

Ep #139: My Experience of Being Autistic (Part 1)



Full Episode Transcript

With Your Host

Maisie Hill

The Maisie Hill Experience with Maisie Hill

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Welcome to episode 139, this one is going to be all about my experience of being Autistic so let's do it.

If you want to do things differently but need some help making it happen then tune in for your weekly dose of coaching from me, Maisie Hill, Master Life Coach and author of *Period Power*. Welcome to *The Maisie Hill Experience*.

Hello, folks. How is your summer going or winter if you're in the southern hemisphere? I am feeling quite shocked that we're coming up to mid-August already. At the end of July, a couple of weeks ago I had my dressage competition, you might remember. I actually had a few of you email in lovely emails, what happened? Have you done it yet? How did it go? So, I started horse riding in mid-April. And after about six weeks, I just took the plunge and signed up for an in-house dressage competition at the riding school that I go to were doing, just for fun, just for the hell of it.

And dressage is a type of horse riding. My coach Robin calls it horse dancing rather than going over jumps and things like that. It's done on flat ground and you're working with the horse to get it to walk and trot and canter at different points. And what the rider is doing is meant to be almost imperceptible but they're giving cues to the horses and often doing really specialised manoeuvres. That was not my experience of doing the test, but it also wasn't my goal. This is why it's so important to be specific and precise about what your goals actually are.

So, it was something that I'm striving for. I do want things to go well, but I just wanted to have fun. I didn't care where I came in terms of result. I was totally okay with coming last. I just wanted the experience rather than coming in a certain position. And a lot of it was fun, but it was also highly frustrating. I was on Darren or Daza, as I like to call him. He's the oldest horse in the stables and I really love riding him. He's very sensible when we go out on hacks down the roads and through the fields. He's got a lovely bouncy trot.

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I could trot on him for ages without any issue, but I can have a bit of a hard time getting him to transition into canter because he's just so blooming bouncy. But I've kind of figured it out now, but it's been a thing for me to get to grips with. So thankfully this test didn't have any cantering. It was just walking and trotting. And the final part of it before you take your bow in front of the judges was to trot down the midline of the arena. And I could not get him to trot for love nor money. He just wasn't having any of it. It was so frustrating that it was laughable.

So, I came eighth out of ten. I got a rosette that says 'special' on it. I'm very proud of it and the judge gave me a lovely comment on my score paper that said you did well with a hard ride. So that's how that went. And I've also started doing some jumping lessons. And oh, my goodness, it is so much fun. I really thought that Nelson, my son would be the one to do the jumping and the cross country and all of those things but I freaking love it, which is really weird and fun for me because I don't like moving fast and I struggle to jump in any way, shape or form.

Even jumping over something that's really low on the ground can be very challenging for my brain to do, but with this I'm not actually jumping, the horse is jumping. And because you have to focus on the line that you take coming up to the jump and the line that you take after, I don't notice the speed as much, only if it's feeling too slow or fast as we're approaching it.

And I've also signed up for the British Horse Society Stage 1 certificate. I'm doing it with two friends and our test is booked in for the start of November. Horse riding is one of my special interests, so I'm very happy about this plan. I'm actually going to talk more about special interests later on in this episode because this episode and then the one that comes after it are all about my experience of being Autistic, so this is a two parter.

And I get so many questions about being Autistic, both from people who are Autistic or suspect that they might be as well as from people who are just curious. And also, from folks who have loved ones, colleagues, kids who are Autistic and they want to understand more. And I get questions all the time about this. And it's been a while since I did an episode about being

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Autistic. So, this is just an opportunity for me to talk more about it. And I'm actually using some of the amazing questions that you asked over on Instagram to shape both of these episodes, so thank you for asking them. They've been incredibly useful.

Now, a few caveats before we jump in. This is about my experience of Autism, my flavour of Autism. My experience does not equal the experience of everyone else who's Autistic. We're not monolith, and there are things that are a huge no go for me that other Autistic people will really enjoy and vice versa.

So, I started to suspect I was Autistic in 2019. That was then confirmed by a psychiatrist in 2020, but without knowing it, I have built my life around my Autism long before I knew that I actually was. I've always given myself a lot of space in my schedule, not overloaded myself with clients. Throughout my career, all the different careers I've had, I've consistently chosen space over making more money. Because I know that if I don't have space then I end up not being able to work and make any money.

And I've had some requests from my clients to do an episode about my business mindset and I will definitely be doing one of those. So, some of the questions that have come in that are more work related and about me having a business and being an entrepreneur. I'm going to kind of park those for that episode because there's a great deal of crossover between the topics. So, this is just about the things that affect me because I'm Autistic.

And I'll also probably talk more about how Autism has helped me professionally in the business mindset episode as well as the struggles that can come up on the business side of things. And finally, it's important to caveat all of this by saying that I have a lot of control over my life. I have plenty of accommodations etc and loads of tools to support myself and good support around me. And there are things that I struggle with. I get dysregulated, these things happen. But think about what it's like for people who don't have these things in place.

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There's a reason why only 22% of Autistic people in the UK are in some kind of paid employment. And I'd be so curious to know about what percentage of those people are actually thriving versus surviving.

Alright, the logical place for me to start with is waking up in the morning. So, my brain is on as soon as I wake up and I'm just coming up with plans and ideas and thinking things through. That does not mean that I am ready to engage with others. Those things are different. And I've mentioned here loads of times how I love to start the day on my own. I love to have my morning cup of tea on my own. That is an amazing time for me to be creative and come up with ideas and solutions to things. I absolutely love it.

And I love to start work as early as possible. It really bothers me when I start work late and it's not like my business has an official start time or that someone is tracking what time I login and start work. But for me, starting later than eight in the morning in the summer, that for me is late. And not getting to start work at the time I want to, does really bother me. And it's a way for me to end up getting dysregulated pretty quickly at the start of my day.

When I say dysregulated, I mean experiencing stress and overwhelm and less able to respond to life's challenges. Stuff that at other times when I have more capacity and I'm more regulated just isn't a big deal. But when I feel dysregulated I'm less resilient, more stressed and less able to manage my emotions. And although this is prevalent among Autistic folks, it's actually something that all humans experience. And I've had other Autistic people tell me I'm wrong to say this and that it diminishes the experience of Autistics, but this is just how the nervous system works.

When we move outside the window of what we have the capacity for, we experience stress responses. Sometimes we go to fight or flight. Sometimes we withdraw or freeze and shut down. That is true for all of us. Now, Autistic folks are more likely to have these experiences and maybe take a while to recover from them, there's also specific triggers that can cause them, many of which are a complete non-issue for non-Autistic people.

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They can also feel more intense and the ability to monitor them and to modulate the strength of what's being felt can be challenging. So, there can be what's referred to as outbursts, behavioural outbursts. But also, I can have a meltdown and nobody else would know just because of my ability to control and mask what's going on. And this is something that researchers have identified as being particularly relevant to those socialised as female who are Autistic.

So, in Autism, we talk about fight and flight response as having a meltdown and withdrawing going into freeze as a shutdown. So, Paul, my partner, does most of the school drop offs in the morning so that I can crack on with work at the time that I want to, especially if I've got a big project on. If I don't have a big project on then I'm less fussed about it. I love walking with Nelson into school and chatting and looking at all the flowers and the status of the blackberries.

So, we look at the Blackberry bushes all year round and analyse what stage they're in and enjoy picking them when they're ready to be picked. And today I took him to summer camp, and I didn't mind if we were late getting there and I didn't do any work until after my horse-riding lesson happened, the all-important horse-riding lesson.

So, it's not like every day has to be the same or that I can't have a chilled non-work morning but if I have something that I need to do, then it's important to me that I get to do it and it can dysregulate me if I'm unable to for some reason. And when I say need, that can be because of an internal company deadline or an external one. But it can also be because my brain has just come up with an idea or it's curious and interested in something and maybe just getting all fired up. So, I need to be able to go with that, that's important to me. So that's the work side of things.

And leaving the house on time is also really important to me. A lot of my neurodiverse friends kind of report the same thing even if we, we as in my family, we don't actually need to leave at a certain time. I will have determined a time in my head. So even though we're not actually late, according to my brain, we are. And if I don't manage this through

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self-coaching and tending to my stress responses, I can get very caught up in this. And it's just like being in a stress loop and I can see that I'm in it and that I don't need to be in it.

And I can identify that we're not actually late, all of those things. Most of the time I can do that. And it doesn't make any difference what time we leave and yet there is this really strong need to leave on time. I've noticed this is lessened to a degree if I do actually leave the house. So even if we're late, but Nelson and Paul are just getting ready or whatever, putting their shoes on. If I leave the house and I sit on our garden wall or I go and I sit in the car, then I have left, I have moved through that. I've changed the environment that I'm in.

So, we haven't actually left, we're not on our way somewhere, but I have left and I think that helps. It doesn't completely remove the stress, but it does reduce it enough to give me a bit of space to work with. So, I think the change in environment supports that because my brain is registering different surroundings. So, I find that helpful.

Most mornings I go to work at Forts, one of our local cafes, I just love it there. The people who work there are amazing. They have the best coffee and amazing menu. I highly recommend that you go there if you are visiting Margate. And a lot of my friends are amazed that I'm actually able to work there because of the background noise. But if background noise is low level and it's not varying that much, it's kind of consistent, that's totally fine for me. I am incredibly productive there. I do most of my best work in there. And it's become my routine and structure.

It's actually hard for me to not go there, especially during the week. It's easier on weekends because it's just too busy for me to show up with my laptop and take up a table and that's just not something I'm going to do. But during the week, if something else is going on and I don't go during the morning, that is something that I have to kind of wrap my head around a bit. And I do find it really hard to sit there with someone else purely because my brain has to work so hard to separate out what someone is saying from all the other noises and conversations that are happening in there.

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So, I can do it for brief interactions but for a sustained conversation it is exhausting, and I'm just not prepared to do that to myself. So, I'd rather get a takeaway and go for a walk with someone. I also don't like being interrupted when I'm hyper focusing on something. So, if I'm in the midst of something and Paul, my partner comes in to get a coffee or have a meeting with someone, I pretty much blank him. I also have a specific order that I like to order in. So, whether I'm at home or I'm eating out, I just don't like having a hot drink with my food, they have to be separate.

So, I get a filtered coffee then when I finish that, I'll order breakfast. And when Paul and I eat there together, I can't break from that routine, from that sequence. So, his food usually arrives before mine because he's usually hungry and wants to eat and kind of move on. He's got other things in his day, different time parameters, whereas I'll kind of park up for a bit there. And I just hope that as you're all hearing this, you can see that in doing things that way, we are both honouring what we need and want and not making it a problem.

Sometimes we do eat at the same time if it's lunch because then I'm not having a coffee, but I have to do things in that order and that's it. Now, if someone else is in there and they're playing with their keys or they're tapping the table or I can hear them chewing or sometimes I can hear them breathing, then there's not much chance of me being able to concentrate. And there's just the instant rage to deal with. But when that isn't going on, it's quite rare that that is going on.

But the hyper focusing in there works really great for creating so whether I'm writing, preparing podcasts or creating webinars, etc, I can get a phenomenal amount of work done in a short space of time. But I also need lots of downtime after that and I need lots of time alone. Time alone is like breathing for me and that is different to quiet time.

So last year in the summer we went to Sicily, we had a great time. It was a holiday that was based around photos of desserts in fridges. So, my friend Claire, she's a pastry chef. If you haven't been to her café, Violet in Hackney, then you really need to. She'd been on holiday to Sicily years ago

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and I'd saved some of the photos on Instagram to refer to for when we would eventually go there. So, we just based the whole holiday on the various cafes that we would go and eat desserts in and it was a fantastic holiday.

I would also now base holidays on horse riding as well, but basically I think you can't go wrong on basing holidays around food. But when we were in Sicily, I had time on my own when we'd go back to the Airbnb for the middle of the day and we'd all be doing our own thing, it was quiet and I kind of felt okay. But when we got home I stopped being able to speak and I couldn't work because I needed to rest. And it's because I hadn't had time on my own for 10 days. So, there's a big difference between quiet time and everyone doing their own thing and being completely alone.

And I watched a recent TikTok video. I can't remember the creator, but they were talking about how Autistic people can be uncomfortable with being perceived. And as I was watching the video I was like, "This is totally me." So, the creator spoke about how if you have time alone at home and then someone else comes home, it's hard to adjust to that, even if you love them very much, you've lived together for a decade and you're very comfortable with one another. You love, you like, enjoy each other's company, all of those things.

And even if they give you a lot of space within your home it can still be hard to go from being alone and not being seen, there being no expectation of communication, no possibility of that, to being perceived. And I was like, "That is totally me." So, I can spend time with people I love and really enjoy myself and it can also have consequences. I had a recent spell of burnout because we had friends over for a few hours on a Sunday and then on the Monday I had lunch with Paul, which was lovely, but it came with a consequence because Monday is my reset day after peopling at the weekend.

And I don't even mean a crazy amount of peopling, it can be quite a small amount. And then something else happened, I think, yeah, he was just kind of working from home that afternoon, so I wasn't alone as in the only

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person in the house. And we weren't chatting or anything, he was just getting on with his thing. I was getting on with my thing. But I think it's the low-level expectation that I will be, or I could be interrupted and need to engage with someone else.

So, I also have a hard time adjusting to people coming to our house. I hide in the kitchen a bit whilst I'm adjusting to people being there. Once I adjust I'm usually fine, but sometimes I'll just remove myself and go upstairs and be alone. I also need to do all the washing up after we eat, one, because I don't like the smell of food to linger. I hate coming down to dishes the next day, but it's also a way for me to kind of remove myself and just have some time.

And also washing up is quite regulating to me and I have a process that I need to do it in. There's an order that I need to do it in. And so, people will often offer to help do the dishes and I just, I'm like, "No, please don't. Don't take this away from me." This is a coping strategy. So having someone dry the dishes is although they're helping, they're actually causing more of an issue. So, everyone who comes over to our house knows that I have to do it alone and that they need to leave me to it.

I love it that they offer, I appreciate the offer, but please don't because like I said, I have this process for washing up and it will bother me if someone interferes in that, especially if I'm using it as a way to regulate. But we'll get on to that in a moment. In fact, let's just move on to food and meals now because that's a thing too.

So, I never used to think that food was a thing for me. There's a lot of Autistic people who have quite restrictive diets and I just didn't think that Autism affected eating and food and things like that for me, but actually it does. So, I can eat a huge variety of foods but if I'm dysregulated then I can only eat safe foods. The Autistic community has a couple of terms that describe relationships with food. There's safe food and same food. So safe food is a food that is comforting, we're able to eat it, but more importantly, it's foods that don't distress us.

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And same food is a food that we have got quite attached to and that we can or do eat every day. So, for me one of my main safe foods is homemade macaroni and cheese. And when I'm dysregulated it can only be a particular make and shape of macaroni. So, Italians, cover your ears up because the only macaroni I can have when I'm dysregulated isn't actually curved. I don't think technically it's macaroni, it's sold as macaroni but here's what's interesting.

If I'm regulated and just making pasta with cheese sauce, I never pick that pasta shape. So being dysregulated does really impact what I'm able to eat. A cheese and crisp sandwich is also a solid option and I really mean basic white bread with butter, cheddar cheese that has to be thinly sliced and then salt and vinegar crisps or salt and pepper ones. It kind of depends on the levels of dysregulation. And I would never let anyone else make it for me because although it's a basic sandwich, if it hasn't been made correctly, I won't eat it.

So, let's say that I am feeling burnt out and I need to eat, I still need to make the sandwich. I should probably invest some time in training Paul up in this because it's not like he wouldn't be able to do it. He's quite capable of making a sandwich. He makes them all the time. He offers to make them. He's also really great with criticism because of who he is and just professionally he's a graphic designer. So, feedback is no big deal to him at all. So yes, someone else could do it if they understood the importance of ratios and thickness of the cheese. I can be very specific here.

Mashed potato is also a good option. There's also Tony's chocolate, specifically the white chocolate with the raspberry popping candy in it. That for me is amazing because the sensory experience of that popping candy can really help me when I am kind of withdrawing a bit and in a bit of a shutdown because it's just a delicious and fun way to bring me back online. Experiencing that popping candy is a gentle and fun form of sensory input that just helps me kind of come back to myself and to the world.

And there have been many times where I've been dysregulated and got very specific about what I can eat and not be able to get or make that food

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and end up fainting. I have a history of getting lightheaded and fainting. Sometimes not to do with food, sometimes it's just standing up as in going from sitting to standing or staying standing for long periods of time or when I get hot, especially if I'm standing still and then I get hot. I used to faint on tubes a lot. So, I do love food and eating, I really do.

If you work in a restaurant and you serve good food, you will love me as a customer because I always order the best things and I really savour the whole experience. I love to eat out on my own. I like going out to dinner with friends, but I also love eating out on my own. And people in restaurants often think that I work in the food industry, in hospitality because of how involved I get in my meal. And I think that's Autism as well, just that ability to really enjoy the sensory experience of the whole thing.

So, it just goes to show you, Autism can end up meaning that there's not many things that I'll eat, but it also means that when I'm regulated, I can really enjoy what I'm eating, very cool. And then there's the last bite, the very important last bite, this is quite common among people who are Autistic. But the whole time I'm eating something, I am assessing what my last bite is going to be and curating the perfect last bite.

And long before I knew that I was Autistic, I remember going out to a cafe and getting some cake with my ex-husband. Well, he was my husband at the time. And at the start he didn't get any cake. I got a slice of Victoria sponge. I remember it very clearly. It was really delicious, and I said to him at the start, "Would you like some cake?" And he said no. So then there's a way that I eat a slice of cake so that I have what I think is the best bite last. So, he said no to my offer of cake, but then he came in and he took the perfect bit and I mean I'm still upset about it.

I get bothered when I curate the perfect last bite and then someone wants it, whether that's my kid or my former husband or whoever, that last bite is very important to me.

Someone asked how I plan for meals and shop appropriately and this is really different to what life used to be like prior to having Nelson and the

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first year or so after his birth because back then I spent a lot more time planning and prepping meals. These days it's a lot more loose and last minute. But I do love flicking through recipe books, doing a big shop and then cooking meals, that to me is all hugely regulating. It's only an issue if there's rushing involved.

And I will say that our kitchen isn't the most relaxing to cook in. We've had a temporary kitchen for six years and it's not sensory friendly. And I'm really looking forward to renovating our house fairly soon so that it is more sensory friendly, and we can kind of get back into cooking in the way that I would like to.

So, my question for all of you is really if there's something that isn't enjoyable to you and if it causes issues, how can you make it as easy as possible? What accommodations can you bring in? And where are you creating unnecessary additional pressure on top of whatever it is that is challenging for you?

I'm also very specific about what spoons I use and what cups, certain drinks require certain mugs, cutlery needs to feel a certain way. A lot of cutlery actually feels painful in my hands either due to its texture or its shape. I also can't touch the handle on our fridge door with my skin because of how it feels. It's this brushed steel and it's just awful to me.

I also don't always eat with my family. This will largely depend on where I am in my cycle. So, hearing people eat is just the worst thing for me. If you ever heard that I have been arrested for something, it would be for lunging across the table and attacking someone for chewing with their mouth open, for sure. So, I have misophonia, it's a disorder in which certain sounds trigger you, it's also called sound sensitivity syndrome and sound rage, which for me is the most accurate name for it.

I get very angry about noises and not even loud ones, just plain old normal human noises like breathing, chewing, tapping nails on a device. So, if Paul or Nelson's nails are ever so slightly long, we couldn't really even call them long, but long enough for me to hear the sound of their nails on the laptop

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trackpad, that's just hideous. The same with long gel nails, I just can't deal with them. I just want to scream and run out of the room. And it just amazes me that I've never actually done that, but I've kind of done it a lot internally.

It can also be electrical noises and hums. And a lot of these noises, other people don't seem to hear at all, or they just don't have that same kind of reaction to them. So, it's this extreme sensitivity and I will need to cover my ears and I will leave places and conversations in order to protect myself from them.

And one of you asked if there are specific gadgets and sound reduction headphone brands, things like that that I would recommend. I don't have many. I do have a small noise machine that my coach, Robin, recommended. I haven't got into the habit of using it yet. I do like to use the loop earbuds. They reduce the volume, but you can still hear what's going on, but I can't eat with them because I just hear myself chewing, which is also the pits. So, I do want to try some headphones that block out noise. But I really struggle to have anything on my head or around my neck.

I don't wear hats or sunglasses or scarves because it's just a no for me on a sensory level. And I was worried about needing to wear a horse helmet but that's been fine, again, probably because of the regulating effect of being on the horse and needing to pay attention to so many other things.

Alright folks, that was plenty for this episode. Let's leave it there for this week, we'll pick it up again next week with the second part. I will catch you next time. Have a great week.

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