

**Full Episode Transcript** 

**With Your Host** 

**Maisie Hill** 

This is episode 140 and it's the second part of two episodes about my experience of being Autistic.

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.

Hi everyone, welcome back to the second part to this conversation about my daily experience of being Autistic and how Autism, my particular flavour of it shows up for me. So, we're going to continue on and I'm going to keep talking about food but in a slightly different way. So, I've spoken about what kind of foods that I'm able to eat depending on whether I'm regulated or not. I've spoken a bit about my washing up process and the all-important last bite of a meal.

But when it comes to preparation of food, there's a few things that can get to me. First of all, crumbs can be really hard for me to deal with and sometimes Paul will come into the kitchen after I've been in there and he can see the point in which preparing food or tidying up the kitchen. I've got to a point and then I can no longer continue. And although visually looking at crumbs really makes me feel weird, how it looks.

And so, I'll have a strong urge for there to be no crumbs on the surface. I feel weird even saying it, but I don't necessarily have the capacity to clean them up and get rid of them because of how it feels for me to interact with them. So, I'll often say to Paul, "Can you just deal with those crumbs?"

And he's also responsible for all ham interactions in our household. I've spoken about this before on Instagram because a lot of those cold meats and things, I just can't touch. I don't like the smell of them. I don't like how they feel. I don't eat them myself. So, when it comes to making ham sandwiches for kids or something like that then I either use tongs or a fork to do it but ideally Paul is the one that does it. He's very happy to be chief ham person of the household.

But it's not just that, the inside of certain fruits and vegetables can also make me feel very weird. So, the inside of peppers and melons, they could make me feel weird and also any seeds, especially if they're all together and touching.

So, there's this thing that I only found out a couple of years ago because some friends of mine have it, they're not Autistic but they have this thing, I think it's called trypophobia, where you feel disgust or fear when you see patterns that have lots of holes in them. So, if you look at a sunflower, which is making my face itch. I don't know if you can hear me itching just thinking about it. So, sunflowers, honeycombs, sponges, and seedy fruits and vegetables can all be a problem as can lots of little bumps or holes on a surface, so I feel itchy and nauseous and yeah, disgusted.

And when I think back to school, you know when you do science experiments in school when you use those iron filings and a magnet? Iron filings made me feel really nauseous in my science lessons because of how they look. The same any time a farmer or someone would bring in some honeycomb, I would just be like little horrible, horrible, horrible. So those kinds of things can bother me and that can affect what I'm able to do at home.

Even if I want to eat peppers, I have to kind of coach myself through chopping them up sometimes or I'll just ask Paul to do it. There are ways around it for the most part. Also in the kitchen, I can't talk when the kettle is on. If I'm using an appliance that makes noise, that tends to be okay. And I do think there's something there about if I'm using something and I'm in control and it's initiating the noise then that is okay, it's different if someone else is.

Also on the sound front, oh, man, the sound of cables when they come into contact with devices, they make this scratchy, weird noise and it's hideous to me. So that's a problem for me. So, usually Paul will give me a heads up that he's going to plug in an external drive or do something where there's the possibility that the cable could scratch against the top of the laptop or something.

And then kind of similar to that, I can't concentrate or listen if I have a sensory sensitivity thing going on. So that could be feeling thirsty, having dry hands, the feeling of a loose hair against my skin, if you put a top on and one of your hairs is kind of loose inside the top. All of those things, just all I can do is think about them unless there's an emergency going on in my environment. I just can't focus on those things when those things are happening.

So that's definitely come up before in relationships when someone's initiating a conversation that's really meaningful to them, it's really important to them that they have my attention. But if my hands are dry, I can't listen to them, I cannot take it in even if I'm in agreement that this is important conversation, it's necessary that we have it. I can't do it if my hands are dry because it's just like my hands are screaming at me whilst someone else is talking to me. So, I have to deal with that.

And I've learnt to be able to say, "I really want to have this conversation with you. I just need to take a moment to sort some things out so that I'm able to really listen to what you're telling me." So, it took me quite a while to realise that's what was going on and then figure out how to communicate that in conversations.

And then things like touch. Touch can be very tricky, very tricky, especially if it's touch that is not initiated by me and even more so if I don't see it coming. So, if someone approaches me from behind and taps me on the shoulder that is like I'm in fight or flight. It's a huge reaction for me, it's a shock.

And this actually happened in Aldi yesterday when I was queuing up to pay for one thing. I had Nelson with me, and someone tapped me from behind and they just wanted to get through. They were unable for some reason to speak to anyone. And I went and saw them kind of work their way through the line to move past where we were by just tapping everyone on the shoulder instead of saying anything. And it was really funny because I was like, "There's a gentleman trying to get through, but he's not saying it to

anyone. So could everyone just move out the way." I just have to take charge in situations like that.

And it was really funny because then his wife started talking and I was like, "Oh, man now there's going to be a whole scene here in Aldi at the checkout." And she was like, "Well, that's Peter for you." So clearly she's fed up with him doing it as well. But that's the kind of thing that produces a very strong response in me and it does take me quite a long time, I would say, to recover from it.

And I'm quite particular with the amount of pressure. I don't like light kind of tickly pressure or that transition into touch from not touching to hands on the skin, needs to have a certain amount of pressure, but not too much because I don't want to be squeezed to death either. So, it's this Goldilocks amount and ideally it's initiated by me and also there's a lot of the time, especially premenstrually when my sense of personal space does change, and I just prefer not to be touched. That's something that's pretty common in all Autistic people really, I hear about it a lot.

Okay, let's talk about showering. So, I love it when I'm in the shower but the sensory input of getting in, it can be too much for me as well as the adjustment after. So, it's like going from being standing in the bathroom and it being a certain temperature and then getting into the shower and feeling all the drops on me and then the change in temperature and then it's fine when I'm in there. But then I have to then kind of coach myself into coming out and how that's going to feel.

There's just, especially for a shower, which is usually quite short, there's so many transitions involved in having that short shower. So, most of the time I don't shower, I wash in other ways that mean I'm not having to cope with so much sensory input because for me it's just not worth it. Of course, I wash myself in all the necessary places. Hygiene is important but I think it's also worth remembering that being too clean also causes problems. So microbial diversity is important for our skin, for our gut, all the places basically.

And this is why when Nelson was a baby and we lived in London, I would take him to the city farms and most of the time he was asleep in a wrap on me. I would just walk around with him there. The idea being that he would get to breathe in those microbes that are present around farm animals and that that would support his immune system. Now, of course, we just go horse riding all the time. So, having long showers every day and really scrubbing yourself can remove all those beneficial bacteria from your skin.

Also on the hygiene front, I am very specific about how I apply creams to my face. I have to use my right ring finger and recently I got some bad blisters on my ring fingers from riding without gloves. And I couldn't use that finger to moisturise my face, so I had to use my index finger and it really bothered me. And I don't know, it's just in the same way that there's certain spoons that gets used for certain things, there's certain mugs that get used for certain drinks. There's also certain fingers that gets used for putting on moisturiser, so that's a thing for me.

In Autism I think there's this very stereotypical type of Autism that's presented, which is the absence of empathy. And I actually have a huge amount of empathy. And it took me decades to be able to figure out how to have that level of empathy, and it not affect me so much. So, I think a good example of this is watching movies. When I'm watching a movie, I really feel like I am the person acting in the movie. So, I'm quite cautious about the types of things that I watch.

I don't have to do it so much now, but certainly when I was younger, films, books, things like that would deeply affect me and I have what I would describe as hyper empathy, really feeling it. And I think that has really served me in many ways, especially professionally but also in personal relationships. But it's something that I've had to work with in order to experience the benefits that come with it without it kind of taking over my emotional life.

And then when it comes to books, I see what I'm reading, apparently not everyone does that when you read a book and it's like watching a movie. That's how it is for me. That's why I love to read books often more so than

watching the movie. I taught myself how to speed read I think when I was a teenager or in my 20s. So, I can skim read an entire book in 15 minutes. And that's really wonderful when you want to go through a lot of research papers and kind of take in key points and kind of get a good overview of a topic and then go in, in a more detailed, rigorous way.

And of course, that's been really useful to me in my career, and I've made a career out of my special interests. I've spoken about this in various ways, not just on my podcast but on other people's podcasts as well. A great one was the one that I did with Else Kramer, which we'll link to in the show notes but yeah, I spoke more about that there. My special interest, of course, reproductive health, the menstrual cycle, hormones, all of these things.

And that's continued over into understanding the nervous system and stress responses. But really it all comes from that foundation of being fascinated by humans, being fascinated by human behaviour, how hormones and mindset and nervous system stuff all influences how we think, how we feel, how we behave. And I think that's a lot to do with being Autistic and wanting to understand people and make sense of how everyone else in the world is going about living their life.

Because it's something I've had to try and figure out in order to get by, because a lot of it has been, I don't know if it's fair to say a lot actually, but some people's behaviour can be very confusing to me. It still is, but I think that's what makes me a really fantastic coach is how I approach things is probably quite different to people who aren't Autistic.

We've got to talk about car sickness, because this was something that was a really, I would say, early indicator of me having sensory integration issues or needs. Because as a young kid I would get car sick even on very short journeys and I still do now. I need to be the one driving. If I'm driving then I don't get sick. I did just buy these funny looking spectacle goggle things that stop you from getting travel sickness because Nelson and I are going away in a week or so's time.

And I didn't realise until the other day that I've actually been to this area of Spain before when I went on a yoga retreat in my 20s and I got so sick on the drive from the airport to the town. That I was just like, "Oh my gosh, I can't repeat that because it's just me and Nelson going away." So, I need to find ways of reducing the likelihood of that level of nausea.

And I saw someone with these goggles on TikTok. So, I've been testing them out and so far so good. They look hilarious though, they really do because they don't have any glass in them, and they've got the round bits at the front like regular glasses. And then there's round bits on the side and they're white and they have this blue liquid that sloshes around in them with movement, I guess, so that your eyes are perceiving a horizon all the time.

Anyway, they look hilarious, but so far they've been working good on the small, non-hilly journeys that we've been doing so far, so fingers crossed they're going to work. I will let you know. And then when it comes to travelling, I love travelling. So, it's kind of weird because sometimes I get this, well, now I understand it, but it used to be weird to me that I would feel this anxiety about going to places, even places that were quite familiar to me, this kind of apprehension I suppose.

And especially with new places there would be something that's more not quite anxiety, but I think you understand what I mean when I describe it as anxiety. And it wouldn't be because the place was different. It was more because I didn't know what clothes to wear, not because of how I'll look, it's all about how I'm going to feel.

So, especially with how hot a venue is going to be, making sure I'm wearing clothes that mean I'm not getting too hot because then, especially if I'm there to give a talk or something like that, then that's going to impact my ability to do my job. So, it's really helpful if I know someone who is familiar with the venue that I'm going to who can give me a bit of a run down or let me know if they've got air conditioning that they blast out or if it gets hot and things like that, that really helps me.

So, I've just got a bit better about being upfront about needing to know those details in advance. And this is all going to be amped up if the acoustics of the venue are awful for me. I think that's the number one thing, if the acoustics are horrible, it's going to be challenging for me. So, I try to find the things that I can make accommodations for. I used to take great pride when I went on holidays in my minimal packing style, because I'd go away on a three-week holiday with just the backpack that I use every day.

But now I pack in a way that gives me lots of options and means I'm taking things with me that are going to help me to be regulated and take care of myself whilst I'm on a trip. And I'm just not having to have that additional thought about am I going to be too hot or am I going to feel this way? Have I got enough stuff that feels soft and takes care of my sensory needs? Or have I just packed things that I'm going to feel uncomfortable in and cause me to feel dysregulated?

And this came up during the master coach training that I did a while back, which is just advanced coach training. And we all got coached a lot during that training. And at one point I just received this amazing coaching. It was a week before I was due to go to Paris for a 24-hour trip just to see my friend Simone who was visiting from Korea, and our friend Vicky Louise, who's been on the podcast. She was also going to meet us there, so I was just really excited about being with them.

I hadn't met either of them in person before, but we just knew each other so well. So, we had this intimate relationship from coaching one another and seeing the coaching that we'd get from other people around us, but we'd never actually met in person. It was also my birthday, but I was worried about going out to dinner and struggling with the sensory experience of it.

And I can't remember what the specific coaching I got was, but it was around me getting to the point of being fully okay with leaving at any point in the evening where I deemed okay, I'm not going to do this anymore. I'm going to leave, it's lovely to see you, but this environment isn't working for me.

And I hadn't actually put this together until I'm saying this now, but that was the beginning of me shifting my mindset in my business to where I am now, which is being fully okay with cancelling workshops, calls, webinars on the day I meant to do them even if thousands of people have signed up for them. If, for example, I stopped being able to speak or something along those lines happens because that does happen. It happens a lot less now, but it's a significant way that Autism impacts me, I lose my verbal skills.

And if I'm just feeling dysregulated or a bit shut down, then I'm going to take care of myself. Anyway, I needn't have worried because Simone was staying at the Ritz, and we had dinner there and it turns out that the Ritz is very sensory friendly as in if every restaurant was like that, I would never have to worry about going out to dinner. The acoustics, the lighting, the materials, the whole sensory experience was amazing, and it was really powerful for me to experience that.

Of course, it's not something I can do every day, but it's good to know that's how I can feel. I can feel in a social setting out with my friends when the sensory stuff is taken care of.

A couple of you have asked about making decisions. One question was, how do you handle the overwhelm of too many decisions to make and then prioritising where to take action first? I always know where to take action first. That's just how my brain works and it's just how I think about myself as well. So, feel free to borrow that thought and that belief. There can definitely be some areas where I need support in doing that. But for the most part I just know what to do.

And it's not necessarily knowing what needs to be done, although I think I can break things down into a process very quickly. But it's more like I just trust myself. It's so rare for me to not know what to do. But the issue can come in with communicating that plan to others, whether that's my partner, Pau,I or it's someone on my team. So, it's usually I know what to do, I have a plan, but can I communicate that effectively and in a way that everyone else can do their thing and I can just focus on doing my thing?

Another question about decisions, do you ever struggle to make decisions due to going blue screen/shutdown? How do you take care of yourself when you struggle with shutdowns and executive dysfunction? I don't make decisions really when I'm having a shutdown. The only decision I make is to remove myself from making decisions and to not be available for them. Or it can be quite black and white, protective decisions of, yeah, I'm just not going to do that anymore. But it still comes from this very rooted place inside me of just knowing that's what needs to be done.

So even if I'm in a shutdown, I'm not necessarily making those decisions from a place of fear, it's still coming from a this is just what I need to do kind of place.

And then we have to talk about demands, because I got quite a few questions about this. So, there's a phenotype of Autism called PDA, which stands for Pathological Demand Avoidance. But a lot of folks in the Autistic community prefer to refer to it as a persistent drive for autonomy, which I prefer. Although if I was going to start a heavy metal band or host a radio show, I would call it pathological demand avoidance because I think it's just such a great name for something to do with heavy metal. I don't really like it as a way to describe my behaviour though.

But it's basically once someone tells me to do something, it becomes infinitely harder for me to do it. Sometimes it's an executive functioning thing, but a lot of the time it's to do with once I've perceived something as a demand, it's really hard for me to do it. Even if it's something that I want to do, that I've decided I want to do, and even if no one else has told me that I need to do that thing, once I register it as a demand, it does get harder.

So, a good example of this happened a few weeks ago. So, Paul and I were in the car together. I was going to drop him off at the building where we both work and then drive off to do my thing. And so, I pulled up at the back of the building, he got out the car and down that road where I would usually drive were a couple of other cars, and they were stationary. Clearly there was something going on that was meaning that the road was blocked.

Now, before you get to the end of the road, you can make a right turn and kind of come back on yourself.

So, in my head I was like, I'm going to make that right turn and not sit behind those other cars waiting for it to clear. But as Paul and I were saying goodbye, he said, "You might want to take that turn." And I was like, "Oh, bollocks." Now I can't do it. So even though I had decided I was going to make that right turn, that's what I wanted to do. It was clearly the best way forward. But once he said that, I just couldn't make that right turn, that drive for autonomy was so strong.

So, I just drove and sat behind these cars, and I could see Paul at the other end of the road just kind of stood there watching me thinking what on Earth is she doing anyway? Anyway, eventually I coached myself and was able to reverse and then take that right turn. But that's just something so trivial and basic. So now I want you to think about other things, other demands in life and because this can really bite me in the arse, I have to say. And like I said, it's even things that are my plans that I really want to do. Once I perceive them as a demand, it's going to require more for me to do it.

Thankfully I have a lot of skills and resources that I can bring in, which helps me to get past it a lot of the time, but it's not always possible. I've also got a team now which helps a lot. Beck, my DOO is my right hand. She used to be my assistant years ago and she really knows how to communicate with me in a way where I'm less likely to perceive what she's asking for as a demand.

Robin, who joined the team as an assistant a few months ago, she's also got a knack for it. In fact, I think everyone on the team is really good at this, whether they're doing it intentionally or not. So just shout out to my team for being amazing. It can become more challenging with external contractors especially with timelines because everything in the business has a timeline determined by me, which as I said can also, that can be an issue.

But I do think communicating with external contractors has got a lot easier now that Beck is back as DOO, Director of Operations. Because at the end

of last year I was communicating with so many contractors for various things and thankfully one of them, Kronda Adair, who I just love to bits. I love that woman and what she does so much. We had a conversation and she brought up my tendency to go into ostrich mode in the middle of our work together.

And she brought up the importance of having someone who could do that project management and operations side of things. And that what I was actually doing at the time was multiple jobs and so no wonder I was kind of feeling quite stretched and struggling to do all the things that I was attempting to. And Kronda actually asked, "How can I better support you as a service provider", when I put the post up on Instagram requesting questions about Autism.

And my answer to that is honestly, I don't know. I'm not sure that there is something that you can do better to support me because you already do so much to help me. And I think just the fact that you are asking this question and considering it, says a lot about who you are, how you work, and it means a lot to me as well.

Now, what's fascinating about this demand side of things is when I go horse riding, my instructors are telling me what to do all the time. And I said to one of them recently, "It's pretty amazing how much I'm able to tolerate you telling me what to do because it really does blow my mind." And I think I'm able to do that because I know very little about horse riding and staying on the horse. And having a safe lesson is largely related to listening to your instructor and following what they're telling you, going with their feedback. So, it would be dangerous for me to not do that. I think that's the biggest thing.

Plus, I'm on a horse that's regulating in and of itself so there's an accommodation, a constant accommodation that helps me to do what I'm being told. Also, I'm very invested in riding, so I really want to know what they're thinking. And then there's the way that they naturally communicate or are willing to communicate with me because they have a good understanding of how my brain works. And they know that with constant

talking, I just stop being able to hear what they're saying, and it just all gets jumbled up in my brain, which is exactly the same as riding, by the way.

If you nag a horse all the time, they stop listening and they stop responding to what your leg is telling them to do or any of your other aides. So that's my theory on why they get that less is more with me because it's the same with riding. Verbal instructions are also a big no, no. So that's been interesting with riding.

I have slow audio processing so it can take a while for me to actually hear what's being said. And it helps me if I say the thing out loud, either just to myself or saying it to them in order to get confirmation that I've heard it correctly. But if you give me flat pack instructions, if you give me written instructions, I am all over it. I am great at stuff like that. Tetris, putting things on the conveyor belt in the shops, I love that. That for me is just delightful for my brain.

And when we go camping, I get very annoyed if anyone tries to help me put the tent up because they're robbing me of the joy of it. We have a huge tent now, so there is a point where I do need other people to help but all the bits leading up to that I have to do. It's the same with the washing up, sometimes it's like, just let me do it, let me do it my way because I love being able to do it my way. I will ask for your help. Thank you for offering. Just please sit back down.

And a couple of years ago when we were camping, Paul was sat down with his friend just chatting in some deck chairs and I was putting up this massive tent. And these other campers were kind of silently judging the situation and totally judging Paul for sitting there, watching me put the tent up and just chatting to his mate. But it's not that at all, he just knows not to interrupt me because he's going to rob me of the joy of putting it up.

Another great way for me to regulate myself is doing puzzles and also things like figuring out kitchen design and layout. My brain works really well with that kind of thing. When I look at houses that are for sale, I go straight to the floor plan. That's why as soon as our house came on the market, I

knew we had to see it as soon as possible just because of the floor plan. I knew that I would like the dimensions and the layout for the most part. Even though some walls would need to be removed or moved, I knew that we could work with what was there.

And similarly, to that, paint charts are also a wonderful visual stim for me. I'm very moved by visuals, especially in nature, but it can also be the colour of a piece of clothing or lipstick on someone. So, if I feel it's very complimentary to their colouring it really affects me, and I just get this urge to tell them. So, I will often abandon a conversation I'm having or interrupt someone else in their conversation so that I can tell them how wonderful they look.

And it's really interesting as a social experiment to see how the vast majority of women and those socialised as female are very uncomfortable with being complimented in that way. Other stims that I have are pressing my lips together, flicking my fingers and touching certain types of materials. I actually got through junior and secondary school I'm pretty sure, by using the point of my tie, my school tie, because we had to wear uniforms. Using the end of my tie to make patterns on my skin and feeling the edges of my tie or the blazer that I wore, just feeling that on my fingertips.

And this is something that continued into adulthood, feeling the edge of material or just rubbing it between my fingers. And I used to feel a lot of shame doing this as an adult because it's something that kids do, adults don't do it. It's like having a blankie. But thankfully I had a really great therapist and when I told him that I was trying to stop doing it, he just immediately questioned why. And he pointed out that it wasn't hurting me, wasn't hurting anyone else, and it was actually very soothing for me.

And that's when I just dropped this idea that I needed to stop doing it, and I still find it very soothing. I've spoken, I think before about Paul's big, hooded dressing gown that I love to wear when I need to regulate because it's not just a very sensory pleasing regulating thing for me to do. It's also a strong visual cue for Paul and Nelson that I need time to regulate and that I need to be alone. So, if I'm struggling to speak and to communicate that I

can put on Paul's dressing gown and it's an immediate heads-up with where I'm at.

A few other questions I've got. How do you combine things that make life doable and enjoyable for you with what makes the day okay and enjoyable for kids? This is interesting because in most circumstances, Nelson and I have different sensory profiles. I'm quite sensory avoidant, he's quite sensory seeking. There is some crossover, there are things that I'm sensory seeking with, there are things that he's avoidant with, but we are kind of opposites.

But basically, my approach is if I can do it then I will. If I can't do it then I don't. It really is that simple. And just maintaining that congruency and consistency in my communication with him, I think that's what matters. Not being like that's going to be really hard for me, but I'll give it a go. Then it gets a bit more kind of wishy washy and things. I just try and be straight up with myself and with him. And I think because I do, do it when I can, he's understanding when I can't. And it can upset him and annoy him too.

He does his best to understand, and he can feel sad and frustrated that I can't, and I feel that way too sometimes. And we've had some great conversations about holding space for all of that at the same time. Yes, it's the kindest thing to do for yourself. Yes, I get it and I wish this was something that didn't have to be a thing. Yeah, I get that. Thankfully, we both love horse riding and that's been amazing for us. I don't know how long that will continue for, but I'm just soaking it all up at the moment.

Another question, how do you stop yourself getting to the point of a meltdown when it's not appropriate? Well, my standpoint is that meltdowns are always physiologically appropriate. The issue is how they are perceived in society and within relationships. And for the majority of my life, my meltdowns have been internal and it's only in the last year or so that I've been able to have them in a way that's actually noticeable to others.

And I recently had one in a horse riding lesson whilst actually riding. I shared about that experience in my weekly debrief email that goes out on

Fridays. So, this is maybe a bit more of a challenging question for me to answer because my life is just set up in a way where I can't really think of an example when it's not going to be appropriate but that's also down to my approach to it as well.

Okay, how do you get the conversation going about Autism, especially to people who are resistant to the idea that you're neurodiverse? Well, I just tell people upfront, I say quite soon usually after meeting someone, "I'm Autistic", so blah, blah, blah. And that's it, it's that simple. Now, most people in my life are wonderful. I have very little contact with people who don't understand or are unwilling to try to understand. That's just a standard that I have for my friendships and relationships.

There are people on the periphery of my life who don't believe that I'm Autistic and I'm sure there's plenty of strangers on the internet who don't think I am too. There are lots of people who know bugger all about me who have plenty of ideas about me. Good luck to them is all I can say. I'm not going to spend time considering or catering to those people. But also, I get it because five years ago, if you'd have told me I was Autistic, I would have told you to stop being ridiculous.

Most people have a very limited understanding of Autism, especially in girls and women and that included me.

Okay my loves, that is it for this episode. I hope you found these two episodes helpful, and I will catch you next week.

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