

Tourette Syndrome and Autism with Martin Moxness

Chantal Boyle:

Welcome to the Sunflower Conversations with Chantal. Joining me today is Martin Moxness from Denmark. He is a very talented photographer, and is also an Instagram and TikTok influencer. Martin is autistic and uses his platform to raise awareness of his health conditions, which include Tourette Syndrome and ADHD. Hi Martin, how are you?

Martin Moxness:

Hi there. Thanks for having me.

Chantal Boyle:

Would you mind explaining to me Tourette Syndrome, how does it affect you? What is it?

Martin Moxness:

Tourette's is, well, it's one of those things that people, they think is mostly people making swear words or involuntary movements and stuff like that. And it can be for some, but not everybody does the swear words. And usually it's mostly just movements or verbal tics. But it doesn't really have to involve swear words, but some do. And I do. And I think it's only about 10 to 15% of people with Tourette's that actually does that. So it can be inconvenient and it can be entertaining for some and annoying for others.

Chantal Boyle:

The social expectation, particularly with swearing, I guess, is unexpected and can cause, I guess like you say, interest in one way or another.

Martin Moxness:

Very true. Very true.

Chantal Boyle:

So you are autistic and you have ADHD. Do you feel that gives you superpowers as you see the world from a different perspective?

Martin Moxness:

I wouldn't say, it depends on the day, I would say, because sometimes I'm not very happy about it, and sometimes I do see that I have some traits that other people don't that gives me a bit of an advantage at times. So sometimes it's a superpower and sometimes it's not a superpower.

Chantal Boyle:

Can I ask when you were diagnosed as autistic, the Tourette Syndrome, and ADHD? Was it all done together or have they come at different stages?

Martin Moxness:

Actually the prime diagnosis was Tourette Syndrome, but one of the, or some of the comorbid diagnosis is autism and ADHD, or OCD and others, so it came with that package, for sure.

Chantal Boyle:

It very often, it comes with comorbidities, doesn't it?

Martin Moxness:

I got a nice package here with everything.

Chantal Boyle:

And so your tics, a tic is it an involuntary verbal or physical movement.

Martin Moxness:

For a Tourette's diagnosis, one has to have both, for they base criteria off of some... If it's a tic that lasts longer than a year and there are other things, like how many motor tics, you have and how many verbal tics and stuff, because there are other tic disorders as well. But for me it's motor tics, but it's also mostly verbal tics.

Chantal Boyle:

Okay. And are your verbal tics, did you say that they're swearing or they're not swearing?

Martin Moxness:

Mine mostly is, but it's also simple tics, like animal-like sounds, or like at the moment I have one that's a bit like an angry parrot kind of sound.

Chantal Boyle:

So they change then. It hasn't always been the same.

Martin Moxness:

I haven't had one that's lasted throughout my life, but I have had some that has been what you'd call chronic tics and very long lasting, which lasted for decades. So that was very annoying, which to me it's very annoying because it's very repetitive, but also for others

obviously. But yeah, having more variable tics is more fun for me as well, because if I have one that's just the same, it gets boring for me as well.

Chantal Boyle:

Stimming is something which neuro diverse people who have autism do to... It's a relaxation, isn't it? Just to bring down the levels, is that correct? Am I getting that right?

Martin Moxness:

That's correct. Stimming can help in a lot of ways, but obviously it's something that other people see and they might not understand it. But autistic people do it for different reasons, but some of them is just to stay calm and kind of regulate, typically, the sensory input, which can be overwhelming for some where it can be sounds, or lights, or other cues that feed into this whole sensory experience, which can be very overloading for some. And therefore, stimming helps to balance it out.

Chantal Boyle:

And stimming is a repetitive movement. So it involves touch or movement, is that right?

Martin Moxness:

There's lots of different ways to stem. It can be a visual thing where you watch the sky or something else that you find pretty, or it can be movement, or fidgeting with something, like something like this that I'm fidgeting with here. And it's just really fun for us. And it keeps a process going that, even though you'd think that it would be disruptive to do things while you're trying to focus on something else, it can actually have the opposite effect, and you actually focus more because you balance it out and you keep focused by actually having more things feed into this whole thing that'll lead to more focus somehow.

Chantal Boyle:

And does stimming help with tics for your TS?

Martin Moxness:

I'd say, sometimes if I stem a little bit more, I'll have less tic because it gets my hyperactivity a little bit on the side as well. So obviously, if I get very hyper or I get anxious, which stimming can keep down, then I'll be more likely to tic if I don't stim.

Chantal Boyle:

Yeah.

Martin Moxness:

Yeah. Yeah. You're correct. It helps.

Chantal Boyle:

So it's really important then that, as a society, we understand the importance of stimming, isn't it?

Martin Moxness:

Yeah. I think so, because it's a very, well, you could say autistic culture per se, because it's something a lot of... I mean everybody stims, even neurotypical people that do, but autistic people really, often, do it more or for other reasons than just...

Chantal Boyle:

I found in the UK, in a school environment, particularly in secondary school, they're very strict on what they think students should be doing when they're sat at their desk. And one of the complaints that my son always used to receive was that he's looking out the window, or he's doing these doodles, drawings on the cover of his book, or fidgeting with a toy. And the teacher found this very offensive. And I didn't understand that because to me it was like, "Well, it's keeping him focused." The structure of the lesson is not comfortable for him. So what's the issue if doodling? What difference does it make as long as they're learning and absorbing?

Martin Moxness:

Exactly. Yeah. I mean, autistic people sometimes learn in a different way, or need a different approach, or a more accommodating approach when it comes to things like stimming that actually help us to learn and to progress really. And sometimes if you limit all of that, it becomes even more harder for us to learn something that we might not be interested in, or that might not occupy our mind enough to keep on track and keep focus. And sometimes the stimming helps us to stay within that and be able to learn things that we otherwise wouldn't learn.

Chantal Boyle:

Did you experience difficulties when you were at school and college?

Martin Moxness:

I went to public school in the start. And it was fine until I got to age seven maybe or a bit later. And then it got very difficult the way that they were teaching and the way the whole system was set up. And a lot of students, and a lot of things that was interruptive for me as far as keeping focus. And there was a lot of things that led up to the way that it was built didn't really work out for me. And then I was put in a special education school. So I was there until I was 18 pretty much. And they were way more accommodating as far as stimming and everything else. So that helped a lot. But it really does say that sometimes you need a different approach in order to feel comfortable and to be able to really learn in a different way that's more suitable to your needs.

Chantal Boyle:

Yeah. And so may I ask, just going back to tics, with your physical tics, is that tiring?

Martin Moxness:

For me, I don't really have all that many that are really physically, well you could say, demanding.

Chantal Boyle:

Yes.

Martin Moxness:

Usually they don't really tire me out. It's more the mental process of keeping them in that will tire me out.

Chantal Boyle:

I see.

Martin Moxness:

One of those natural coping mechanisms that you get and you suppress your tics because you're used to, or you have been used to getting either punished for them, or just people giving you an odd look once you do them. And you just naturally learn to... I mean, some does. Far from everybody can suppress their tics, but some can, and I'm usually good at it when I really, really need to.

Chantal Boyle:

Yeah, so when you are at home and you're away from everybody, will you not suppress it? And you'll just be?

Martin Moxness:

I'll usually just let it run its course, and I'll do it more than if I'm out and about. And I'll be less likely to suppress them. But at home I don't feel I really need to, so I won't.

Chantal Boyle:

Yeah. Do you have any idea, I don't know whether you know the answer to this question, but do you have any idea how verbal tics are formed in a person's brain?

Martin Moxness:

The tics that I've had that I usually get can be... I mean, sometimes it starts off as more of an autistic thing with echolalia or palilalia. But it's more the repetition of things that you hear, or that you've said, or you read, or something like that, from TV. And when I was little, I usually, when I watched movies and stuff, I'm really good with tones and with music. So I can hear the pitch in everything. And it feeds into my brain, and makes this loop where it runs its course. And sometimes that'll develop into a tic if I'm not too careful. That's a theory at least. But sometimes it's also words that, when I was little, I used to say they taste good in my mouth. And it can be really fancy words that I don't know where I heard from, but suddenly they're in there, and it feels good to say them. And sometimes that'll be a tic as well.

Chantal Boyle:

You are listening to the Sunflower Conversations with Chantal. To learn more about the Sunflower, visit our website. Details are in the show notes. So when you have a verbal tic or a physical tic, when you say that out loud, or you have that movement of your body, does that make you feel good? How does that make you feel good?

Martin Moxness:

Something that people that think of people with Tourette's is they don't see the things inside the head before the whole thing comes to an expression, like a verbal tic or a motor tic. And it's called a premonitory urge. And it's usually, well, people describe it as different ways, but it feels like a very uncomfortable feeling inside the body that boils up. And it wants to come to that expression and that's how that works. So it can be very uncomfortable unless I let it out. And once I let it out, I obviously get a bit of relief and it'll reset. Eventually it'll reset the whole volcano that I feel inside.

Chantal Boyle:

Yeah. Wow. That's a very descriptive way of describing it. Like, it feels like a volcano inside about to erupt.

Martin Moxness:

Especially if I'm really good at suppressing them, I'll just keep on feeding the volcano until it'll eventually erupt when I get home. And it'll be even worse if I've suppressed it for a while. And that's what people don't see when I actually hold. There's also these other things, like mental tics, and intrusive thoughts, and all of that, that people don't see with Tourette's. And one of those is that urge that really can be very difficult to fight.

Chantal Boyle:

Yeah. I think the general perception is, "Oh, if somebody has Tourette's, they swear." Obviously it's a lot more to it than that.

Martin Moxness:

But yeah. I mean, it's one of those things, like with autism, it's a bit of a spectrum for some. And although not as vast as the autism spectrum, I'd say it does have its different ways and different tics and all of that. And also it has some components that lean more towards like OCD and ADHD, like intrusive thoughts and the mental tics as well, of course. They can be different, but it's also something people don't see usually.

Chantal Boyle:

Would you mind telling me what a mental tic is?

Martin Moxness:

Mental tics would be, well, it can be, I know they're, again, very fancy words like palipraxia, and echopraxia, and copropraxia. It's more like the tics, like coprolalia or other vocal tics, or stuff like that. And it's more inside the head. So it's the process that goes on in the head, but it's like if I was going to make a vocal tic, I would say a different word, and that word would run its course inside my head as well, sometimes. But only for me obviously. And it would pop up and it would be something that's also very repetitive. But that doesn't necessarily come to, you could say, a verbal tic or something that other people would see, but it's only something that's inside.

Chantal Boyle:

So it's popping up inside your head.

Martin Moxness:

Yeah.

Chantal Boyle:

When you are asleep, does your mind at rest then? Or does it still feel quite active when you're dreaming?

Martin Moxness:

I think it's one of my superpowers probably, but I'm very good at dreaming and being able to do lucid dreams and all of that. And I feel very relaxed mostly, and I usually don't have tics in my dreams. I don't know.

Chantal Boyle:

That's really interesting.

Martin Moxness:

I usually don't actually.

Chantal Boyle:

Yeah.

Martin Moxness:

So that's interesting.

Chantal Boyle:

Yeah. It is interesting, isn't it? Because Tourette Syndrome is a neurological condition, isn't it?

Martin Moxness:

Very much so. Yeah. But the fun thing about Tourette's is that, again, if I stim with something, or if I play music, or if I sing, or if I play computer games and stuff, it sometimes goes away for a while. And it gives me a break. And I figured that out early on with music. When I play piano and stuff, I wouldn't tic during the music. And that's very interesting that it occupies something that puts it at bay for a while.

Chantal Boyle:

Yeah, it does. I've had a look at your Instagram account and you are very creative aren't you?

Martin Moxness:

I've been told so, yeah.

Chantal Boyle:

What instruments do you play?

Martin Moxness:

I play piano and I play guitar. And then of course, I sing a little bit as well.

Chantal Boyle:

And did you take lessons for that or are you self taught?

Martin Moxness:

Piano, I did actually. But I didn't like the lessons at all. And I think it was more the approach to it, because again, I'm really good with tones, and being able to hear a song, and then play it on the piano or guitar, but I'm not good with sheet music and needing to be structural about it in that way. And that wasn't the approach for me. I'd rather just listen and play.

Chantal Boyle:

Yeah. Well, I mean, that's a massive talent to be able to do that, to teach yourself.

Martin Moxness:

[inaudible 00:15:58].

Chantal Boyle:

Do you play with other people? Or do you play just on your own?

Martin Moxness:

I have done when I was at school, but after school I didn't really ever play with others. So sadly, no. A lot of people have asked me to join a band. I don't think it would be the case because I'm not usually that social.

Chantal Boyle:

You have to do what makes you happy. And if playing music on your own makes you happy, then that's good, isn't it?

Martin Moxness:

Although I do like playing with others, it's the social aspect gets a little bit too much, maybe.

Chantal Boyle:

So I know that you wear the sunflower, Martin's wearing the sunflower right now in a lanyard format. Can you tell me why you wear it?

Martin Moxness:

I mean, it's still a very new thing in Denmark relatively so, but I think it's a very, very smart concept, because before, I spent a lot of energy with needing to explain myself if I did anything weird, like if I had any tics or if I did some movements that people didn't really get, or if I felt like I was in a position where it was very important for people to know that I was a bit different. And they could expect that from me. And I usually had, I actually have it here, it's another lanyard, but it's a little bit more obvious, what it is, hidden disability and all of that.

Chantal Boyle:

It's a black lanyard, which says, "Hidden disability," in white writing.

Martin Moxness:

Exactly. And I think the sunflower lanyard is a bit more casual, but it sends the same message if you know what it's about. I think it's important to spread the message.

Chantal Boyle:

And how have people been responding to it?

Martin Moxness:

I mean, the first place where it was really implemented was at the airport, which makes a lot of sense. And since that's where I work, I was one of the first ones to actually wear it there. So it was really new, but also really cool, really great initiative. I think it's taken to the public very well. Also stores and other public establishments have adopted it here as well. And it spreads a lot and it's really, really cool to see. Somebody message me and it was this flight attendant and she had never understood what it was about. She had seen it before on her flights, but she didn't really know what it was about. So she was very happy that I was explaining what it was.

Chantal Boyle:

How'd you find being in an airport because it's a very busy environment, isn't it? With lots of noise and sound and movement.

Martin Moxness:

A bit of a mixed feeling there, because yeah, obviously it's a very, I wouldn't say necessarily, sensory friendly place for somebody that has sensory issues, or just issues with the whole business, and all the people, and everything. But I got used to it. And I mean, when I was little, my parents, they had a cabin in Norway and we usually took the plane there. So, I was used to airports from an early age, and that works for me that way, I suppose.

Chantal Boyle:

You are a fantastic photographer.

Martin Moxness:

Thank you.

Chantal Boyle:

I've seen your photography and it's beautiful. When did you discover you had a talent for that?

Martin Moxness:

17 or so, probably, when I took my first, really, somewhat interesting pictures. It's not something I do that often anymore. I really used to do it when I was in photography school

and wanted to be a photographer. But the social aspect got a bit too much there as well. So I had to step aside, you could say, but I really did like the end results because I always came up with somewhat good pictures, at least I think so. But it was more the demanding social aspect leading up to and everything. It wasn't easy for me.

Chantal Boyle:

Yeah. So Martin, do you spend a lot of time on your own? Or do you have a best friend? Your social interactions, what are they like?

Martin Moxness:

I have a boyfriend.

Chantal Boyle:

A boyfriend. Well that's the best friend, isn't it?

Martin Moxness:

Yeah. So, there is some socializing going on there. And then I have some friends I see now and then. But generally, I'm somewhat socially a recluse, you could say. And it's not because I don't want to socially interact, but it can be a bit difficult. There's a lot of things that goes into socializing that isn't naturally, you could say, at hand for somebody like me to partake in.

Chantal Boyle:

Yeah. When my previous role would organize work events and get people together, and I had to realize that that is not for everyone. Some people want to do their work and just go home. They don't want to hang around afterwards, and they don't want to talk to people if they don't have to. And that's okay.

Martin Moxness:

That's very true. We're very, very different people. And that's really great to have that dynamic, and different contrast, I suppose. But I do better with other people that are autistic, I think, because it doesn't create that barrier where you have to explain yourself, and people are more... They understand that you're different.

Chantal Boyle:

Yeah. So the social... What do we call it? Small talk and chit chats, which is very neurotypical, where we just talk about anything just for the sake of talking. The weather. In England, we talk about the weather a lot.

Martin Moxness:

Yeah. That's usually what I resort to as well, the weather. And chit chat doesn't come natural to me at all, but I've written notes. So I know what to bring up if I feel that empty silence coming along.

Chantal Boyle:

And then when you're with other autistic people, if there's silence, it doesn't bother.

Martin Moxness:

Not as much. It's more like a passive hanging out, you could say, in a way that's still fulfilling, but more like we're doing separate things in the same spot, pretty much. And connecting socially still, even though we might not interact in the same way necessarily. Of course, sometimes we do, but it is a different way of finding both comfort and inclusivity in a way that's still somewhat not overloading.

Chantal Boyle:

It's very interesting for somebody like me who has to feel any silence, and I feel very uncomfortable if there's silence. Even my own family say to me, "Why are you forcing a conversation? Just be quiet." You are listening to the Sunflower Conversations with Chantal. To share your story, details are in the show notes. And let's just finally talk about your TikTok and your Instagram following.

Martin Moxness:

I suppose I developed more into the awareness with being autistic, and all of the other things that I felt like I maybe able to shed some light on, that other people might not know so much about. It gave me an outlet for my socializing, as opposed to that... You could say I'm a bit social on there. Yeah.

Chantal Boyle:

Oh, you're very social on there. You've got, what is it? Over 29,000 followers, nearly 30,000 followers. So I think you're pretty social on there.

Martin Moxness:

It's funny, a few months ago I didn't really have that many.

Chantal Boyle:

Really?

Martin Moxness:

I think I had 1,000, and then I made one video, and it got over 24 million views or something. And then it exploded. So now, I have a voice that I can share, and people will listen a bit. And that's really cool, I guess.

Chantal Boyle:

I think it's very cool. I think it's a wonderful way for other people, society, to take a glimpse into your world, to understand what life is like for you. So for example, you do lots of great videos with stimming, with your, it's almost like a lightsaber, isn't it?

Martin Moxness:

Yeah, definitely. A lot of stimming videos and stuff because it helps to normalize everything.

Chantal Boyle:

Exactly.

Martin Moxness:

I mean, I get a lot of messages from parents that say that they understand it now. They get what it was about. And obviously a lot of parents of autistic people that are not speaking as well message and talk about how they see some of the traits that I have. It makes a lot of sense to them, that their child might not have been able to express to them. And also things like comfort items, how that works.

Chantal Boyle:

Martin's just held up, I think is a penguin, is it?

Martin Moxness:

It's a penguin all right.

Chantal Boyle:

So you have different items for different emotions.

Martin Moxness:

You could say that, yeah. But some items just generally help a lot to just feel that familiarity and comfort. And also a bit of routine that I can bring with me if I have the routine of bringing my penguin with me every time when I go to work. It gives me that comfort that I can take with me. Parents just, they go, "Oh, that's why." Or, "That makes sense." And they might not be as keen to push those coping mechanisms away that might help their child in the end.

Chantal Boyle:

Yeah. I mean, I'm sure that so many parents are so grateful to you. One of these social expectations, particularly around soft toys, is that, "Okay, you are a certain age now. You don't need soft toys. We're going to remove all of these lovely things that we've told you are your comfort for X amount of years. Now you don't need them." I mean, that's-

Martin Moxness:

I can't deny that it might work for some to grow up and stuff like that. But for autistic people or for neuro divergent people in general, sometimes they need that extra comfort in their life.

Chantal Boyle:

Yeah. Do you have any hopes for your social media or are you just going to keep doing what you're doing?

Martin Moxness:

I just take it as it come. And I create what I feel like is really fun for me.

Chantal Boyle:

So how would you advise people to respond to someone that has Tourette Syndrome who is experiencing tics?

Martin Moxness:

Oh, that's difficult, because when I do tics and stuff in public, it can be a big issue. And for me, when I feel that they're finding somewhat annoyance in what I do, it's difficult because people don't really get it. You can say you have Tourette Syndrome, but even so, they might still think you're just weird, pretty much. I think it just takes awareness and we'll grow as a society to maybe normalize these kinds of things in time. But at the moment it's still an issue for me to tic in public, and all of that, because I really want, naturally, to suppress them so I don't get in trouble. Yeah, it's also the reason why I don't really do as much public transport outside of... Because yeah, I can take a plane, but I don't really take buses, Metro or taxis, or anything like that because of the tics and because of the social anxiety that comes with that interaction when you're different.

Chantal Boyle:

So it's more about people educating themselves and just being accepting. Just accepting.

Martin Moxness:

Just being accepting of different people for whatever reason really.

Chantal Boyle:

Yeah. Because it must be exhausting for you suppressing them all day every day.

Martin Moxness:

Definitely. And it's even worse for my boyfriend when I get home because that's when all the tics come out.

Chantal Boyle:

Yeah.

Martin Moxness:

He'll get annoyed.

Chantal Boyle:

Oh, dear.

Martin Moxness:

Yeah. It's a balance really.

Chantal Boyle:

Yeah. As a society, we need to educate ourselves.

Martin Moxness:

Yeah. Educate, and normalize, and find acceptance in all those differences that we have as individuals.

Chantal Boyle:

That's one of the key things of the Sunflower, it's to be kind, be understanding, and just offer a bit more time and patience. And I think it speaks perfectly to what we've been discussing today.

Martin Moxness:

Yeah. The Sunflower is awesome.

Chantal Boyle:

Well, Martin, I want to thank you very much for giving me your time today. And I found it very educational and I would definitely suggest for people to come and check out your Instagram account. It's called A Different Spectrum. Martin has lots of really interesting engaging videos that are very enlightening, and educational, and fun.

Martin Moxness:

Thanks a lot for saying that. And thanks for having me on here. It's great to be able to see that people listen and take it in, that there is so many different people, and everything that makes you who you are. And also the different ways that we function, it's really cool that people will listen and try to find acceptance somewhere and understanding. Thank you a lot for that.

Chantal Boyle:

Oh, thank you, Martin.

Speaker 4:

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