language to understand that disability doesn't mean less able. When I say I'm disabled, it doesn't say anything negative about me. It just acknowledges the barriers I experience. And because the world, the world doesn't often consider bodies like mine *Biscuit! Cat!*.

Steven Bruce
And the second part of the question, second part, there's several questions which relate to this. People asked me about the onset of Tourette's and you said that your motor tics came on, I think

later than your verbal tics. So the question was, if we were in a position to suspect that someone had Tourette's, what would we do to point them in a direction?

Jess Thom
Biscuit! So I had tic since I was about six, it's believed to be an inherited genetic condition. And the pattern of inheritance isn't always clear, but it does run in families often, and but not exclusively *Biscuit!* And *Biscuit!* actually, motor tics are often, often sort of commonly the first tic so I think I did have I had motor tics, but they're quite simple motor tics. So I had jumping and blinking tics, blinking is a very common and simple motor tic and I then also I'm about six I was a squeaker, I have a squeaking tic *Biscuit!* But my tics intensified in my early 20s, and began to have a much bigger impact on my life at that point, and *Biscuit! Cat!*, that's not theirs, they're, it's usual for tic to show up in childhood. So six or seven is quite a common age for Tourette's to start first being noticed, and *Biscuit! Fuck! Cat!*, and for some people that gets that lessons, like after adolescence into into adulthood. But for other people, Tourette's will be an ongoing part of their life, this game, it's quite possible for someone to have tic and have had Tourette's all of their life and not really know that that's what they that's what they have, or for it to suddenly start manifesting itself in a new way. And so that you might find, you might come across someone who is an adult who is having difficulties with with movements or noises or other coexisting conditions, and who has reached adulthood without really having engaged with that part of how their body works. And the best route for supporting that is to encourage them to think about and talk about their experiences, is to encourage them to go to their GP and to seek a referral to a specialist clinic, that would be the ideal. That's the sort of simplest strand way, way through it. And *Biscuit!*For me, I've got two because I sort of know I knew I had to act really from being a teenager without a formal diagnosis. And I got I was in my early 20s. And I thought I didn't see what what diagnosis would add to my life, there was a part of me that was like, I've got this far, I don't know what it's going to add *Biscuit!*But actually having a formal explanation to be able to explain to people, whether that's socially or whether that's employers, whether that's healthcare practitioners, and scared and being able to learn about the condition and learn about something, let's get this always been a big part of my life was more powerful than I would ever have imagined *Biscuit!*So I think it's important diagnosis is an important step to understanding setting your body. And I think that that answer finding solutions and to getting the right support. So if I hadn't taken that step, loads of the things that I've been able to do that have been really positive man in my life, because I've understood myself better because I've been known how to ask for help, and and the right sort of get the right sort of support, and wouldn't have happened if I hadn't taken that step. So but some people will need more support without than others *Biscuit! Cat! Fuck!*.

Steven Bruce
I've got so many so many questions coming in. I'm a person who's calling themselves Scotch bonnet, and I don't know who this is. But they said, Yeah, don't ask. But there's a there's a bunch of people to give themselves weird names on the Wii. And I think it's in the Vimeo, scotch one, it says could a person learn when you saw a knife on a workshop, the thing to do is go into another room? And could parents teaching their children that sort of behaviour? Or is it just too overwhelming the desire to have this oppositional reflex.

Jess Thom
And it depends person to person. So and I, nine times out of 10 can say knife, or can say could make a noise that is not necessary, not necessarily a coherent sentence, “there is an exposed knife on the side”, I don't have the language at that point for that, but I and sometimes it is very quick and risky. I also have sheaths on my knives. And they also I don't straightforwardly know where they're kept in my house. So that like the challenge about tic is that there, there are like self interest, like there is a risk of myself in terms of self injury, but it's not driven by the normal by the sort of usual thing. It's not intentional self injury in a way that might be and that you might be where there might be clear pathways for this get. And so for me developing practical strategies and thinking why if I like and the same with like open windows or sight exposed, stairways work anywhere where there is like that. And I think most people will be familiar with that. I mustn't do that, like it's an instant thing that you're not consciously even thinking about. People with Tourette's, that impulse control is to switch and it's really fast often and but I think that there are strategies and approaches to that and ways of managing that. And also the key thing is to sort of limit opportunity. So I know I have a sort of stairgate on the top of my stairs and my communal block and *Biscuit!* we keep sheaths on knives and I avoid the kitchen when people are cooking *Biscuit!Cat*.

Steven Bruce
Again, I've got so many messages coming in just full of praise for you. Your approach to this? before we let you go, Could you just tell us a bit about your Tourette's hero website? Because I'm sure that's a useful resource for both us and for people with Tourette's.

Jess Thom
Yes, so Twitter, I was a creative organisation, as well as a superhero persona. And we have a, we have a website at Touretteshero.com. And, and there there is sort of 10 years worth of writing about tics. And there's things about the sort of funny aspects of life with Tourette's stuck around the challenging aspects of life with Tourette's. There's lots of advice and blog posts that are aimed at other people with the condition but also at their friends and families and teachers, as well as stuff that's broadly more broadly about disability generally, and disability culture. So the art activism and thinking that comes out of the lived experience of being a disabled person and experiencing barriers in the world. And you can also follow us on social social media. But can I share something that I've said is a funny tic each day on Facebook and Twitter and you can follow that by looking for the hashtag daily outburst. And some of the things that I say are funny, and so we'll and have vivid imagery *Biscuit!* and, and as well as sharing them on social media, we also invite people to make artwork in response. And so one of the big parts of Tourette zero and one of the changing life changing moments for me, was when I had a conversation with my friend Matthew, who's the co founder of Tourette's hero. Now, but but long before that, and we had a conversation at a point where I was finding, adjusting to life with tics really difficult. And he described my tic *Biscuit!* as a crazy language generating machine, and told me that not doing something creative with it would be wasteful escape. And for me, that was transformative, I was able to hear that sentence in a different way and engage with the creative, spontaneous creativity, let's get him an unusual perspective that Tourette's gave me access to and it was the first time that I'd really felt able to

positively engage with that and see value in that and it was the starting point for Tourette zero. It's also how I know that what we say to each other matters, and your roles as clinicians matters, not only in improving people's well being *Biscuit!* but helping them understand and accept themselves in their bodies and find ways of living well with a range of different impairments *Biscuit!*

Steven Bruce
Just very quickly, what's the comedy show that you've recorded that we should be looking out for?

Jess Thom
And it's going to be aired on BBC Radio four, and what's called the 13 million club and it will air later in November on a yet on the radio and it will be it will be a sort of celebration of disability culture with disabled comic comedians centre stage this game

Steven Bruce
That's fantastic. Someone accused someone accused you of being brave earlier on just not sure whether they had the right you do public speaking and you do stand up comedy which are the two things in the world. And I am honest, I was just amazed. Thank you so much for giving up your time today.

Jess thom
You know what I only ever have to write half a set because Tourettes does the rest and I don't have to worry about awkward silence, and the heckler I'm most worried about is always me. So really, the audience are generally quite brave coming to see a comedy act that where we where we can't guarantee what will happen.

Steven Bruce
I'm so grateful for you giving me your time. I knew this would be a great show and it did my expectations and everybody else's from what I'm getting here. Thank you so much.

Thank you. Thank you for inviting me *Biscuit!Cats!*