

# Tourette's

with Jess Thorn  
5<sup>th</sup> November 2020

## TRANSCRIPT

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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 Jesse Thom, who founded the website, Tourette's Hero, 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 4 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 get a picture of you up in a second? Are you there, Jess? Thank you. Yes. Right, good. Jess, I've just said that 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. 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 shared laughter and enjoying the sort of humour of a situation or the surreal things, **biscuit**, 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. But there is a difference between that and laughter that is sort of at someone and is more mocking. So yes, I would definitely encourage people to laugh if I say funny tics, **biscuit**, that they're going to hear the word biscuit and hedgehog, a lot during our discussion and, biscuit, I think you've got some biscuits to hand just in case you get peckish, **sausage, biscuit, cats**, biscuits but no sausages, and no hedgehogs. Fuck. And finally, several times a day, my tics intensify and I completely lose control of my body and speech, which looks seizure-like and needs similar management. If that happens to me, don't worry, 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 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.** So, 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. **Biscuit, sausage, cats.** Vocal tics and motor tics can both be simple. So, they can be simple noises like sniffing or humming or throat clearing, **biscuit**, or they can be complex words and phrases. **Biscuit.** And 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**, my motor tics include banging my chest hundreds of times a day, **biscuit, cats**, 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. **Biscuit.**

**Steven Bruce**

Right? So, does that not hurt.

**Jess Thom**

**Hedgehog, biscuit.** For the first few months, **biscuit**, my chest bruised really badly. And I was needing to wear dressings to protect the skin, **biscuit**, but actually 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, a smooth lump emerged. So 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 help us with that journey to sort of adapt and accept ourselves as we are. **Biscuit, cats.**

**Steven Bruce**

Out of curiosity, where do you put yourself on the spectrum of Tourette's in terms of very little effected and very, very much effected?

**Jess Thom**

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 mobility. 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 for me and actually sometimes people with milder tics or people with coexisting conditions, so, **biscuit**, 80% of people with Tourette's will have coexisting conditions like obsessive compulsive behaviour or attention deficit and hyperactivity disorder, ADHD, or OCD, **biscuit**, and sometimes those coexisting conditions can be more disruptive in someone's life than the tics themselves. So what's visible externally isn't always the sort of whole picture of what's going on, **biscuit**, and for me, I'd much rather talk about what somebody, what 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**

No, I take that point, I suppose that the purpose of the question was, if we see someone with Tourette's in clinic, are we likely to see people who throw out their arms more often than you do, or have more difficulty communicating you do or are you sort of, at the extreme end of that spectrum?

**Jess Thom**

So, tics are really variable. **Biscuit**, and lots of people would qualify for a 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's 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 that might be helpful in making them more comfortable in a clinic environment. **Biscuit**. There is an 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 body still, that can have a sort of suggestible effect, an oppositional effect to mean that the opposite is more likely to happen. So, it's then useful to talk through with someone the best way of framing expectations 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 or be easier for them 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, biscuit, and my tics are quite, **biscuit**, quite consistent in that they tend to be at 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 pretty visible and pretty immediate, **biscuit**, there are lots of people who do have to think more carefully about when they tell someone that information and I think 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 how they're 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 be able to get the best information about that person. **Biscuit, fuck**.

### Steven Bruce

There's a widely held perception, isn't there, that people with Tourette's swear a lot but that's not necessarily true is it?

### Jess Thom

No about 10% of people have coprolalia which is the technical name for obscene tics. And that's the name for obscene vocal tics. Copropraxia is obscene movements and gestures, **fuck it, biscuits, sausage, cats**. And then there's echolalia and echopraxia, which is, echolalia might be familiar to people because it's present in other neurological conditions like autism, where you might repeat somebody's speech, and, **biscuit**, and 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. **Biscuit, cats**. So, I think the perception of Tourette's as the swearing disease is a big myth. And I think it's a myth that often does get in the way of people getting the support they need or being supported well by clinicians and by practitioners. **Biscuit**. Also swearing like I'm someone who has swearing tics I do have coprolalia, **biscuit**, but they still make up quite a small percentage, **biscuit, fuck**, of the things that I say involuntarily 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 swear words as swear words because they don't have that intent. **Biscuit, sausage, fuck**. But anything I've ever known or experienced has the potential to become a vocal tic,

**biscuit**, why certain words turn up and stick around, biscuit, is as a mystery. **Hedgehog**. Some people think I trained myself to say biscuit. And that's not the case at all, that's just what my, **biscuit**, it's 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. **Biscuits, sausage, cats**. 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 most people tend to get used to the verbal interruptions and slowly learn to edit those out. **Biscuit, cat**.

### **Steven Bruce**

Raises so many questions, and we've had a number come in from our audience already, Jess. 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 being yourself, **biscuit**, 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 there's barriers, has a degree of courage. **Biscuit**. I also don't feel like I have loads of choice, **biscuit**, because I want to live an 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 experience barriers 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, **biscuit**, when you're likely to experience barriers and blocks and assumption I think there's lots of courage within that. **Biscuit. Cats**.

### **Steven Bruce**

I infer from 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 their tic.

### **Jess Thom**

**Biscuit**. Yeah. And that's a totally understandable. That's a totally understandable reaction. And I think it's really important when we think about disabling barriers in the world, biscuit, that there's no judgement on the way that different individuals respond to them. **Biscuit**. 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 tics. I've learned to do that as a way of, **biscuit**, making the world work for me, **biscuit**, 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 what it really means to be a disabled person and how everybody has a shared responsibility in 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 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 Tourette's will have understandable anxieties around being in public spaces or have had

traumatic or exclusionary experiences that have damaged their confidence. **Biscuit.** There's sometimes this idea that Tourette's is straightforwardly tics or straightforwardly caused by nervousness. **Biscuit.** And I don't think that that's a useful way to think about it. Some people with Tourette's will be anxious, **biscuit,** 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, **biscuit,** but lots of it will also be based on experiences. And some people, like I'm not super anxious, **biscuit,** but my tics increase if I'm really excited or really frustrated or if I hear certain noises, so any sort of heightened emotion can intensify tics, but it's not the cause of it. **Biscuit.** I tic pretty much all the time and having your body scrutinised by other people and there's often an understandable desire, particularly amongst health care workers and practitioners to try and understand the causes and understand the triggers and look for patterns. And I think that that is useful to a point 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, **biscuit,** or behaving in a certain way or is processing sensory information, **biscuit,** in a certain way, that that is indicative of feeling a particular emotion. **Fuck.**

### **Steven Bruce**

Can I just digress for a second to make a quick technical announcement I've just heard from my technical team, we have so many people watching today that the system that controls our access is having trouble. It's a computer based somewhere in the States. Obviously, you don't have any problem watching, you wouldn't be hearing me now. But what we will have problems with is registering your attendance. If you clicked on the email that I sent earlier on, in order to get to this broadcast, then we will know you're here. If you logged into the website using your password, then we will know you're here. If you simply went to the website and clicked on the broadcast, and you got here without entering any details, then we won't, so please send us a very brief email with the headline, Tourettes, that's all you need to say, we will make sure that you're registered. And we only need to know that so that we can give you your certificate. Anyway, 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**

To answer the question about emotions, emotions do impact on tics, but they don't cause tics. In my experience, if someone's feeling a heightened emotion, they might tic more, **biscuit,** also people might tic more when they're really relaxed. **Biscuit.** It's not a straightforwardly linear process, but just like lots of conditions might be influenced or exacerbated by certain emotional states tics, obviously, are sort of suggestible and sort of vulnerable to that, **biscuit,** but that's not the sort of root cause of it. **Biscuit, sausage cats. Biscuit.** Also, you can't necessarily and shouldn't necessarily avoid all types of stimulation, it's like I want to feel excited. **Biscuit.** But it's also about having strategies to manage maybe more negative impacts of tics. So, I have padded gloves that I can wear if 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, **biscuit,** has been a big part of thinking creatively 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. **Biscuit**. And sleep sort of falls into that, **biscuit**, some people tic in their sleep and some people don't. **Biscuit**. I used to tic more in my sleep than I do at the moment, **biscuit**, when I'm very deeply asleep I don't tic but I do have some tics in my sleep and they can wake me up. **Biscuit**. It can also be very difficult to fall asleep and part of that is because of the tics. Some of that might also be the sort of oppositionality that I mentioned earlier. So, my tics will often increase when I'm really tired 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. 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**. I also use melatonin if I need it. And I'm really sort of thoughtful about my, I try and be really thoughtful about my sort of sleep routine, **biscuit**. As someone with Tourette's who's getting older and, **biscuit**, 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. 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 certain types of chronic pain, because of the way that my body needs to move about. So, I think that those things are often not talked about or not planned for. That's why it's really exciting to talk to all of you, **biscuit**, 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 wellbeing longer term and reduce pain. So pain also impacts on my sleep. 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. **Biscuit**. I have sort of medication and routine based things that I can do if that's particularly difficult.

### **Steven Bruce**

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**

I have 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 chance of injury.

**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, in a sort of rushed clinic environment where there's sort of pressures on time, then it can be easy for us to maybe not give people the time to explain their own circumstances and condition in their own words.

**Biscuit**. I think there's also really a lack of information about conditions like Tourette's that are maybe long term neurodevelopmental or neurological conditions, but maybe not conditions that are sort of life threatening or are ones that people will see or that are really common, where people will be able to see them all the time. Tourette's isn't a rare condition, it's estimated to affect about 350,000 people in the UK alone

but I'm aware that it's not something that people will see in clinics loads and that individual practitioners might not be working, one might only be working with one or two people. I suppose the things that really help is people listening, people being ready to adapt, the appointments, particularly physios, 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. I think that people who work with bodies and work with muscles and work with joints are often some of the best people at creative problem solving and adapting because that's part of what they'll have to do with lots of different types of condition and circumstances.

**Biscuit, cats.**

**Steven Bruce**

One of the questions that came in earlier on was about your chest punching, occasionally your arms going the other direction, as you did just then, and I think people are wondering, 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. 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, **biscuit**, I'll try and set my hands as we do this so I don't, if we talk a lot about hitting yourself in the head or something, **biscuit, fuck, biscuit**, it is much more likely to happen. **Biscuit.** So, it's good to sort of talk about how we're going to keep people safe and to ask, are there tics that I should be aware of that might happen suddenly? **Biscuit.** But also, being aware of people's 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 information is shared with them. So, for example, I'm very sensitive to gentle touch so if somebody touches me in a very light way, **biscuit**, then it can be quite uncomfortable for me or if I'm surprised my reactions are heightened and that doesn't represent me being genuinely scared, my body overreacts. But if someone touches me in a really firm way and uses sort of deep, consistent pressure or communicates that they're about to touch me, then that prevents that but people will be very individual around that. But I think understanding that some people with Tourette's and other neurological conditions will process sensory information differently or will have different communication preferences. And having that as part of what you go through at the start of 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 asked earlier on, they haven't given me their name, but they've also said a lot of your tics are very repetitive, do 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 had a, **biscuit**, I had a physio and a doctor, a consultant, at some point recently say, he suspects that lots of the pain I experience is a sort of constant, ongoing repetitive strain from doing lots of movements in exactly the same way, **biscuit**, and not gently for decades. So that obviously does have an impact, bodies obviously also adapt to that in surprising ways. **Biscuit**. And probably I compensate for that in other ways and get used to, you know, that's not a surprise to me, it will look quite dramatic if it's not something that your body does all the time. But for me, that's something that I'm accustomed to. **Biscuit, sausage, cats.**

### Steven Bruce

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

### Jess Thom

Yeah, I think absolutely. And I think particularly in a clinical environment, it's really important to ask those questions. I think it's important to ask them in a way that is, **biscuit**, respectful and doesn't make assumptions. So, for example, I wouldn't describe myself as a Tourette's sufferer and I wouldn't describe 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 be able to do things in a more, like certain tasks more successfully, like 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 asking them about what they need and I would expect that to be a sort of ongoing conversation. **Biscuit**. For me, I often give people permission to ask questions, because I would much rather, they asked me, and I was able to say, than that they made an assumption or got information that was unreliable. **Biscuit**. Not everyone will find that as easy or will feel comfortable doing that. And it is important, **biscuit**, that, you know, there's a labour on energy, like people with Tourette's, it's not our job to educate people about our condition if we just want to access a service, but I think it is really important that as part of a service, particularly one that's providing a physical health treatment or benefit, that tics 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, the worst thing to do is to say, lie still. How should we approach that?

### Jess Thom

I think that "Lie still" isn't such a problem. I think if you say "Don't move!" If you said "Whatever you do keep this bit still!" I often use the example, **biscuit**, 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 brake, whatever you do, don't put your foot on the brake. And the young person then got really anxious about doing that thing and

knowing that he had an automatic oppositional impulse to do that thing. Whereas actually, as soon as we refocused it and concentrated on how he should be driving and what he should be approaching, he found that much easier. So, I think it's about framing of questions. **Biscuit.** And sometimes there'll be things where I'll just be like, don't tell me the things that I'm not allowed to do or say, because I just would rather not know. That's about dynamic risk assessment, I think is a really important part of life of Tourette's.

**Biscuit.** The difficulty with that is actually, with lots of neurological conditions 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, **biscuit**, 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 quite a complicated, weird condition from that point of view and 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 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 complexities and to find solutions. **Fuck.**

### **Steven Bruce**

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 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 that there is a risk of that, but I have mental capacity and most people with Tourette's will be able to take informed consent. I think if you're in any doubt, I would ask again, **biscuit**, and most people can quite quickly, **biscuit**, differentiate chosen speech, **biscuit**, and tic speech and, **biscuit**, as the person observed, lots of the movements, **biscuit**, that I make are very sort of stereotyped and repetitive, **biscuits**, lots of the noises, **biscuit**, and vocal tics, **biscuit**, will have a different pitch and have a different intonation to them. So, they do seem to sit outside of, **biscuit**, chosen speech. So mostly you can differentiate, I find it quite easy, **biscuit**, listening to other people with Tourette's to be able to differentiate what is their chosen action and what is a tick, but if you're not sure, I would always ask again or find different alternative ways to communicate. So, for example, reading something through or emailing through, there's different ways to do that if you're not sure. **Biscuit.**

### **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 have someone in our treatment room and we suspect they may have Tourette's, what do we do about it? Or 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, **biscuit**, I identify as a disabled person, **biscuit**, within the context of something called the social model of disability. So, 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 our bodies and minds and our relationship with them. **Biscuit**. 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. **Biscuit**. For me when I say I'm disabled, I'm using the social model. The social model was, **biscuit**, developed by disabled people decades ago, **biscuit**, and it understands that it's normal for bodies and minds to work in different ways, **biscuit**, and for some people to have impairments or conditions and some people not. So the facts about our body are the facts about our body, that's our impairment, we have an impairment or 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, **biscuit**, I have a chronic health condition, which is also part of my impairments, **biscuit**, but they're not the things that make me a disabled person. I'm a disabled person, because 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. **Biscuit**. The exciting thing about that is that by thinking about a diversity of bodies, **biscuit**, whenever we set something up, whether that's, **biscuit**, how we lay out our treatment room or how we communicate information or, **biscuit**, 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 feel proud, that I can give and receive solidarity, and I can be part of finding solutions and making a more inclusive world. **Biscuit**. In the UK, that way of thinking about disability is quite well established amongst disabled people, 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, **biscuit**, but it's saying that when we think about what disables 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, are the things that are preventing participation, rather than someone's body. And it's, of course, there are things about my impairment that won't be solved 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 by taking that type of action. **Biscuit, cats**. That was the first part of the question. I know that in the US, person first language, so saying a person with a disability, **biscuit**, is the dominant way of doing things. For me, that doesn't fit with a social model, because a disability isn't with me, it's with the world. **Biscuit**. And when we say disabled person, we would describe that as identity first language. So again, language around disability is often changing and it's something that often people will feel uncomfortable about. It's about going with what someone's preferences are and then when in the UK, when you're writing about disabled people, that is the way most people would encourage, that's the sort of standard practice to write 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 doesn't often consider bodies like mine. **Biscuit, cats**.

## Steven Bruce

The second part of the question, there's several questions which relate to this. People asking about the the onset of Tourette's and you said that your motor tics came on 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 the right direction?

## Jess Thom

**Biscuit.** So, I had tics since I was about six, it's believed to be an inherited genetic condition. The pattern of inheritance isn't always clear, but it does run in families often but not exclusively. **Biscuit.** Actually, motor tics are often sort of commonly the first tic so I think I had motor tics, but they were quite simple motor tics. So, I had jumping and blinking tics, blinking is a very common, simple motor tic, and then also from 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. **Biscuit, cats.** it's usual for tics to show up in childhood, so six or seven is quite a common age for Tourette's to start first being noticed, **biscuit, fuck, cats,** and for some people that lessens, after adolescence into adulthood, but for other people Tourette's will be an ongoing part of their life. **Biscuit.** It's quite possible for someone to have tics and have had Tourette's all of their life and not really know that that's what they have or for it to suddenly start manifesting itself in a new way. So that you might come across someone who is an adult who is having difficulties with movements or noises or other coexisting conditions, who has reached adulthood without really having engaged with that part of how their body works. 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 way through it. **Biscuit.** For me, because I sort of know I knew I had to act really from being a teenager without a formal diagnosis and I was in my early 20s and I thought I didn't see 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, **biscuit,** and being able to learn about the condition and learn about something, **biscuit,** that's always been a big part of my life was more powerful than I would ever have imagined. **Biscuit.** So, I think diagnosis is an important step to understanding and accepting your body. And to 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 in my life, because I've understood myself better, because I've been known how to ask for help, and get the right sort of support, wouldn't have happened if I hadn't taken that step. But some people will need more support without than others. **Biscuit, cats, fuck.**

## Steven Bruce

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

## Jess Thom

It depends person to person. I, nine times out of ten, can say knife or can could make a noise that is not necessarily a coherent sentence, there is an exposed knife on the side, I don't have the language at that point for that, and sometimes it is very quick. **Biscuit**. I also have sheaths on my knives and also, I don't straightforwardly know where they're kept in my house. The challenge about tics is that there self-injurious, there is a risk to myself in terms of self-injury, but it's not driven by the normal thing. It's not intentional self-injury in a way that there might be clear pathways for. **Biscuit**. So, for me developing practical strategies and thinking, and the same with open windows or exposed stairways, anywhere where there is 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 just switched and it's really fast often but I think that there are strategies and approaches to that and ways of managing that. 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 in my communal block and, **biscuit**, we keep sheaths on knives and I avoid the kitchen when people are cooking. **Biscuit**.

## Steven Bruce

Again, I've got so many messages coming in, Jess, full of praise for you and 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 Tourette's Hero was a creative organisation, as well as a superhero persona. And we have a website at touretteshero.com. and there is sort of 10 years' worth of writing about tics, there's things about the sort of funny aspects of life with Tourette's, stuff 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 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. You can also follow us on social media. **Biscuit**. I share something that I've said as a funny tic each day on Facebook and Twitter and you can follow that by looking for the hashtag #dailyoutburst Some of the things that I say are funny and surreal and have vivid imagery, **biscuit**, 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's Hero, and one of the 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 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 tics, **biscuit**, as a crazy language generating machine, and told me that not doing something creative with it would be wasteful. **Biscuit**. And for me, that was transformative, I was able to hear that sentence in a different way and engage with the spontaneous creativity, **biscuit**, and 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's Hero. It's also how I know that what we say to each other matters and your role as clinicians matters, not only in improving people's wellbeing, **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**

And Jess, 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, it's called The 13 Million Club and it will air later in November on the radio and it will be a sort of celebration of disability culture with disabled comedians centre stage. **Biscuit, cats.**

**Steven Bruce**

Fantastic. Someone accused you of being brave earlier on, Jess, not sure whether they had the right, you do public speaking and you do stand-up comedy, which are the two most intimidating things in the world. And I am just astonished, I am 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 Tourette's 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 where we can't guarantee what will happen.

**Steven Bruce**

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

**Jess Thom**

Thank you. Thank you for inviting me. **Biscuit, cats.**