

16. Autism



Full Episode Transcript

With Your Host

Maisie Hill

Period Power with Maisie Hill

16. Autism

If you are in the horrors with menstrual cycle issues or you want to learn how to harness your hormones then you are in the right place.

Welcome to the *Period Power Podcast*. I'm your host Maisie Hill menstrual health expert, acupuncturist, certified life coach and author of *Period Power*. I'm on a mission to help you get your cycle working for you so that you can use it to get what you want out of life. Are you ready? Let's go.

Hello, hello folks. Here we are another podcast episode. And this one is a rather personal episode of the podcast. So a few months ago I shared on Instagram that I'm autistic. And since then I've received a steady stream of amazing messages from you, lots of questions about how it was that I realised, how did I get assessed? What's that process been like? People asking for tips, all of those things, and many of you who have been in contact with me have children and young people in your life who are autistic.

And you've told me how helpful it is when I talk about my experience of being autistic which I'm really grateful for because it has really made me stop and take stock and assess the privilege that I hold as someone who is neurodiverse. And it's helped me to commit to sharing more of my journey and my experience, so thank you for that. And this is what today's episode is all about.

But before we get started I have a couple of disclaimers for you. So the first is that I'm only going to be talking about my experience. I'm not speaking here for everyone out there who is autistic because we're all uniquely different. And there's a meme that I've seen going around in some of the autistic communities I'm in that says, "If you've met one autistic person you've met one autistic person." And that's so true. The point being we are all different. So one instance that I can give you of this is that I am largely sensory avoidant. I like to avoid sensory input most of the time.

But some people are more sensory seeking. And I'm going to go into more detail about this as we get going with stuff. But I wanted to just give you a

16. Autism

quick example of one difference that can exist. And you may have heard of the phrase 'autism spectrum'. And a lot of people think that autism spectrum means that you're either a little bit autistic or a lot autistic but that's a myth. It isn't a sliding scale that we exist on. You're either autistic or you're not, that's it.

What the autism spectrum means is that there are various ways that autism affects an individual. For example, for me it really shows up in my sensory needs and challenges, also in my interest in particular subjects. And it also shows up socially too. So rather than it being a sliding scale from left to right of a bit autistic or a lot autistic. It's actually more like a circular graph that shows different aspects of life and how autism shows up in those different areas.

I also want to mention that language around autism and neurodiversity is nuanced and it's often problematic. And we also all have our personal preferences. So mine is that I don't like the term 'diagnosed' when it comes to an autism assessment because the way I see the word 'diagnosis' is that it implies illness. That being said, sometimes I will struggle to find a word that replaces it easily.

And so today as I'm talking about it there will be times when I use the word 'diagnosis' because sometimes an alternative just escapes me and I'm not really sure how I can get around it. If you have any tips for me please let me know, I'd love some. And some of you have had some really great questions for me over on Instagram because I put a post up saying I was going to be talking about this in an upcoming episode. And I'm going to be answering those too.

How this is going to work is that today I'm going to be sharing my story of realising that I'm autistic and what that process has been like and being assessed. And then next week I'm going to go through all of your questions because there were a lot of amazing ones. So it just felt better to separate them out into two episodes.

16. Autism

And the other final thing I want to mention is that I haven't actually researched autism heavily yet. I really want to. I've done some light reading. But because my journey to realising that I'm autistic coincided with researching and writing my book *Perimenopause Power*. I've had to hold back and practice constraint from going down that rabbit hole, which was really hard. But it means that what I'm talking about is down to my experience and for the most part anecdotal evidence, which I think is hugely valuable and I'm happy to share with you all.

And I'm hoping that someday soon I'm going to get to really explore autism in the way that I want to. Okay, disclaimers done now let's talk about the journey.

So if you'd have asked me a couple of years ago if there was a chance that I could be autistic I would have thought that you were being weird or I would have laughed at you. It's just not something that I'd ever considered to be possible for me. And it also never came up in my childhood. I mean I can look back now and see it for sure but no one else picked up on it. And I've also done lots of talking therapies over the years and it's never come up there either.

So what I would have identified as being is being a highly sensitive person and I know some of you do as well. And for those of you who have never heard of HSP which is a highly sensitive person, I want to give you some of the common traits. So they are things like being perceptive and picking up on the emotional energy of others, a big tick for me, finding busy environments overwhelming and chaotic, another big tick for me, often feeling emotionally exhausted and needing to withdraw, also strong for me.

Being deeply moved and captivated by art, music and nature, this one is quite big in autism. And having a rich inner world full of deep thought and daydreaming. Feeling that we absorb the mood of others, I mean there's lots of reasons why someone might feel that way, including experience of trauma, co-dependency etc, etc. But autistic folks which may be news to you this, it's quite different to how autism is generally portrayed. Autistic

16. Autism

folks can have hyper empathy and this was so intense for me as a teenager. And I'm going to talk about that next week.

Now, if you identify with being a highly sensitive person then I really recommend reading up about autism and something called sensory processing disorder. Because – and I'm possibly going to put the cat amongst the pigeons with this, but I suspect that a lot of women who think they're highly sensitive are actually autistic. I have no evidence for you at this point but that's what I would bet my money on if I was going to.

So you're probably wondering how on earth I came to realise. So here's what happened. A colleague that I don't know all that well happened to post on Facebook that she had been 'diagnosed' as autistic. And in all honesty my reaction was there's no way she's autistic, that's ridiculous. She's capable of empathy. And I just had all these misconceptions about autism and particularly autism in females. So I am sorry to say, really dismissed what she was saying. I didn't say that to her but in my own head I was like come on, really?

And I know that some people have had the same reaction when I've shared that I'm autistic. So believe me, I've been there where you are and I get it. But what happened is that this person started sharing more posts about how autism presents in females. And I was just interested so I started clicking through and reading the articles. And I immediately realised that this was a professional blind spot for me, something that I just wasn't aware of. So I started reading a bit more and the idea was just that this is something I should know about as a professional.

But very quickly it all started to feel quite familiar to me and then I found this one list which I will link to in the show notes because I think it's really helpful. Please check it out. But it isn't a list that's used diagnostically. It was put together by someone called Tania Marshall who is very experienced in how autism presents in females. So I was in bed with my partner when I started reading this list. And I was just reading it in my head

16. Autism

and I could just feel my whole body reacting to what I was reading. I just felt myself coming alive as I was reading it.

So then I read it out loud to Paul my partner, but I didn't tell him what it was that I was reading. I just started reading out the items on the list. And eventually he stopped me and he said, "I don't know what you're reading but this is you. You are describing you. What are you reading?" And I was so grateful to him in that moment and still so grateful to him now for giving me that acknowledgement. Because although it felt so true for me inside, I was also doubting it somewhere and I think because it had just come out of the blue, nobody had ever suspected it.

And the way he responded to me just really allowed it to sink in. And around this time a close friend of mine was going through something that also helped me to figure this out. So the nursery that her daughter was going to at the time had suggested to her that she might perhaps have sensory processing disorder. And so we were discussing that a lot and reading lists of how sensory processing disorder can show up and did her daughter have it? And as we were discussing it I realised that I met a lot of the criteria for sensory processing disorder.

And just again it was another example of how a lot of my life suddenly made sense. Like how I'm very particular with how my clothes fit and it's got nothing to do with how they look on me and everything to do with how they feel. And I always get very car sick very quickly in cars unless I'm driving. And it's always been that way even with very short distances. And I don't like spinning. I don't like jumping. There's a lot of physical things that can really impact me. I'm also extremely sensitive to noise. And I'll talk about that more on next week's episode.

But I'm really grateful to my friend and to her daughter because I learnt so much about myself by being part of their journey to learn and understand what was going on there.

16. Autism

I should actually backtrack a little bit for you because there's one other kind of piece of the puzzle that was really instructive. And this all started happening around the time that Period Power came out. And I would say maybe six weeks or two months before it came out I decided to stop drinking alcohol for a few months. So alcohol is a depressant just across the board. And for me it's a very strong depressant. I can just drink a few sips of wine and feel the impact on my mood for a few days.

And because I wanted to be on the ball should I get called up for an important interview, I wanted to have my head clear and to be able to think straight and to be in a positive frame of mind. So I decided to stop drinking for a few months around the time Period Power came out. And my intention was just to do this for a few months until the publicity slowed down and then I just planned on starting to drink again. But what happened is that I realised how I was using alcohol as a bit of a buffer in social situations.

And I know a lot of people have this experience so I'm going to explain how specifically. Basically it made noise tolerable to me and especially competing noises. So you know how if you're in a restaurant and someone's trying to talk to you? But there's also music playing and maybe there's some noise from the bar and people talking at the other tables. That's hell for me, it just scrambles my brain and I can't think straight. And it actually feels painful. But with alcohol in me I could get past it either for the most part or entirely.

So for years I've had this sensitivity but I wasn't entirely aware of it because I was drinking alcohol in these situations. And the other part of this when it comes to social side of things is that small talk doesn't come easily to me. People who are autistic often have what I refer to as special interests and we like to talk about them a lot. So talk outside of my special interests is challenging for me. And I happen to be very fortunate and privileged in that most people want to talk to me about my special interests.

I can go anywhere and people want to talk to me about the menstrual cycle, about hormones. I also love business and entrepreneurship so they

16. Autism

are my special interests. And I can get down with any conversation that involves the pros and cons of particular pieces of software in an online business. But I can forget that it's not all that interesting to other people in my life like Paul or my friends so most of the time I save that chat for my colleagues who are also my friends.

But because Paul runs Margate Radio, the community radio station here in Margate sometimes we'll get talking about technology. But I get really into it and have this urge to finish my train of thought because the idea of leaving it incomplete is very uncomfortable to me.

So if I meet someone at a social event and it's all small talk or even if I'm just down at the beach and I meet someone for the first time and it's just kind of small talk getting to know you conversation. I will often feel tense and exhausted by it because to be honest with you, I just don't get it. I understand that it's a normal thing to do but it eludes me a lot of the time.

Now, where I am in my cycle 100% influences this because sometimes I find myself doing it and it just comes quite easily to me. And I always have the image of it being like when a kid realises that they're cycling on their own and nobody's holding onto the bike for them. And then they immediately like oh my God, I'm doing this. And then they kind of freak out a bit, that's what it can feel like to me. But sometimes depending on where I am on my cycle, small talk can go quite well to the point where I might start even questioning whether I am autistic, so there is an influence.

And I did actually find some interesting research on how people who are autistic can do the whole small talk thing once we've connected through deep and meaningful conversation that would usually be around our special interests. Whereas for neurotypicals, and that's for all of you who aren't autistic or have ADHD, things like that, it's usually the other way around. And what happens first is small talk and then that leads to deeper conversation. So it may just be that it's the other way around for autistic folks.

16. Autism

And the other thing I want to mention here is that I can very effectively kill the vibe at a dinner part by referencing research papers. And Paul and I love to joke and have a laugh about this. So don't go thinking that this is a problem. It's just something that I see and we get to joke about, I'm okay with that. But dinner parties basically involve me observing conversations. So any group setting, I find being in a group challenging for multiple reasons and I'll explain why next week.

But I really enjoy just sitting back and observing and enjoying the company of others. And sometimes I will want to take part but I'm not quite sure how to. So I just kind of keep observing and keep an ear out for an opportunity basically for me to say, "Well, yes, actually there's some interesting research on this. Let me tell you all about it." And that's how I join in and contribute to the conversation.

And when I think back to my childhood I think I did spend quite a lot of time either on my own and just enjoying my own company or being around others and not knowing how to join in. It just felt like there was a way to do it that escaped me and that others people knew how to do and I didn't. So when I was preparing for this episode I was thinking about the whole journey to realising that I was autistic. And especially once I found out and gone through the assessment, and looking back on the previous months and seeing it all through a different lens.

And I remember there was this one time that I was going up to London to talk at an event. And I posted on my stories over on Instagram that I didn't know what to wear. And so many of you responded with these lovely messages about how I'd look good in a bin bag and that it just doesn't matter what I wear. And I was really surprised because I hadn't been thinking about how I look as the focus of that question. I was feeling anxious about what to wear because I didn't want to end up being too hot or cold when I got there.

And I can't remember what the venue was but I remember messaging a friend and asking if she'd been there and did she know what the

16. Autism

temperature of the room might be like. Because room temperatures are always the same but in my mind I just needed to know so that I could plan what to wear based around temperature. So I'm extremely sensitive. And if I'm too hot or too cold, if I'm thirsty or hungry, or if my clothing, or the lighting is distracting me then it's really hard for me to concentrate.

And it's the same with smells, perfume can really throw me. So going to an environment and especially one with a lot of people in it has its challenges. And my focus will just shift to the sensory input rather than on what I'm saying, and speaking, and doing my job. I've come to see it as a protective let's get the hell out of here mechanism. But it can be challenging when it comes to the public facing side of my work.

I remember speaking at Wilderness Festival a couple of years ago and I know some of you have been following me since then. So it might be interesting for you to hear about this. But at Wilderness Festival I kind of freaked out a bit and I had to go and lie down in the field next to where my car was parked and have a cry and just try and regulate myself. So now with hindsight I understand what happened.

So the audible stage that I was speaking on was built in the round, it was a circular stage with all of the crowd sat around the stage in a circle. And because of that and I wanted to make sure that I was kind of including everyone in the audience, I was moving around the stage a lot. And the stage had also been built on uneven ground because it was in a field. So it was slightly off kilter and this really threw me. It was also a hot day and I wasn't drinking alcohol so I didn't have that as a bit of a buffer and I was premenstrual as well which definitely didn't help.

And then I saw someone that I know and it just felt like a lifeline. I felt like you're here and it was like they were an anchor. But I also got a bit stuck because they were with people that I didn't know. So then the whole small talk thing was happening and I was struggling to do that. And things just kind of escalated quite quickly and I went into what I now know is an autistic shutdown. So I was just lying down in the park crying my eyes out

16. Autism

with no idea what to do, just questioning, should I leave? Should I find somewhere to stay? I was meant to be camping and meeting other friends.

And in the end I just drove around the Cotswolds until I felt regulated enough to make a decision. And that's because the focus of driving can actually help me to do that. I just mentioned autistic shutdown so let me take a moment to just explain some autistic terminology for you.

So autistic burnout varies but it usually involves intense physical, mental or emotional exhaustion. And this is often accompanied by the loss of skills. So for me I have strong verbal abilities. But when I'm in burnout I can lose the ability to talk and it's really scary when that happens. Now at least I know what it is but when it started happening it really freaked me out, it was extremely concerning.

But I remember the first time it was really noticeable, I was trying to order fish and chips with my son and I couldn't do it. So even now I feel emotional thinking about it. So it's like the loss of those skills, the ability to talk. And autistic burnout often happens because it can be exhausting living in a world that's designed for neurotypical people. And when it happens it's like all my resources are depleted.

And I just need to lie down and be still, and be left alone, and just stare into space. And do other gentle sensory things that help me to regulate myself like I will wear Paul's big soft dressing gown, which is also helpful because it's a way that I can signal to him. Because I was thinking I should just get one of these dressing gowns for myself. And I thought no, it's quite a good way for me to non-verbally signal to him that I'm feeling sensory and that I need to be left alone and regulate myself.

And if someone asks me a question when this is happening, even a very straightforward simple one it's really not great for me. I just need to be left alone and asked no questions, even simple ones. So I have learnt to become very boundaried when this is going on, which I have to say it does

16. Autism

happen a lot less now. And some of you have asked questions about this that I'm going to get into next week.

As I've just described, burnout can lead to a shutdown. And what autistic shutdown looks like can vary greatly and also how long someone can be in it can also vary. But it basically looks like a reduction in movement, in speech, needing to retreat and hide, or just conking out and sleeping, that kind of thing.

And autistic meltdown is a loss of control which can be verbal or physical, so that might look like shouting, screaming, crying, punching, biting etc. It's not a temper tantrum. And when young children do this or teens, people who are around them observing it tend to think that they haven't been parented properly and that they just need some stronger boundaries and proper parenting in order for it to stop. But it actually comes from overwhelm, it is not a temper tantrum. As I said, it usually comes from trying to fit in with the world around us which is not designed for neurodiverse folks.

So something that autistic folks do, especially those of us who have been socialised as females is that we mask. And I found this great definition of masking for you that I wanted to share and it's this. Masking is a complex and costly survival strategy for autistic people. It's basically camouflaging or suppressing and hiding certain behaviours and autistic traits. And we just learn, and practice, and perform certain behaviours in order to fit in. So girls and women are particularly likely to do this which is one of the reasons why autism is diagnosed later in females.

And masking is exhausting, sometimes I don't realise I'm doing it. I'm getting better at discerning when I am though and that helps. But man, it's exhausting. And a lot of you have been asking how I went about getting diagnosed. So where I live in Margate which is in Thanet, apparently there is a two year wait to be assessed. And I didn't want to have to wait that long.

16. Autism

I was also concerned that because of my ability to mask that during an assessment I might be able to mask my way through it, especially because in medical situations that I'm used to working in I think I'd be able to mask very well and kind of hide it. So what I did instead was I started looking for a place to be assessed privately. But they were usually in £3,000-4,000 range which wasn't possible for me.

But then I was telling a friend that I thought I might be neurodiverse in some way because I was thinking I'm pretty sure it's autism but it could also be these other things because a lot of neurodiverse conditions have overlaps. And people can also have one or more conditions. And she just happened to share that she had recently found out that she has ADHD. And so she put me in touch with the psychiatrist that she saw because he charged a lot less, like a quarter less than anywhere else that I found.

And it helped that the assessment that he did was in two parts. So you do the first part and you pay for that and then the consultation – well, just in consultation with him you figure out if it's worth progressing to do the second part and then you pay for that. So that's what I did.

And his office recommended that I ask my GP to refer me to them even though I would be paying privately, which is what I did. And I think the kind of rationale for that is let's say you do end up being diagnosed with ADHD, if you've been referred through the NHS my understanding is that then it's easier to receive prescription drugs through the NHS than if you'd done it all privately and then tried to re-enter the NHS. That's my understanding. I may be wrong, just as a disclaimer, but that's kind of why his office recommended that I do it that way.

So the first part was a clinical interview with him and I loved it. I mean I am genuinely very fascinated with myself as a person. And I'm quite psychologically minded so I tend to love any kind of talking therapy. The problem is that I'm great at masking and I'm especially great at masking over Zoom which is how the assessment took place because of Covid.

16. Autism

Because I'm used to being on Zoom and in the clinical interview I could feel myself performing which is one way that masking shows up.

So at the end of that we agreed that we would continue to the second part of the assessment and we booked that in for a few weeks later on. But between the two parts of the assessment I sent him an email explaining that I had been masking. And I gave him a list of all the things that were making me suspect that I was autistic which was really useful for me to just get off my chest and also for him to see some other examples that we hadn't touched upon thus far in the assessment process.

And the second part used a formal assessment tool for autism. And it was really great to do it. I also loved going through that because it really helped me to understand things about the way I behave. And at the end of it all he said, "Yes, according to my assessment you are autistic." And I just felt so proud when he said that. And I'll talk more next week about what happened post diagnosis. But in that moment I felt proud, at peace. I just understood myself so much. It was like everything had just fallen into place.

I felt joyous; it was a fantastic day that I really got to celebrate. And I will put a link to Doctor Max as I refer to him. I'll give you a link to his website in the show notes in case any of you are interested in working with him. Some of my clients from The Flow Collective have gone through assessments with him. And some of you that follow me on Instagram, I've passed on his details to you. And everyone's feedback has been hugely positive. So I'm very happy to recommend him.

So that's what my journey to suspecting autism and then having it confirmed was like. I hope this has been helpful for you. And next week I'm going to be answering all your fantastic questions about why I wanted to be assessed, how I look back on my childhood now that I have this understanding, what it's changed in my relationships, how it's impacted my work and of course the intersection between autism and my cycle. You have all asked such fantastic questions and I can't wait to get into all of that with you.

16. Autism

So thank you for listening to today's episode and I will catch you next week. Have a good one.

Thanks for listening to this week's episode of the *Period Power Podcast*. If you enjoyed learning how to make your cycle work for you, head over to maisiehill.com for more.