

## Ep #173: Dysregulation and Recovery



### Full Episode Transcript

With Your Host

**Maisie Hill**

**The Maisie Hill Experience** with Maisie Hill

## Ep #173: Dysregulation and Recovery

This is episode 173, and this week I'm getting personal with a story of dysregulation and recovery from my own life, so I hope you find this really useful.

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. I am in storytelling mode at the moment. I recently shared a few examples of things from my own life with the members on one of our coaching calls. And when I thought about what I wanted to do for this week's podcast, I realised that I wanted to tell you a story too. So recently I've had a few different people ask me about my self-care and the things I do to support myself on a regular basis. And it's not something that I've thought about or been asked about in a while.

So it's been really interesting for me to consider what it is that I do because I do a lot of things, but they're automatic. I don't need to think about doing them, they're just really practised behaviours that I just do. And there's several reasons why I want to share this with you today. Mainly, I'm feeling at the moment, everyone, I'm feeling, and I want to be honest about where I'm at. It would be weird for me, or it would feel weird for me to share anything else other than that right now.

And my sense is that my story is what needs to come through today so I'm trusting that. Also it's a reminder that these things happen to everyone. Life isn't about ensuring that stress and dysregulation never happen, and that life is always smooth and lovely. And I also want to give you some tangible examples of things that I find helpful when I don't feel great, I mean they're also things that I just do on a regular basis anyway, and how I take care of myself.

We've also been getting more requests for me to talk about my experience of being autistic. So you're definitely going to get that today as well because this is very much about my experience of being autistic. But I

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guarantee that what I share today will be relevant and helpful to all of you, whether you're someone who's neurodiverse or not. So today I'm feeling dysregulated, less so than yesterday, but the edges of me feel permeable and a bit frayed and I feel exposed and maybe a bit vulnerable.

It's a very physical thing for me. I can hear it in my voice at the moment as well. And I don't feel teary. I mean, we're going to see what happens as I get into this. Who knows where we're going to end up. But it's a very physical experience for me, and there's a bunch of stuff that's led up to me feeling this way.

So we were in Scotland for two weeks. We drove up there, we stayed in Manchester on the way. We went to three different places in the south, the west and the north of Scotland. Then we had a very long car journey back. The first stretch to Manchester it was raining and windy and dark and foggy. And there were stretches on the motorway where I could see just three cat's eyes in front of me and that was it. And we got to Manchester at 1:30, 2:00 in the morning, slept in a hotel room, woke up at 7:00, had breakfast and we were on the road again.

On this day, it was a really hot day and the air conditioning in our car stopped working. So it was very much a journey of two halves, and I was just really pleased to get home again. Now, I love exploring and adventuring, so I do quite well with travelling. I'm the kind of person who has booked things last minute, like flights, places to stay. I'm just quite happy to arrive somewhere and sort somewhere out in terms of accommodation when I get there.

And I say that because some autistic people would really struggle with that and need to have a plan in place. But even though I feel at home doing those things, it can also be unsettling for me somehow. And all the love to Paul and to Nelson, but bloody hell, those two can talk. And even if they're not talking, they're making noises. And even if they're not doing anything particularly noisy, I can hear them existing. The sound of their clothing when they move their arms, the sound of them eating.

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Paul shaves his head and he'll rub his head. And I know that that's a nice sensation for him to do, but I can hear every bristle as he does that. And Paul is very aware of my sensory stuff and he's very considerate of those things and how noise impacts me. But humans make noises through existing, and there's just no getting around that. So there was all the moving around, the driving, the noises, the chatting. There was a lot of wind up there.

I saw my friend Vicky Louise in Manchester, which was amazing. We visited friends and family in the places we went to, which I loved. I got to see my good friend, Rebecca as well. It's been years since I last hung out with her face to face. I can't even remember when the last time was, but I know Nelson was tiny. So we had Sunday lunch with her and her partner. We got to talk about horses and writing because she's got horses and she's an author.

And by the way, her book, *Earthed*, she has several books, but I want to talk about her memoir, *Earthed*, which is the story of her moving to the countryside and having a breakdown. And it's so good, it's rare for me to stay up to finish a book. But I think when I read that book, I stayed up till 3:00am to finish it because I was just hooked. So I was hanging out with her and her husband and at some point in our afternoon together, I just realised I was done. And when I get to that point, I have to go. It's immediate, I'm out.

So I told Rebecca, and she gets that. I know I don't have to explain it to her, which is so wonderful and such a gift in a friendship. And she just looked at me and she was like, "You look really pale." So it's a very physical thing to have these experiences. And the point I want to make here is that I can be doing things that I love. I can be hanging out with people whom I adore. I can be around people who are considerate of my sensory needs, and I can be having the best time and end up dysregulated.

So of course dysregulation happens in environments that aren't great for us or for me. They can happen when I'm around people that I don't feel at home with, which is pretty rare because I have a very low tolerance for

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those people. I think that's a good thing. But dysregulation happens when I'm doing things that I love and with people that I love.

So it was so good to get home again, to be home, to go see my horse, Mr Buttons, to get a coffee, and specifically a batch coffee, which is my usual order. But there was no batch coffees in the cafes we went to in Scotland. So that also has an impact on me because I'm unable to follow my routine. And yes, I can get an Americano, that's fine, but it's also not fine. And I know that these things might sound trivial and privileged, but these disruptions can be deeply upsetting for autistic folks.

This is why autistic kids, autistic adults as well, often eat packaged food. It is reliably the same. We know we're going to get what we expect. And although my diet is varied, I am specific about how things should be cooked and presented, and I have my go to safe foods for when I'm feeling dysregulated. And I'm unable to eat the varied stuff that I am at other times when I'm feeling more regulated.

And when I go to my local café, Forts here in Margate, I know what to expect. The coffee I get, the food is always consistent and there is also consistency in my experience of going there. I know the staff, they know me, they know how I like to order and how I work there. I'm there most days. So not going there is also a disruption to my routine. And whilst I was away I had a couple of coaching calls booked in, some of the membership, some with my private clients.

And there were several technical and practical reasons why I ended up being unable to do those calls, and thankfully Mars Lord was able to coach instead, which everyone loved, of course. But that was something I had planned and really wanted to do, and I can get attached or even kind of stuck in a plan. And I'm not quite sure how to describe it. It can be upsetting, unsettling, disturbing, something like that, when I don't get to do it, even though it's fine for everyone else, it can be not fine for me.

But there's also times when I can just roll with things and I might be the one going, "Who cares? It's fine. This totally isn't an issue at all." So there's

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variation and there's nuance in this. After we got back from Scotland I had a few days of being at home, back to normal. Then I had this trip to London to do where I was going to be a guest on a podcast. And that podcast recording would also be a video recording and I had an appointment after it.

And both of these things I really wanted to do and had been looking forward to doing. But the night before, when I was going up, because I stayed up the night before to kind of give myself the best ability to do it. I could feel in my body that it probably wasn't the best idea for me to go. And I'm sure this is familiar to all of you, that point where just on a physical level, you know you could do with not doing something and instead taking care of yourself. And that might mean having a chilled-out day in your PJs.

I think for me it would have just been remaining in Margate. I would have worked, but I just needed to be here and not go anywhere and not have so much human interaction. But for various reasons I didn't want to reschedule these appointments and I liked my reasons for that. So when I asked myself, well, if you know you could do without doing this trip, why are you? I liked my reasons. I liked my answers.

If my answer would have been something along the lines of, well, I have to do it or I don't want to let people down, then they're answers that I'm not a fan of. And if they had been the answers, I wouldn't have gone, or I would have coached myself on them. I would have figured it out and not gone, but I decided I would go knowing that it would likely have consequences. So it's not ideal, but there's a huge difference between doing this intentionally and doing it without any awareness whatsoever.

So this was me making that agreement with myself of, yeah, this might not be great for me. There might be consequences, but I'm agreeing to those, I'm signing up to them. And then that meant I could move into, well, if this is what I'm committing to, then what's my plan? So I decided to stay up the night before rather than getting an early train. I decided to stay in a hotel because I could have stayed with my brother and his young family but

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although I love them, it would have been an additional thing for me to handle.

So in doing this, I'm actively trying to reduce additional things and just kind of lighten the load a bit. But even staying in a hotel is challenging because of how things feel and the temperature and the sound that the vents make, but it's still the best option. Because usually when I travel on tubes during rush hour, during that commute time zone, I often faint. If I can't get a seat, I usually faint on the trains, even if I've had a great breakfast and things like that. And who wants to be dealing with that on their way to do an audio and video recording? Not me.

So I did the interview, and I went to my appointment, both of them with lovely people, by the way. But I was masking, as someone who's autistic, there can be times when I'm masking. And masking whilst on camera adds another dimension because of the level of awareness I have whilst I'm doing it, of my body, of my expressions. And having the conversation with the person plus at least one other conversation I'm having with myself in my head at the same time.

And I was asked some questions about my first book, *Period Power*, very standard questions, but a couple of them were about the content of it. And to be very honest with you, I don't remember what I said in my book. I wrote it six/seven years ago. It's been about five years since I last read it. And it's so delightful, when people share my writing on social media, and they tag me in it. And I read my own words, and sometimes I don't realise they're my words. And I'm like, "This is good. Who's this person they're quoting?" And I'm like, "Oh, it's me." I'm great. So that's really cool.

But I have largely forgotten what I said and it's the same with birth related stuff. So I was a birth doula for over a decade. I had so much experience and knowledge, very easy for me to retrieve. But it's just not my world anymore. I've moved on. That's why I largely recommend other people for this kind of thing.

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So I was trying to bring forth knowledge that I had for decades that I used on a daily basis for most of my career. But it's just not my thing anymore, not in the way that it was, and especially not the medical side of things, because I'm not a practitioner anymore and I just don't have those conversations anymore. They just don't interest me, not like that. Plus, there was the lights when we were recording, the smells. All these things add up, but I was done with both the appointment and the recording by 1:00pm.

And then I was getting a train home from Stratford International, which if you know it, means you kind of go through Westgate shopping centre. It's a very large shopping centre. And that's when I realised that I was having a hard time because all the lights, the noises, the smells just felt like they were invading me. But I knew I was hungry and that eating would be a good idea before getting on the train. So I went to get ramen, which is always a good bet for me. It's a safe food.

So I usually get the same order and I can't tell you why, but on this day I decided to order something different, and it was delicious. But the broth wasn't the same consistency as the dish that I usually order. And although the broth they gave me made sense for the ramen that I got, it still felt wrong because it's a variation from what I was expecting and what I know. And again, it's such a small thing, but it also isn't.

And if I wasn't feeling dysregulated at that point, it probably wouldn't have mattered, but I was, so it took me a while to get over this. I really had just this sense of something being wrong and I still ate it, it was lovely, but it was still wrong. Again, not because of the recipe or how it was made, just in my brain it wasn't right. So there's all of these things, as I said, on other days, if I'm feeling regulated aren't as much of a deal or aren't even an issue at all but these things, they all added up.

So now that I've given you the story of how I got dysregulated, I want to give you the story of how I recovered. So the first thing I did before I even left to go up to London knowing that there was likely going to be a cost to me going up but again I'd made that cost benefit analysis in my mind and



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agreed to that. So with that in mind, I made sure that I had space the day after this. If I'm intentionally going to go into the red, then I always ensure that I have time to recover afterwards. That means no meetings, no peopling, I may work, I may not, it depends on what I feel up for.

Because remember, my work is an autistic special interest, so doing it can be regulating. But on other occasions I might not be able to do it at all. On this day I was expecting the vet to come out and see my horse, Mr Buttons. So I did a couple of hours of focused work in the morning then I went to the stables, I gave Buttons a brush and then I gave him a massage for half an hour. And I just got so in the zone with doing that and that is what made the biggest difference. That was my recovery moment.

That was when I went from kind of just coping and getting by into resetting and recovery. And I did actually have a call to do, but it was with my coach, Robin Langford, who is wonderful. And it's very rare that I feel unable to do a call with her. So I actually ended up doing the call with her from the field that the horses were in. So it was a double win, double regulation there.

And usually I would do my best to give Paul a heads up that I might need to be on my own and that would help him be like, "I'm going to do this with Nelson. I'll take care of that." And we kind of figure it out together. But he was doing this music residency that week, so knowing that he wouldn't be around as much, I had booked Nelson in for extended day, which is the after school club just to give myself some extra space.

And this is a place where I think, particularly if you're a parent, particularly you're a mother, there can be a lot of judgement about when we need that. So I just want to remind you that it's okay to need those things. It's okay to do those things. So he was in extended day. Once he got home I made things as easy as possible for me and for him. So we're talking oven pizzas for dinner, getting under our weighted blankets on the sofa, watching a movie together.

So in other words, how can we be together in a way that means I can continue to regulate, take care of myself whilst doing something together?

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Because there's other things that maybe he might want to do, which I totally get, but they're not a possibility for me at that moment in time. I would also do things like put Paul's dressing gown on as well. I forgot to mention this earlier actually, but if I'm feeling dysregulated I will only wear my most sensory friendly clothes.

My whole wardrobe is fairly sensory friendly at this stage, but there is some stuff in it that I'll only wear for a few hours and only when I'm feeling regulated. And then there's the stuff that's the softest, the best option that really helps me to recover, so that comes into it too. And of course, even doing this episode is also self-care because writing down my experience in order to prepare for this episode has been a way to process it all.

So all of these things are what helped me to come back to myself. Notice how simple they are. I'm not saying they're always the easiest thing to do, but they are simple. There's probably other things that I do as well, but as I said, they're just so automatic to me these days that it's harder for me to actually see the things I'm doing because they just happen. Now, I wanted to answer some of your questions because I asked on my stories, what would you like me to cover when I'm talking about this experience?

And you had some great questions and I'm going to answer some of them now, but I've also made a note of other ones for future episodes. So the first question. Does my dysregulation turn into ruminating thoughts? It doesn't, probably because I coach myself all the time. So when I spot thoughts that could turn into rumination, I know how to interact with them so that it doesn't go down that route. And really this just comes from having an excellent relationship with myself and watching where those thought patterns are going.

And then interacting with them in specific ways so that they don't escalate. Plus tending to my emotions, my physical sensory experience, and I'm saying all these things like they're separate, but they're really not, but each of them gives me a different route into my experience. I could do a whole episode about this.

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Okay, next question. How have I learnt to navigate my cycle through this? Well, there's different cycles influencing things. So we've got my menstrual cycle, of course. And this happened in the premenstrual phase. So for sure that influences things, but nowhere near as much as it used to, because of how I work with my sensory experience, how I coach myself, how I make space for my feelings and responses, etc. This is the whole reason why I teach these methods in the membership. I use them day in, day out myself.

But this was more about everything that had happened in the weeks leading up to this day in London as well as the things on the day and the astrological cycle. So the sun was in Aries. If you've listened to my podcast with my coach Robin Langford then you'll know that Aries is in my 12<sup>th</sup> house. So when the sun is in Aries, which is end of March into April, March 20<sup>th</sup> or 21<sup>st</sup> to April 20<sup>th</sup>, something like that. Or when the moon is in Aries, which happens for a few days in every 28-day lunar cycle, then that can be a trickier time for me.

And at one point in the last month the sun was in Aries at the same time as the moon was in Aries, and we had a solar eclipse in Aries. This all happened whilst we were in Scotland. And that bears just as much relevance for me as my menstrual cycle, especially when those things combine with my luteal phase. So basically, I'm now just beginning to come out of my most internal phase of the entire year.

This is where I typically like to seclude myself, go into hermit mode. But I was in a car with my family driving around Scotland, and that was great, and I loved it but when we got home, I really wanted and needed to be home.

So this leads onto our next question, which is, how do you regulate from sensory overload when you still have things to do, things that need to get done? We all have this happen. So here's the coaching I'm going to offer you, and this is how I would coach myself too. Is it true that these things have to get done? Is it true that they have to be done now? If it's true that they have to be done, do they have to be done in the way or to the extent that you're telling yourself they need to be done?

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Now, some of your answers to these questions will be yes, they do need to be done and they do need to be done this way. Some of them will be a no, but remember when you are stressed or dysregulated, you are more likely to perceive things as threats and therefore think things are more important than they actually are. There will be the sense of urgency and importance there. And this can look like saying to yourself or other people, “I have to get this done. It’s really important. It’s urgent. If I don’t do it, there’s going to be consequences. The world’s going to fall apart.”

That’s what your brain is offering you, that doesn’t mean it’s true. And yes, there will be some occasions where that is true, but on the whole you’ll hopefully find that it’s your brain being dramatic. So immediately, just get rid of the things that don’t actually have to be done. I was telling myself that I had to do my podcast for that week. And I would have loved to have recorded the episode I had planned, that was all ready to go, but it was too much for me to ask of myself.

So how can you reduce your expectations of yourself? And if you are able to, can you communicate with others that you have less capacity? And I say if you’re able to, because I’ve had so many well-intentioned, usually neurotypical people tell me, “Maisie, if you’re struggling, just let us know and we’ll do this and that to help.” Very well-intentioned, but when you are in this place it’s not necessarily easy to communicate that, it isn’t for me.

Communication with others isn’t the easiest for me on the best of days. So when I’m dysregulated, there are additional challenges that can prevent me from being able to do that even if I want to. But sometimes it doesn’t even occur to me that I can do that. And if I could communicate that way, I’d probably be able to just do whatever the task is that I’m meant to be doing. So if I’m in a place where I can’t do the thing, I also am unlikely to be able to communicate that I can’t do the thing. So it’s all well and good in theory, but actually doing it is another thing.

I am getting there with telling Paul no now though, it’s definitely got a lot better. So once I’ve removed this idea of all the things that I have to do and need to do and I’ve kind of reduced my expectations of myself there. I’ll

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also just do things that I've already touched on, like working from our sofa or bed, being under a weighted blanket, wearing my softest clothes which might be my pyjamas or have a really hot bath, that always helps.

And I forgot to mention this as well, but on my recovery day, so after getting back from London, the pipe under our kitchen sink burst and we just had scorching hot water spraying out from under the sink over the kitchen. So whilst we were waiting for that to be fixed we had to turn our water off. And I couldn't have a bath and really a hot bath, really hot is one of my go-to ways to regulate. So that sucked not being able to do that. And it actually still sucks because although the pipe has now been replaced, we realised we don't have any hot water.

But I think the main thing is really just being aware of when I'm using internal or external resources to cope versus recover. And I'm so thankful that I have my own horse now. I was answering a bunch of your questions over on Instagram about owning a horse. And one of the questions was, is it expensive? And my answer was yes and no because yes, buying a horse and owning one involves money. But it would cost me more to not have him because horses are a special interest of mine.

I get a lot of autistic joy from horses, being around them is amazing, riding them is regulating as well. So having my own horse means that I'm more regulated. I'm more able to connect with the humans in my life. I'm better able to do my job, etc, etc. If I hadn't gone to the yard and hung out with him that day and been in the field with the horses, if I hadn't had that opportunity, I am 100% sure it would have taken me days to recover.

I came back from the yard that day a different version of myself. I was different to the version of myself that left the house. When I got back and I walked in the door, Paul was in the house, and he took one look at me and said, "Owning a horse is really good for you." Because he could see and hear the difference. And you may not have a horse in your life, but you've probably got other things that are going to help you, whether they're people, objects, passions, other creatures, could be a dog or a cat, could be your plants, could be a teddy bear or a blanket of some kind.

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These things aren't juvenile. We can really beat ourselves up for that, but they're just comforting and help us to regulate. They're great for adults, too. Have you seen those weighted cuddly toys you can get? My gosh, it would be amazing, something to hold that also is solid and heavy and regulating in all of those ways. So this is also about being in the environment that works for you.

Is it being on the sofa out of the wind? Is it being somewhere where nobody else is going to be able to perceive you? Is it lying on the ground and feeling the earth underneath you and holding you? Is it feeling the rain on you or hearing it? So how can you use your environment to support you?

Okay, final question for today. How did I talk to myself pre diagnosis? Because I only found out that I'm autistic in 2019, I think it was. And the answer is, I talked to myself the same way because all the tools I use now are tools that I used before I ever suspected that I was autistic apart from the weighted blanket, that's an additional one. But everything else I've told you is what I've done for years and years prior to all of this.

That's why I started off this episode saying it's going to be useful for you if you are autistic or neurodiverse but also useful for you if you are not. Okay, I lied, there's one other question I want to answer, and it goes back to communicating with others. And this person asked, how do you explain being dysregulated to others? And I have some info about how I describe it on my highlights on Instagram. But here's what it felt like on this occasion, because I can distinctly remember this as I was walking through the big shopping centre.

So you know how when an electrical device starts glitching, maybe the wiring is a bit loose, and the connection is intermittent? That's one way it can feel on a sensory level. Things just aren't quite connecting. And I also lose my words. I mix my words up. I can struggle to compute what is being said to me and make sense of things. So it can feel like that. It can also be like the impending sense that my battery is on 2%, so I have to conserve it in order to just get home. So I'm not going to talk. I'm not going to do anything that uses that battery up because I've just got to get home.

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But I can also feel like a volcano is going to erupt and like the red warning light is flashing and going, “Hey, there’s an emergency going on.” And for everyone who isn’t autistic or neurodiverse, we can be experiencing this, and you would never know to look at us because we will often mask our way through these experiences. So I can have the red light flashing and the alarm beginning to sound and my face might be completely pleasant and you have no idea that this is going on. I can be talking in a way that would in no way communicate the experience that I’m having.

So sometimes autistic meltdowns are very obvious, but they can also be internal and completely hidden. So it’s been really lovely to share this with you today. And I just wanted to give you an example of how dysregulation can happen, particularly in relation to being autistic, as well as all the things that I do to take care of myself. I think there’s probably, yeah, there’s way more stuff that I do, but hopefully that’s given you a sense and I hope you can hear how simple it is. Again, doesn’t mean it’s easy, but it can be simple. Alright, my loves, I’ll catch you next week.

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