

## 19. Receiving a Diagnosis



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With Your Host

**Maisie Hill**

**Period Power** with Maisie Hill

## 19. Receiving a Diagnosis

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 my friends. We have got some very weird weather happening here in Margate today. There is this heavy fog here that I've never seen before in Margate and it's just rolling down the roads. I can't see the sea. And interestingly that really relates to where I am in my cycle because today I feel very focused in what's in front of me. There are times in my cycle where I'm very focused on future goals. But right now all I'm focused on is the here and now and literally what's in front of me, the tasks that require my attention before this cycle comes to an end.

It's a bit like how at the end of the day you might finish things up before you turn your computer off or before you get into bed. That's where I am at. So it's day 25 of my cycle and I have been sitting on my bed with my laptop doing some work today, just balanced on a yoga bolster, I mean my laptop, not me. I haven't been balancing on a yoga bolster. Because this is when I like to be pottering around and just getting bits and pieces sorted, whether that's in my business, my home or even just the stuff that's rolling around my head.

I like to use this time in my cycle to come to a point of completion somehow. So my period is likely to start in the next few days. And my sense is that progesterone is already starting to decrease because my cervical fluid has gone from being quite tacky and quick to dry to a bit egg whitey and stretchy, which we commonly talk about in the run up to ovulation as that's when oestrogen is peaking and we get fertile quality cervical fluid, that can resemble egg whites.

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But you can also get it in the second half of the cycle depending on what oestrogen and progesterone are up to and their relationship to one another. And I would say that my progesterone production isn't what it used to be. I am 40 so I'm in the age range where the hormonal landscape starts to shift and progesterone levels start to lower. And what I've been noticing is that the quality of my cervical fluid is different towards the end of my cycle these days which gives me just another heads up that my period is close to starting.

So before we crack on with today's topic which I'm very excited about I want to take a moment with you to celebrate that my book *Perimenopause Power* got into the top 10 of all books on Amazon recently. Isn't that incredible? Thank you to all of you who have bought it, especially those of you who have bought multiple copies for your friends and things and also to all of you who have taken the time to rate and review it because you're all helping to spread the word which is exactly what we want. We all need this information.

And I just love that a book about perimenopause got into the top 10, that my friends is what we call progress. Okay, so the past few episodes we've been talking about autism and PMDD. And the response from you all has been incredible, very touching and I really appreciate your feedback. I'm glad you found these episodes so helpful.

I was going to talk with you about something different this week but as I was reflecting on the past few episodes and the feedback that I've had from all of you, I had this idea for something else so that's what we're going with because I just thought it would be a helpful follow-on for anyone who is or has been or has received a diagnosis of any kind. And I'm going to be talking about the process that I have observed in my clients and also that I have experienced.

So I know it's going to ring true for many of you because there are highs and lows to receiving a diagnosis, it's not always a straightforward process. And of course it's going to vary between people depending on lots of

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things, including their mindset. And also someone's approach to receiving a diagnosis, one person might be thrilled because they're just so happy to find out that there's actually a reason why they feel a certain way.

And another person might be devastated because they're thinking about what this means for their life in a kind of negative way. I mean it might be realistic as well but they're looking at it through that lens. But what I see happening is that each individual who receives a diagnosis goes on a journey which includes some highs and it includes some lows. And so that's what I'm going to be walking you through today.

As I was considering this topic and making notes for this episode I realised that there are seven stages to getting a diagnosis and you might not go through all of them and you might have a different experience. You might not experience them in this particular order. And you also might go back and forth with them because processes like these are rarely linear. But for me I could see that there are seven distinct stages. So here they are.

The first stage is pre realisation. So at this stage you just don't know. You know there's something going on but you don't know what it is. You are having an experience that you're trying to make sense of but you don't have a way to do that because you need information. Or you might have an inkling or a suspicion but are still kind of unsure. So let's say you don't know anything about PMDD but you have a really intense experience of the second half of your cycle. You have severe mood changes that impact on your personal and professional life.

Now, if you don't know anything about PMDD and maybe at this point you haven't actually realised that your mood changes are related to where you are in your cycle you're probably thinking why do I feel great one week and so awful the next? What the fuck is wrong with me? Have I got bipolar disorder because PMDD can be diagnosed or misdiagnosed as rapid cycling bipolar disorder?

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You probably spend a lot of time assessing and questioning your behaviour and ruminating on interactions with others. And really thinking about why sometimes things just don't bother you and other times the smallest comment destroys you seemingly without rhyme or reason. But then you come across a post on Instagram that mentions it or you read about it in one of my books. And suddenly your brain is lighting up and you're thinking this is me. This is me. This explains everything.

Or if you have a bunch of weird apparently unrelated symptoms and you come across a list of them all in one place. And you realise that they're common in people who have an underactive thyroid, or histamine intolerance, or who are going through perimenopause. And suddenly you're thinking this makes so much sense. So this is stage two, realisation. And this stage feels pretty good because when you're thinking this explains everything then that thought will create an emotion such as relief or gratitude, something along those lines.

And it's like going to an ophthalmologist and they put a corrective lens in those funny glasses that they have you wear. And suddenly you can read the bottom line of the chart or you can see all of the chart. Another word for this stage could be validation because through naming your experience it is brought into focus. And what you've been going through is validated by the diagnosis. You might not think you need that and some of you won't. But it can be hugely positive for someone to say, "Yes, this is real. This is what it is. I'm sorry that it's taken so long to get to this point."

And I say this because so often our experiences are discounted and we're made to believe that it's all in our heads. It's like the impact of the hysterical woman just lives on, particularly when it comes to reproductive health. And so even though we know in our bones or we know in our wombs that something isn't right we can end up doubting ourselves, patriarchy is extremely adept at causing distrust of ourselves. So this stage is quite a nice one to be in I'd say but it's often short lived because what usually follows is outrage which is stage three.

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So this is when you'll be asking why didn't I know about this sooner? Why did nobody tell me about this kind of thing? Why hasn't this been picked up until now? So although these are questions and they're important ones, they come from thoughts that you're having such as it's appalling that I've only been told about this now. And someone should have picked this up sooner, and I've been struggling for eight years and only getting a diagnosis now.

By the way, that's the average age for someone with endometriosis to get a diagnosis from the time that they first present with their symptoms. It's a long time. And clearly thoughts like these aren't going to be generating emotions such as the relief and gratitude that were there in the realisation stage. Instead they'll create emotions such as anger, disbelief, frustration, annoyance, disgust, those kinds of ones, the fun ones.

And if in your journey to receive a diagnosis you've been dismissed or ignored by a healthcare practitioner, or the healthcare system as a whole, or if your employer, your mates, your family have ignored or belittled what you've been going through then this stage might be significant for you. There can be a lot of emotions coming up to the surface. So this stage doesn't feel so great but it is important to acknowledge those thoughts and feelings.

And in my work I talk to my clients about how we always want to process emotion and then look at the thought that caused it. And then question if it's a thought that they want to keep. Is it helpful? Or do they want to think a different thought? And I think this is a good example of a time when you might not want to change the thought. It's going to depend of course on the individual.

But some people will be consumed by this stage, and the anger they feel and that's when I'd be looking at if someone has really let themselves feel the rage, and the disappointment, and the frustration of being let down by an education system and a healthcare system that is lacking when it comes to reproductive health and to help them do that. This is also when

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something can initially feel appropriate and helpful to someone but with time that may shift and they might realise that actually being here isn't serving them anymore.

Now, this next stage is the one, yeah, it's the only one that I suggest that you get out of as quickly as possible. So listen up if you've drifted off or are multitasking because this one is important. So stage four is confusion, so you've been diagnosed, you've gone through the initial emotional highs and lows probably several times. And now you're thinking, well, what do I do? And that's a great question to be asking. But it can tip over into I don't know what to do. Or I don't know who to trust. I don't know what recommendations to follow. Everyone's advice is so different.

And because those are your thoughts you feel confused. Please be onto yourself and notice if you're doing this. And don't hang out here for long because confusion is never helpful. It doesn't get us anywhere and we can get stuck in confusion. Now, you might not know what to do, I get that. But you could choose to feel curious instead of confused, that would be far more helpful. Or you could be decisive and start taking action of some kind.

That might look like going to a reputable website like Endometriosis UK or The Eve Appeal or the Vaginismus Network. Or it could be asking friends for recommendations or asking your GP to refer you to a specialist service. Don't let yourself be confused. You don't have to have all the answers or a clear defined path in front of you, just take that first step.

Now, possibly around the same time as this you could find yourself in stage five which is despair. Perhaps you realise that your treatment strategies are going to be quite involved or more involved than you thought they would be, or long term strategies, or expensive ones, or that you're going to have to make some decisions and make some changes that you'd rather not do. And that's completely understandable. This is part of the process and is part and parcel with owning a brain.

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And depending on your diagnosis and what the likely trajectory of what that diagnosis can look like, depending on your particular needs as an individual, the colour of your skin, the country you live in and the healthcare system that you use, things like insurance and payments etc. Even down to the actual postcode that you live in, these things as well as plenty of others will all impact as well. And there might not be great options for you. There might not be any options available to you because of the condition you have or because certain medications and strategies aren't an option for you.

So in this phase you could find yourself thinking this is so hard, this isn't going to get any better. I remember this stage when I found out that I'm autistic. And how it showed up for me was that my brain was telling me that my son has inherited my genes. That my brain has fucked him up and that's not true at all on any level and every level by the way. But it's what I was thinking for a while so I was feeling despair, and shame, and disgust, and rage. And I was just bawling my eyes out a lot and punching the mattress a lot. I really went through it.

But I knew, I was kind of observing myself going through it and as I was going through it I knew that this was just part of the process. I didn't make it mean anything about me. I just let those thoughts be there. I let my emotions be there. And I let myself cry all the tears that I needed to. But after this hopefully comes hope.

So this is stage six. And whilst hope is not a strategy being able to see a bit of light between the clouds can be helpful. Perhaps you read about a type of medication or your doctor lets you know that the wait list for an investigation or surgery isn't so long after all. Or maybe a friend of yours tells you that dietary changes and supplements have made a massive difference for them. So then you start to feel hope because you're thinking things like, maybe this is going to help me or this could make a difference. So that's stage six.



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Stage seven is acceptance. And this is where things feel more settled. You might still swing into despair sometimes, or one of the other stages. But you're not swinging wildly into it. It's less pronounced because you're practicing being in acceptance. And I want to be clear that I don't mean you should just accept matters as in put up with shitty things, whether that's your own shitty thoughts, shitty behaviour of others or substandard medical care in any form.

But when you're accepting things you're acknowledging them, you're not resigning yourself to them and you're not necessarily liking your diagnosis either, though that is available as an option. I like that I'm autistic. It comes with challenges and frustrations but ultimately I like being autistic. But let's say you have endometriosis, or adenomyosis, or PCOS, then I'm guessing that given the choice you would rather not have them. So there are differences here. But you can accept things and still want them to change.

That's the seven stages that I've come up with, one pre realisation, two realisation, three outrage, four confusion, five despair, six hope and seven acceptance. Your experience will take on things may be different. But I hope that either way this has been helpful for you to hear. Allow yourself to be in each stage apart from the confusion one and know that you're probably going to move back and forth through them. It's unlikely to be neat and linear.

Okay my lovelies, I really loved putting this episode together for you. If it's helped you I would love it if you took a moment to rate and review the podcast so that others can find it more easily. Have a fantastic week and I'll catch you next time.

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](http://maisiehill.com) for more.