HOUSE OF COMMONS

Women and Equalities Committee

Oral evidence: Women's reproductive health, HC 1773

Wednesday 18 October 2023

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Watch the meeting

Members present: Caroline Nokes (Chair); Elliot Colburn; Kim Johnson; Lia Nici and Kirsten Oswald.

Questions 1 - 46

Witnesses

I: Naga Munchetty, broadcaster and journalist; Vicky Pattison, broadcaster and TV personality.

Examination of witnesses

Witnesses: Naga Munchetty and Vicky Pattison.

Q1 **Chair:** Good morning. Welcome to the Women and Equalities Committee and our first evidence session into women's reproductive health.

I thank both our witnesses, Naga Munchetty and Vicky Pattison, for being here this morning. Committee members will ask you questions in turn. Hopefully, we will make it clear which one of you the question is being addressed to, but if at any point there is anything you wish to chip in with, please do indicate and I will try to bring you in at the appropriate time.

I will start. There is a real challenge in enabling and encouraging people to talk about reproductive health: it is a massive area of silence, misunderstanding, and general lack of knowledge. Can I come to you first, Naga, and ask you a bit about your experience of how challenging it was to speak out about your symptoms and, indeed, what those symptoms were?

Naga Munchetty: There are two parts to me speaking up about my personal health on Radio 5 Live.

First was when I had the coil fitted—which was a traumatic experience—and we were talking about pain relief. I had seen a piece by Caitlin Moran about her fitting and I was talking to my team about it in our morning meeting, ranting about how awful it is that women's pain is ignored. The team picked up on this and we decided to talk about it.

As journalists, we are never the story, or we never aim to be the story; we are there to get the story out of people like you, Caroline, or, indeed, Vicky for example. So I was very reticent about talking about my personal experience, but the reaction from our audience was overwhelming because it was a time when women were told to put up with it. It was normal; pain was normal, discomfort was normal, periods were normal, and anxiety was normal. I went for my coil fitting in my gym gear thinking I would be in the gym straight after, and I screamed the place down. That was about two and a half years ago.

The reaction to me sharing my story was overwhelming, to be completely honest, and we made a change to NICE guidelines for pain relief to be offered to women because I had been told, "Take a couple of paracetamol, maybe a couple of ibuprofen."

Then, last November, I bled for 30 days non-stop. In fact, I have just looked back at my diary, and I bled for a total of 14 out of 15 weeks because my adenomyosis, which was then undiagnosed, was flaring up. I had had extreme pain to the point that an ambulance had been called.

I had a period of about 12 days when I had unnaturally heavy bleeding for that continuous amount of time. Most women know that when you

have a period, be it for three or 11 days, you bleed heavily on the first few days and then it eases off, but this was constant and worrying.

The process of being diagnosed with adenomyosis—not that there is a cure or treatment even if you are diagnosed anyway—was infuriating. I pride myself on being someone who does not take no for an answer. I pride myself on asking questions and doing my research, and I am very fortunate to have the tools to be able to do that, which not all women do, and not all partners of women do. The whole process was so frustrating that, again, I spoke about it on the radio: we did a whole programme on it. It was actually after a weekend when my husband had had to call an ambulance because he had never seen me in pain like that. The response was overwhelming, and I spoke to women who had been crippled for years. One woman could not get onto the floor to play with her child because she was in such pain, to the point that her child never asked her to play, and she felt like a failure as a mother, as a woman, and as a partner.

When you hear stories like that—not stories, when you hear experiences like that, it negates the fear of being seen as someone with an ego or as someone who has a story that they want to be heard for attention, because it was not about that.

Again, we have changed the NHS England website. NHS Scotland had it, but there was no mention on NHS England: its reference to adenomyosis—which I knew nothing about before I was diagnosed—had a link you clicked on and it took you straight to the hysterectomy page. It has changed now, but there is the frustration of being told to have a hysterectomy. I have a friend, who is 28, who has been diagnosed with adenomyosis. She has not had children but has been offered a hysterectomy. You can have a hysterectomy or you are told to go on the pill, put up with it, or have the coil. Those are your options and if they do not work for you then suck it up. That is why I speak about it.

Q2 **Chair:** I appreciate that some of this is really, really personal, but can I just ask, how long had you been suffering before it got to the point of calling an ambulance?

Naga Munchetty: I started my periods when I was 15 and I would bleed for 11 or 12 days; I would say about eight or nine of them were very heavy. I would throw up on the first day, at least once or twice—I would be wrapped around a toilet—and I would pass out at least once or twice but I would still go to school. I was very good at school; I was very academic and musical. That lasted throughout the whole of my life. Whenever I went to the doctor, I was told it was normal. I would still go to work, and I have quite a high-profile job. I would not sleep because I would have to set an alarm, say for 2 am, every four hours. I would be lying on a towel and I would have a heavy sanitary towel and a super plus tampon in, and I would set an alarm to change. It made relationships difficult: I had to have very understanding partners. I would worry about what I wore, particularly when I was in front of the camera

because of leaking, but my adenomyosis was not diagnosed until I was 47.

Q3 **Chair:** Thirty two years?

Naga Munchetty: Yes.

Q4 **Chair:** How much of that time were you told that this was just a period, this was normal?

Naga Munchetty: Thirty two years.

Q5 **Chair:** Have your symptoms changed since you have gotten older?

***Naga Munchetty*:** No, they were constant. They have always been like that, but I was put on the Depo injection for seven years. I had been on the pill, which had not really helped. The bleeding was still bad, but the pain was less. I then got put on the Depo and the bleeding stopped. It worked for me, so I feel I was incredibly lucky which is madness in itself, to feel lucky that a hormone designed for a woman actually works, but I have spoken to women who felt they were losing their minds while being on the Depo.

I was taken off the Depo in my early 40s due to concerns about osteoporosis because you are only supposed to be on it for a certain amount of time. I was given the coil, which was horrendous for me although it has worked brilliantly for other women, and then I was told there was nothing else. So I had nothing and just had periods with the same pain. When the adenomyosis was diagnosed last November, I was put on the mini-pill and my bleeding stopped three months ago. It was not constant, but I have not bled for three months, which is amazing, and my pain levels are much lower.

Q6 **Chair:** Vicky, a broadly similar question, but how old were you when you first started suffering from your symptoms?

Vicky Pattison: I had what I would describe as relatively normal PMS and period symptoms until I was in my late 20s and early 30s when things really started to kick up a notch. I struggled loads once I hit 30. I went to see various doctors—I have lived in Newcastle, I have lived down south, so all across the country—and I was always told exactly the same thing, "This is PMS. This is what women go through. Every other woman in the world is dealing with this."

I already felt very silly for going anyway, but I felt even more invalidated then, so I reasoned with myself that I would get on with it. I cannot tell you how many times I got told, "Oh, they will get worse as you get older, this is just natural," and you believe it. You absolutely believe it, and you believe that you are weak, that you cannot cope with what every other woman is coping with. On top of feeling rubbish for 10 days of the month, if not two weeks, which is what PMDD does, you now also feel embarrassed that you are not as strong as everybody else.

When I was about 33—I am 36 next month—I started persistently going, and I started talking about it on social media as well because I just felt that I could not be the only person going through this. It was through the online community that I first heard of PMDD: women saying, "What you're describing as PMS symptoms is not PMS, it's PMDD. Look into it." So I did; I started looking into it myself. It took me a while to get the courage up to actually go again, and when I went I was told exactly the same thing, "PMS symptoms get worse as you get older," and was asked if I had tried a certain pill.

For 10 days of the month I was feeling really fatigued, suffering with insomnia, having crippling anxiety, terrible self-doubt, no passion for the things that I normally loved, hated me fella, and almost, in some of the darker moments, thought the world would be better without us in it. I just did not feel good enough.

In the end I went private this year and I could have kicked myself for taking so long to go but, after having been told there was nothing wrong with us for so long, I felt stupid for wasting everybody's time. When I walked in and explained how I was feeling, what I was suffering with, the doctor said instantly, "It sounds like you have PMDD." I proper just sobbed, like I broke my heart, because I felt, for the first time, like somebody actually listened and took us seriously. Now I am working towards finding something that will help alleviate some of the symptoms. It is not a one-size-fits-all thing—everybody is different—and I suppose it is going to be quite a bit of a journey, but, for the first time in probably about five or six years, I am hopeful.

Q7 **Chair:** You have used the phrase that you felt stupid, that you felt you were being a nuisance: how much of a challenge was it to feel assertive enough to go into the doctor and say, "This is what is wrong with me," and waiting for them to agree with you?

Vicky Pattison: I felt ashamed of myself by the end, that I was making such a big deal of something that I had been told every other woman in the world was dealing with. Actually, PMDD affects 10% of women. It could be loads more because it is seriously undiagnosed, and you can see why. I know I felt that I was wasting the NHS's time: that is where I got to. When I was eventually paying to see somebody, I felt like I had more of a right to sit there and speak, and that is mental. That is not right. I felt stupid and ashamed, like I was wasting everybody's time, I felt weak, and I felt that way for years. So, this year it was lovely to finally feel listened to.

Q8 **Chair:** Do you think there is a challenge with the narrative that this is just a period, this is what every woman goes through? Is there a lack of awareness of what the parameters of normal are? Naga, did you want to come in?

Naga Munchetty: Yes. I completely understand where Vicky is coming from, having been told from the age of 15 just, "Suck it up", "You're

normal," and "Everyone goes through this," and especially to be told that by male doctors who have never experienced a period, and then by female doctors who had not experienced period pain.

I never had PMS, I never had any anxiety, I just had that fatigue, that overwhelming fatigue where you just cannot move; you try to pull yourself out of a sleep and you do not understand why you are so tired. I never had the anxiety, thankfully, but it is just that constant, "You're fine. Everyone else is putting up with this, why can't you?" You end up saying, "I have a really high pain threshold, you could punch me in the face and I'll stay standing." You resort to that kind of comparison just to show that you are physically and mentally strong. You just end up fighting harder than you should have to.

I went through the same thing: I went private. I was fortunate enough to be able to have private health care and that was the only time I felt I could sit there and take time to force an issue, force understanding, and force explanations from my gynaecologist and not feel bad that I was taking up more than 10 minutes of my GP's time because there was a queue of people in the waiting room or feel that I was indulging myself as if I was something special. We are all special, and we all deserve to be treated well so we can contribute to society and our jobs.

Q9 **Chair:** Vicky, did fertility play a role in your diagnosis, eventually?

Vicky Pattison: No, it did not. I have chosen to freeze my eggs this year, but that was a completely separate issue. I have been on various different contraceptions over the years. Like Naga, I have tried various different things to help make me feel better. Nothing has quite worked but, no, fertility has not played a part in this, although it might for some other women.

Q10 **Kim Johnson:** Good morning, Vicky and Naga. I just want to say thank you for being here today and providing your personal testimonies. You are very brave.

I have a couple of questions about treatment. Naga, you have already spoken about some options that were available to you, and I wanted to know which of those were the most successful?

Naga Munchetty: My adenomyosis was not diagnosed until November last year. They had no idea why the pain was happening. They said that the extreme pain, the constant pain I had, was because the endometriosis, which goes outside the uterus, splits and tears the muscles when you have a cycle was the pain I was feeling. You can feel it in your thighs, your lower back and in the muscles around your uterus. It is stopped by stopping the hormonal cycle, hence the pill.

When there was pain around my ovaries, the other treatment I was offered was a laparoscopy, but I was told there was a 5% to 10% chance that something else was wrong: why would I take eight days off work to have to be cut open again? So I refused that. As for a hysterectomy, why

on earth would I have a hysterectomy at my age, when I am not even perimenopausal yet? I did not want to go through all that.

I do not want children, and that is the other option that people are told, so the pill was the only thing. I was literally told, "Suck it and see. We'll give it a go, see if it works." It took six months before the bleeding stopped, and then, as I said, three months ago it stopped.

Q11 **Kim Johnson:** You have both mentioned going through the NHS and then having to resort to going private. I just wanted to explore why you had to do that, and the impact that it has on other women. Not all women have those opportunities, do they?

Naga Munchetty: No, which is outrageous. There is a lack of specialism in the NHS because GPs are obviously stretched. When I spoke about adenomyosis on my Radio 5 Live programme, there were GPs who got in touch saying, "We've never heard of it. We have not been taught about it. We've heard of endometriosis, but not adenomyosis, and we do not know how to spot it or diagnose it." The only way you can see it is through ultrasound, and even then, I have had three ultrasounds and an MRI, and only one ultrasound specialist saw it, because they are not all trained adequately or in depth enough to spot it.

I was told I had it and shown the scans. The way it shows is because the muscles have split, you see tears, they almost look like Venetian blinds in the muscles, but then it was not spotted in the next ultrasound four weeks later, which is a nonsense. There is a lack of training, and a lack of awareness. I can only talk about adenomyosis and my experience, but to go private was the only way I could force the issue and say, "I want a different sonographer, a different ultrasound specialist, and I want more scans because I have private health insurance and I can afford it." Of course, not everyone has that.

Q12 **Kim Johnson:** In terms of going through this process, Vicky, were there any support groups available online that you were able to access to get more information? As you pointed out, information about your diagnosis is quite limited. I was aware of PMS and endometriosis before this inquiry.

Vicky Pattison: Honestly, PMDD gets zero sunlight. Not a lot of people know about it or understand it. It is commonly misdiagnosed in women as ADHD or depression. The first thing I was offered was antidepressants. I am not depressed; I am happy, I am strong, I am mentally well, I have a good life. It is not that I am depressed; I have PMDD. The fact that was offered as a first port of call was incredibly frustrating.

If it was not for online forums, Instagram groups, websites, and things like that which provided me with information, helped me self-diagnose, helped me work out what was going on and provided me with support, I do not think I would have got to where I am. I do not think I would have

had the confidence to go private and insist that there was something wrong, because, like I say, I had been invalidated so many times before.

Kim Johnson: Many women are in the same position as well. Thank you both so much for answering my questions.

Q13 **Chair:** Thank you. Can I ask a couple of follow-up questions about treatment? A constituent of mine contacted me about her experiences, and she has emphasised that she felt she was treated that way because she was a woman, that it was a very patronising, "Go away little woman; this is normal," from pretty much every tier. Is that both of your experience?

Naga Munchetty: I have had that experience all my life, whenever I have seen a GP: from having thrush and it recurring and a male GP blaming me, blaming my sexual activity, my hygiene, my hormones—just all nonsense. I remember it was only when I saw a female GP, after six months of agony and no sleep, she said, "You can just take this pill," and it got rid of it. He had refused to even tell me about it. I have had this all my life.

Vicky Pattison: I think with women's health in particular—we are reproductive, we are sexual, everything—it is given less gravity because we are just expected to get on with it, to suffer it, to be brave, whatever it is, be very British, I suppose, but I feel it has to change.

Naga Munchetty: Can I just do a follow-up? I spoke to Dame Lesley Regan—I have the transcript with me—and I said, "Is it fair to say the NHS is failing women at this moment in time?" She said, "Yes, I think that's fair," and, "The reason I'm doing this… I don't think women have got a fair deal."

Chair: That is from the women's health ambassador?

Naga Munchetty: Yes.

Q14 **Chair:** The other point my constituent made was that she felt that there was an onus on her—Vicky, you have referred to this—to do the research herself to find out what treatments might be available for her condition. She also spoke of a particular type of pill that had worked for her being withdrawn from the market because it was a high oestrogen dose.

Have either of you experienced that: a treatment that had been effective is suddenly no longer available?

Vicky Pattison: I am really early; I was only diagnosed about three months ago. It has been a fight to get here, but I am only about three months in to trying to find out what works for me. I am still on my first "suck it and see" experiment, so I cannot speak on that.

Naga Munchetty: I was on the Depo, which worked brilliantly for me. That was withdrawn because I reached my 40s and there were concerns about osteoporosis, not that I had any signs, but they said, "This is one

of the typical consequences of taking it." I was in floods of tears. I was panicked. I thought, "I can't go back to the life I used to have," when I used to have periods every three weeks and bleed for 11 days. It was, "Tough, you'll find something that works."

Chair: "You'll find something that works," not, "We'll find something that works"! Thank you.

Q15 **Elliot Colburn:** Thank you both for coming in. Vicky, could I come to you first? You have mentioned a little about this already, but could you elaborate on how the lack of a quick diagnosis has affected you in your personal life, in your relationships with other people, and, if you had received a different treatment or faster diagnosis, how you feel that would have improved your life if it had been available to you?

Vicky Pattison: I read this really good quote that says, "PMDD is like building a sandcastle every month. A sandcastle of good habits, of positive vibes, and feeling strong, feeling great, only to have the waves come, crash into it, and destroy it every month." That is how I feel. I can go to the gym, I can eat right, I can work hard, and I can nurture my relationships. I can be this bright, best shiny version of myself for about two and a half weeks, but no matter how hard I try, once I reach that part of my cycle, there is nothing I can do.

I am short-tempered, I am irritable, I am exhausted beyond belief, I can sleep anywhere—anywhere. But once my time hits: insomnia. My personal relationships have suffered so much. It is a good thing you mentioned having understanding partners: my current partner is so understanding, and I have to tell him, I have to sit down and say, "I can feel what is coming," and I have to explain, "I'm really sorry about who I'm going to be for the next 10 days."

It is just so counterproductive to having a healthy relationship, to having a successful career, to being happy, because for 10 days of the month, I do not recognise myself.

Q16 **Elliot Colburn:** You mentioned your career, and that is another element. Have you ever had to take time off work? How has it affected you and your employment, and what have employers been like? Have they ever challenged you or been difficult?

Vicky Pattison: I am really lucky in the job I have. It is not exactly what you would describe as normal, and because I am really vocal on my platforms, most people are aware of what I am going through. Most people have been really sensitive, but there is only so much information out there, there is only so much people can understand, there is only so much sympathy someone can give when they do not know what you are going through.

A lot of the time, people say they understand and act like they are giving us sympathy or whatever, but they think I am making a big deal of nothing, which I can feel. So, I try to be strong, I try to put my best foot

forward and go to work and be the best version of me but, inside, it is horrendous.

Q17 **Elliot Colburn:** Thank you, Vicky.

Naga, the same questions to you: how has it impacted your relationships with other people, but also what have your employers been like throughout your career, when trying to make them understand?

Naga Munchetty: It is quite intimidating if you start a new relationship and you are in bed with your partner and you know you are about to start your period and you know you are going to be moaning, curled in a ball, worried about bleeding, getting up in the night, sweating because you are in so much pain, and expecting them to understand it. As I said earlier, I have been very lucky in my life in having very understanding partners.

I never said anything at school. I worried about bleeding through my school uniform, and if it happened, I would always wear an extra pair of shorts underneath my skirt or two pairs of tights.

I never said anything to my employers. I would be dosed up on painkillers for at least 10, 11 days of the month. I sometimes still am. You learn to take two paracetamol and then two hours later take two Nurofen and then two paracetamol. I tend to exceed what I should take. You time your painkillers. You become almost paranoid about when you take your toilet breaks. I am on air for four hours sometimes, and we have what we call the regional opts: it is a two and a half minute or three minute break and I will make sure that in the half-hour before, I flag that I go to the toilet, and no one can be in that toilet when I go. I will be grumpy if someone is in that toilet because I have to go.

Obviously in the last three months I have not bled as much, but it does affect your bladder as well. When you start your period, you have immense pressure on your bladder from a swollen uterus, and you are paranoid about having bled through your clothes.

Q18 **Elliot Colburn:** You mentioned going back to school, wearing extra pairs of shorts or tights and things like that. In terms of the additional pressures on your day-to-day life of having to buy extra clothes, extra products, whatever it might be, have you found that has impacted on your life as well, not just in your relationships and work but in terms of cost? Naga, if I could start with you.

Naga Munchetty: I have been fortunate enough not to notice because I would use my PE shorts as extra shorts and then you just wash them more. You just make sure they are in the wash.

Every woman knows you have period knickers that you wear at a certain time. You make sure they are all ready. There are some great products now, proper period knickers that you can wear so you are not bulky and you are not as paranoid.

Clothing wise, I will make sure I wear dark clothes when I am on set on "Breakfast", or would have done, just in case, and looser clothes as well. I love clothes, but I would not be wearing a tighter fitted dress if I was on my period, I would make sure I wore wider trousers. I am wearing a jumpsuit today, for example, but I would not have worn a jumpsuit because I would need to whip out and whip back in. But those are tiny things. Yes, they are there, but I think it feels normal, does it not?

Vicky Pattison: Yes, you normalise it.

Naga Munchetty: We normalise it. That is just life. Poor us. Poor me. "Oh she has to decide between a jumpsuit and a pair of trousers, oh poor Naga." It is a first-world problem in some ways, but it all contributes to the anxiety.

Elliot Colburn: Absolutely. Vicky, same question to you.

Vicky Pattison: It has cost me a fortune in Dairy Milk. *[Laughter.]*

Because PMDD is predominantly a mental health struggle rather than physical, the cost for me has always been the quality of my life. Ten days where you just do not want to get off the sofa, where you cannot bring yourself to talk to anybody, where you feel like the world would be a better place without you in it.

Listening to Naga talk about how she dealt with this when she was younger, I was so old when I realised what was going on with me, I was in my 30s.

I have had messages from women telling me their daughters are 17 and they are fighting to get diagnosed. The thought of dealing with this, when you are also dealing with all those hormones and all those feelings that you have when you are 17, is heartbreaking. There needs to be better support for them.

Naga Munchetty: At Radio 5 Live we had a mother of a 13-year-old get in touch. Her daughter had ridiculously heavy periods, was having to take time off school, with very similar symptoms to me, bleeding very heavily, wrapped around a toilet, throwing up, passing out, was missing school even though she was an A student, and the authorities were getting involved because of absenteeism. That is the lack of sympathy or understanding in the system, and that is for a 13-year-old girl.

Elliot Colburn: Thank you both so much for sharing those experiences with us. Chair, I will pass back to you.

Q19 **Chair:** I have a question for you, Vicky. It is affecting your mental health, and you get prescribed antidepressants, is there also a stigma that comes alongside that, that people are saying, "This has nothing to do with her cycle. This is a mental health condition"?

Vicky Pattison: There is a lot of stigma surrounding it. When I first spoke out about it on Instagram, I had messages from people—women—saying, "Here we go, another celeb creating an illness so she can stay relevant." I cannot speak for anybody else, but the thought that you would fabricate or create something to stay relevant is insane to me. The thought that I would complain every month like clockwork and it all be fabricated is just mental, but people do not understand enough about it at all, and it is not just the general public, it is GPs as well.

I am not depressed, and maybe I have a personal issue with accepting antidepressants when I am not depressed, but I think that is fair. There is something else wrong with me, and I want it treated. I do not think that is too much to ask.

Chair: It is not.

Q20 **Kirsten Oswald:** Thanks very much both for coming in to speak to us. I am really grateful. I always think the silence around women's reproductive health is a bit like a black hole. It is a real problem for women of all ages, so it is very helpful that you have been able to come in and speak to us.

Vicky, you spoke about women sharing information online with each other as one way that you could try to access information. Do you think there is enough information and support for women to understand their gynaecological health and their menstrual cycle so that they can advocate for themselves on these issues?

Vicky Pattison: There is loads of support and information out there, but if you are someone like me who gets incredibly anxious and nervous—which is heightened by the PMDD—and it is not coming from a regulated, official place, you panic. I panicked: was I getting the right information? Was I speaking to the right people? I would say there has to be something that comes from a real organisation, a medical professional, something that gives you confidence in what you are reading, rather than something that is just run by people who are also suffering, because that is personal experience. My experience with PMDD might be very different to somebody else's, so even though I found it helpful and I found the support lovely, I would appreciate there being more out there from professional spaces.

Q21 **Kirsten Oswald:** What would you look for in that context? What would be better than the chasm that is there at the moment?

Vicky Pattison: When you go on things like NHS websites, it is basically just described as heightened PMS, which is not really accurate or fair, and again, it is invalidating. There needs to be more information. I went on a website where there was a quiz: you answer some questions, and if you get to the bottom, you have PMDD. Why can that not be on a Government-run website? Why can that not be something in a more medical space? Why does it have to be someone suffering who has

created that? I think there needs to be more official avenues for people suffering.

Naga Munchetty: Sorry to interrupt, but I also think that it is not just one condition that we have; often women have multiple conditions. It would be good if there was a flowchart that you started with: do you have this, do you have this, do you have this, and do you have this? Why is it so hard to put something like that down? All these symptoms are available, and all our experiences are available, but we are shunned off into a corner and told, "Try this pill, or try this medicine and you'll be all right. Suck it and see."

There are so many experiences. The knowledge is there, the information is there, and no one is taking what we are saying to them and putting it down on paper or putting it down on a website so we have tools. We are happy to advocate for ourselves. We are happy to do the research. We are happy to care about our own health rather than just be told to go away or told, "It's in your head," or made to feel as if we are a problem. We always feel as if we are a problem. We always feel that we have to push and push before we are heard.

Q22 **Kirsten Oswald:** Naga, do you think that it is amplified when, as you have said, there may be more than one issue that is affecting a woman at any one time? That is not uncommon.

Naga Munchetty: Yes, but you are lucky if you get one issue dealt with well, and if you go with another, you are trouble then. You are a bit of a pain in the bum.

Q23 **Kirsten Oswald:** Do you think that healthcare professionals and research bodies are doing enough to understand women's bodies, to make sure that women are going to be able to receive appropriate treatment, and to ensure that the speed of treatment is appropriate to meet women's needs?

Naga Munchetty: You have two women in front of you who have spent years trying to be diagnosed. I am not an expert on what research bodies do, and nor would I like to say, "This body is not doing enough," or whatever. I have spoken to hundreds of women, I am sure you have too, who have been undiagnosed, and that number is tiny. They are the ones who are willing to speak up.

Q24 **Kirsten Oswald:** Can I ask you the same question, Vicky, in terms of the availability of research and how that impacts on the treatment that you may be offered?

Vicky Pattison: I have to obviously echo Naga's sentiments. It is woefully misunderstood, and there is such an ignorance surrounding it and loads of stigma as well. I think because of all that, women are then ashamed to talk about it. We are just perpetuating this cycle, this horrible culture. Every time a woman does stand up, pops her head up, she gets criticised, called a troublemaker, and it is said she is just trying to make

up something to stay relevant. It is really hard for women to win, and I think if people within the medical profession understood more, then we would not have to fight as hard, and we would not have to feel like a nuisance.

Q25 **Kirsten Oswald:** Do you think that medical professionals themselves are doing enough to understand women's reproductive health, so that they are then able to respond to women's needs?

Vicky Pattison: I can only speak about my experience, and I feel like I was failed, so, no. That is my personal experience.

Naga Munchetty: Until I went private and pushed and pushed my gynaecologist—who was male—to listen to me, it would have been very easy for me to be ignored, pushed aside and left to deal with things on my own.

Kirsten Oswald: Thank you both very much.

Q26 **Lia Nici:** It is fantastic for you to talk about these issues, because we have had discussions here about how women's conversations, as you have illustrated, are actually ignored, or women are told that they are not relevant. Thank you for talking about your experiences and the battles that you are constantly having. I know as an older woman that, sadly, everything you are talking about, we as women talk about all the time. This is not unusual, is it?

Naga, to you first, what do you think is fundamentally going wrong? Do you think there is a male bias in how doctors and specialists are being trained? What do we need to start to do which will mean that the majority of the population, which is women, are actually going to be dealt with properly and appropriately and get a quick diagnosis?

Naga Munchetty: I do not know the statistics for this, but if I have had more than one GP get in touch with me on the programme and say, "I have not heard of adenomyosis," then there is something seriously wrong in the training, is there not? Endometriosis has only just started to be spoken about. My colleague, Emma Barnett, did a whole load of stuff on the Radio 5 Live programme which I took over. She has spoken about and written a book about it. That has been spoken about, and that veil of shame is finally being lifted, but if a GP is saying they have not heard of adenomyosis and is having to look it up, and the NHS website directs you straight to a hysterectomy, that is evidence enough, is it not, and that is just one condition.

Heavy bleeding when you have a period is not acceptable. I will not say it is not normal, because so many women have it, but it is not something that we should be told to put up with. Why is more not being done about it than us just being told to get on with it, or, "You're normal"? Being told I am normal when I am in pain, and my life is being disrupted, is not helpful. That does not help me; that gaslights me. I think that is evidence enough that there is not enough training. There is not enough focus in

the medical profession on women and giving us the tools, or having the medical research, to help us live our lives as we should be able to: anxiety free and pain free.

Q27 **Lia Nici:** I quite often feel sorry for GPs, because they are the jack of all trades, are they not? There are so many conditions out there, and they cannot know everything, but it always seems that they know less about female medical problems than perhaps they do about male ones. Maybe that is being unfair, but that is GPs: they are general, and they have to try to do detective work on what patients present.

Naga Munchetty: In a very limited time as well.

Lia Nici: Yes. What do you think about specialists? Vicky, if you want to take part in these conversations as well, where are we with specialists? You have both had to go privately to get this started. Is there a big difference between specialists that are NHS trained, or do you think it is an NHS/private issue, or do you think even specialist gynaecologists are not being taught or trained in the breadth of things that they need to be trained in?

Vicky Pattison: I feel like it is dead illuminating that I said exactly the same thing to lots of NHS GPs over and over again, and was told every time, "We could change your contraception, but it is just normal. Every woman is going through this. You just have to suck it up." Then I spoke about it on social media, and normal women told me, "Oh, it sounds like you have PMDD." I do not understand how a normal woman with no professional training can diagnose me, just after hearing what I was suffering with, and a GP cannot, when regardless of how broad everything they are expected to learn is, in medicine, diagnosis is what they are meant to do. After feeling ignored and invalidated by the NHS, I went private straight away.

Q28 **Lia Nici:** Was either of you referred by NHS GPs at all?

Vicky Pattison: No.

Naga Munchetty: My GP did specialise in women's reproductive health, but she was the one who said to me, "The system is such that if you have private healthcare, go and get this seen to privately," because of the waiting lists. The time and the resources were such that I would be much better off going private and having a gynaecologist look at me within a week. I had been bleeding heavily for nearly two weeks. I cannot wait. Perhaps many women in my position would have had to wait. I was fortunate enough not to have to wait. I was told to go and see someone privately.

Q29 **Lia Nici:** We talk about resources and we talk about the NHS and the issues that it has with waiting lists, but if a patient presents having been bleeding and in serious pain for several days or weeks, do you think there is an attitude problem? If I was presented with somebody who was saying, "I have been bleeding for two weeks and I am in terrible pain and

I do not know what to do," would I sit there and say, "Well, do you know what? I cannot really do anything. You are going to have to go and pay for somebody to do this"? Do you think there is an attitude problem here as well?

Naga Munchetty: No, not in my case. I will be completely fair to my GP: she looked at me, and her first concern was that it might be something cancerous or a physical problem with my uterus. She established that it was not that. I had a proper examination, and she said, "I do not think this is cancerous," because that was the concern. "I do not think this is damage to your uterus. I think this is something else, but for this to be investigated, do you have private health care? This will be quicker."

I am always reticent to make an appointment at the GP because it is so hard to get one sometimes. As soon as I said to the receptionist, "I have been bleeding for 12 or 13 days straight, and it is heavy bleeding," the response was, "Come in this afternoon." I know they are often seen as guard dogs, gatekeepers, so to speak—no disrespect to receptionists because they go through so much—but with the receptionist at my GP surgery, I got an appointment that afternoon.

Q30 **Lia Nici:** Vicky, it concerns me that the attitude of the first port of call—you being prescribed antidepressants—seems like something from the ark, and that is still happening. Again, surely that has to be an attitudinal problem of "hysterical woman." Do you feel that it was a matter of, "Give her some antidepressants and then she will go away"?

Vicky Pattison: A lot of the symptoms that you suffer with when you have PMDD echo those that people have when they are depressed, such as exhaustion, fatigue, a lack of joy in things that normally set your world on fire. It can be commonly misdiagnosed, so maybe it was an oversight, maybe it was a mistake. Maybe they thought they were doing their best. It felt like a cop-out. It felt like something to just get rid of us, to be honest. I do not know if it is a lack of understanding and education around the issues that women suffer or whether it was just complete disinterest. I cannot tell you.

Q31 **Lia Nici:** I have one last question. What do you believe needs to fundamentally change for us not to have to fight like you and spend years trying to get a diagnosis for female reproductive health issues?

Vicky Pattison: GPs, or anyone within the NHS, any medical professionals at all, need to start taking women seriously when they say something is wrong. I know lots of brilliant women, and I do not feel like we are the weaker sex at all. I feel like we are brilliant. I feel like we are strong and powerful, and we put up with a lot more than blokes do most of the time. If we have got ourselves up and gone into a doctor's, a hospital or whatever, to say something is wrong, the least people can do is listen to us and believe that there is something wrong.

The most important thing is to be taken seriously and to be validated. Then further on, there needs to be better knowledge and understanding

about issues that affect women, reproductive ones in particular, because there seems to be a severe lack of that.

Naga Munchetty: I agree with everything Vicky said, but I would add that when a woman says she is in pain, she has been in pain for a long time. She does not say it straight away; she puts up with it. When a woman is uncomfortable or worried about something, she does not say anything straight away; she puts up with it. She thinks it will go away, or she thinks she will deal with it later. When a woman calls a doctor, it has probably been weeks, or too long, before she has called a doctor; she does not want to bother the GP surgery because she is conscious of people who—in her mind—need real help.

When she screams or eventually asks her partner to call an ambulance, she is scared; she is petrified. When my husband had to call an ambulance, as I was passing out and screaming, I had to say to him, "You must not let them perform a hysterectomy on me," because, even though I am outspoken, I felt I would be overruled.

No woman says she is in pain unless she is in real pain. No woman says she is anxious unless she is really anxious. No woman wants to appear weak or appear incapable until she really is, until she cannot cope any more, and it should not be that way.

Q32 **Chair:** Thank you both; that is incredibly compelling. These may appear as completely random and disjointed questions that may just require yes or no answers, but it is picking up on everything that you have said.

Naga, you said that the NHS website had improved its information around adenomyosis, and, Vicky, you said there is no adequate information about PMDD on the NHS website. Should we, as a Committee, be asking the DHSC to make sure the NHS website is improved in the amount, quality, and perhaps ease of use of information around women's sexual and reproductive health?

Vicky Pattison: That would be my first port of call. The last time I went on, I thought it was woefully inadequate, so, yes, I would suggest more information around PMDD would be a great place to start.

Q33 **Chair:** It matters that the information is on a Government website that you can trust.

Vicky Pattison: It did to me, yes.

Chair: Thank you for that. Naga, you are quite content—

Naga Munchetty: Absolutely, same as Vicky.

Q34 **Chair:** Thank you. I wanted to ask a quick question about education in schools. Naga, your problems with very heavy, long periods started whilst you were still in school. Did you feel that any sort of RSHE education adequately addressed that, and should we be making sure that young women are conscious of what the parameters of normal might be?

Naga Munchetty: I am 48, so it was PSHE when I was being taught that at school. We were just told about the reproductive system; we were not told anything about pain, we were not told anything about flow. We were told you could have pads or tampons, and the only myth that was dispelled is that you can do PE while you are on your period. Once upon a time, you were told you could not do PE while you were on your period.

No, there was nothing. I do not know what it is like now; I do not know what the education is like now.

Vicky Pattison: I am a bit younger, but all I can remember is putting the condom on the cucumber; I do not know if you guys can remember that.

Naga Munchetty: We did not even do that.

Q35 **Chair:** So nothing adequate about periods at school.

Vicky Pattison: Nothing. It makes me really scared that these young girls have no clue about what is going to happen; would it be so hard for them to understand what they are about to deal with?

Naga Munchetty: Forewarned is forearmed.

Vicky Pattison: Exactly.

Q36 **Chair:** You have both been pretty clear that you think training for medical professionals needs to be improved; that is a quick yes.

Naga, can I just take you back? Your GP told you to go private when you had been bleeding for 12 or 13 days. At any point prior to that, in the 32 years you had been suffering, had there been any suggestion of a referral to a gynaecologist?

Naga Munchetty: No, I was deemed normal.

Q37 **Chair:** Do either of you have a view whether the establishment of women's health hubs is likely to improve the situation, or does that have to go hand in hand with better training?

Vicky Pattison: It is a great idea, but if you are going to pump money into something like that, the people who are there have to properly know what they are talking about. On its own, filling those with the type of GPs that I have come into contact with is not really going to help, but people with specialised knowledge in these areas would be great.

Naga Munchetty: I have spoken to Dame Lesley Regan about this. I am encouraged at the idea that it is a one-stop shop. She has this great analogy, which I am sure you have heard, but it is worth hearing. I think she was talking to Matt Hancock when he was Health Secretary; I cannot remember if it was him or if it was Jeremy Hunt, but one of them.

She said, "Imagine you are taking your car to the garage for an MOT—just an MOT—and you are told that your oil needs changing, your

balancing of your tyres is not quite right, and your carburettor is a problem. 'Well, we can have a look at the oil now, but you need to come back in six weeks to get your tyres balanced, and then another eight weeks when we can fit you in for the other problem.'" That is what it is like for women at this moment in time. I am sure you have heard this, but it is such a powerful analogy.

The idea of these hubs is that you are seen, the same notes are there, often you will see the same person who understands you, so you are not going in and repeating yourself, justifying yourself, apologising for taking up their time again. If it is not this postcode lottery that we hear about where, if you live in Newcastle, you are all right, but if you are in Norwich, tough luck, and if these hubs are established quickly and there are enough around the country, women can have this security and know they are going to be understood and not passed from pillar to post, they are a great idea. I just need to see them happen.

Chair: Thank you. Kirsten, were you wanting to come in again?

Q38 **Kirsten Oswald:** Something that was said has set something off in my mind. You have both spoken about the lack of knowledge and spoken about young women, and I share your concerns that young women really need to have much more information made available to them.

But for older women, how confident do you feel that there is information out there somewhere about how your particular conditions will interact with menopause, for instance, and how confident do you feel that whatever support is needed will be available to you at that point?

Naga Munchetty: I have two answers to that. Personally, because I have spoken up, I am hopeful that I will not be ignored. A third of your life is spent post-menopause for most women, if you are lucky enough to live that long. And I feel that there is still that stigma that, once you hit menopause, you are done anyway: "You have put up with it for this long, you will be all right. It is a bit too late now to fix anything, and also you are past it." That is what I fear.

Q39 **Kirsten Oswald:** Do you think it is possible that conditions might change at that point, as well? Maybe I will move that one on to you, Vicky, and how will that impact upon what support people need and will it be there?

Vicky Pattison: I have not hit the menopause yet, but I know my mam, my older mates, and people who are going through it are having a terrible time. I know there is not enough support, there is not enough information, there is not enough anything for them either. I do not think it matters what age you are at as a woman; you are let down.

Q40 **Chair:** I almost want to stop on that comment, but I am not going to. I am sorry; one last question. An awful lot of investment—money—gets ploughed into research for conditions like impotence; we all know how much time and work went into establishing Viagra. Do either of you get the sense that the same amount of effort has gone into those

pharmaceutical treatments or procedures that could have helped you earlier in your symptoms?

Vicky Pattison: There is no way. We were talking about this before we came in. From a very young age, you are recommended contraception, and it is never just, "Oh, you can take this, and you are not going to get pregnant, and you are going to be fine." There is always, "Oh, you might be nauseous," or, "You might gain weight," or, "You might have this," or, "It might start you bleeding," or, "It might make you a bit emotional"; there is never, "This is going to work."

When it comes to the solutions for women's problems, there is always something else you have to deal with. There is nothing that really fixes everything. I do not know enough about Viagra, but it seems like that pretty much solves the problem. I do not think we have the female version, basically.

Naga Munchetty: Side effects are all right for us though, are they not? We will cope with side effects.

Vicky Pattison: Yes, we will deal with them.

Naga Munchetty: Because it makes the other stuff better.

Q41 **Lia Nici:** That is an issue as well; as you go into puberty and then you go to the doctor, the first thing they say to you is, "Are you going on contraception? Do you want to go on contraception?" I do not see any men having those kinds of discussions and how much research has been done for men to be asked; it is the female's role.

Vicky Pattison: It is our responsibility. You are pumped full of these synthetic alien hormones from such a young age. Some of my contraception made me crazy. You just do not know what you are putting into your body, really, and when you are doing that from the age of maybe 14 or 15, how is that fair? No, there is not enough for women.

Naga Munchetty: Whereas, on the other hand, I could not have been more grateful to have those drugs. I would have done anything to not be bleeding and have the pain I had, and that was something I was quite willing to do because my life was—

Q42 **Chair:** You said that the Depo worked for you.

Naga Munchetty: Yes, it did.

Q43 **Chair:** Do you feel there is enough research to establish how you can counteract the negative of osteoporosis to continue taking an equivalent to that?

Naga Munchetty: Well, I fought to stay on it, because I exercise, I do weights, I eat healthily, I run, and I was willing and did do over and above a normal lifestyle to make sure that I could stave off osteoporosis.

I do not have it, and I was willing to do all that, but that was just ignored; it was a flat no.

Q44 **Chair:** It was a flat no. There is no room for manoeuvre.

Naga Munchetty: No continuation.

Chair: Past 40, you are not having it.

Naga Munchetty: No; it was almost like I was not trusted to manage my own body anyway, once I had been given some certain information. I do feel I was not trusted to manage my own body or to know my own body.

Chair: Or to take the calculated risk that you could offset the possibility of osteoporosis by taking additional supplements, managing your diet, resistance training, etc.

Q45 **Lia Nici:** You have both talked about having fantastic partners, husbands. Talking about it is probably the best thing that we can all do, but it must be a very frightening experience for our partners and male members of our family to see what is happening with women's health and the issues you are going through. What do we need to do for men, and boys at school as well, to understand that every woman has this life cycle, and sometimes it needs dealing with in an understanding way and in less than 30 years when somebody is trying to find a diagnosis? What do you think we need to do to involve men in this conversation?

Naga Munchetty: Men want to be involved in the conversation. It is really easy to dismiss men as not caring, and that is just not true; they have mothers, daughters, sisters, partners.

After I was on Radio 5 Live talking about it, David got in touch. He said his partner, "Has adeno and endometriosis. The NHS barely recognises the condition and it is really hard on partners to have to witness their loved ones in agony and are powerless to do anything about it." That was typical; I had lots of men get in touch. They are not given the information; they are expected often to just sit there and be quiet while their partner or female loved one tells their experiences. Because they do not experience it, they are almost not allowed to say it.

It is almost like what they witness—the pain, the anxiety, the sleepless nights, the stress, the physical discomfort—is not important; let us just find your physical symptoms now, and you just sit there, be a good husband or partner or whatever, and sit in the background. They do want to be involved, but if we do not have the tools, they certainly do not have the tools or the information to help.

Q46 **Lia Nici:** Do you think quite often they are worried about getting involved in female conversations? Do you think society prevents them from having that confidence?

Vicky Pattison: If we want men to start understanding more, and showing sympathy and all the rest of it, they have to be part of the conversation. I find it really frustrating that, at 30, I am having to teach my fella about periods. I am not his first girlfriend; you would think I was, but I am not. Whose responsibility was it? Was it his girlfriend's, was it his mother's, was it at school? Why are these conversations starting so late in life when he has already potentially failed loads of women? The teaching does not have to be maybe as extensive as we are taught about it when we are younger, but they have to have a real grasp of what their partners, their mothers, their future daughters go through, and that has to start at adolescence, surely.

Naga Munchetty: This is a generational thing. I am late 40s. I remember when I was nine, and we had the first talk; the boys went fishing, and the girls were told about periods, at nine and 10. It was never spoken about. I suppose it may be very different now that young men are being taught but—

Lia Nici: The worrying thing is I do not think it is different now to the things you have talked about. I have a teenage child, and it worries me that we are almost still stuck in the 1950s. It seems that it has got a little better, because, in my day—I am a lot older than you are—you did not have the discussion about periods until everybody had already been on their periods for years anyway. A nurse came in and looked embarrassed and told you all about periods, and you went, "Yes, great, thanks very much," and the boys were doing metalwork or whatever. It is not changing quickly enough, is it?

Chair: That is about it. Can I thank you both for coming in and giving your evidence and sharing your stories? It has been incredibly helpful, and I hope we will put together some recommendations for the Government that will absolutely reinforce the messages you have given us this morning. Thank you very much.