

Lara: My Endometriosis – part 3
Behind the health statistic podcast
Transcript

Ricky Hellyar:

Hello and welcome to the Behind the Health Statistic. My name's Ricky Hellyar and I'm a lecturer at Cardiff University school of healthcare sciences.

This is a third part in our series covering endometriosis and in this last episode we're going to have a chat with Lara a few weeks after her operation. Hiya Lara, how's things alright?

Lara Cowpe:

Hi Ricky, yeah I'm doing good, thank you, yeah. This week's a good week.

Ricky:

Yeah. So yeah that's what I want to ask you really. Thanks ever so much for recording those diaries, you know, I found it personally really like powerful, and I learned a lot from it and that. You've been through this big sort of process now. First of all, just how are you feeling about things and how you feeling after everything with regards to the operation?

Lara:

Yeah I think you probably can hear from most of my recordings is that it's been a bit up and down. So yeah, definitely that phrase of an emotional roller coaster definitely rings true. Yeah, I've had days where I'm feeling really, really good and feeling well and like I'm moving forward and then I'll have other days where I'm feeling, you know, a bit down. Or like, I don't know, thinking about, the difficult things and I guess the impact of having, I've had the surgery, I've had it removed but I've still got endometriosis. It's is a chronic condition that's not going to go away. Yeah, so yeah, generally I'm doing good though, yeah.

Ricky:

Good, I'm glad. It's such a big thing, it's such a big thing to have. And it's such a big thing to have gone through I think over the past couple of months for you as well isn't it, you know?

Lara:

Yeah

Ricky:

What I want to do, if it's all right with you, is thinking back over the diaries, is I want to sort of start at the beginning really if that's all right. Of when you first, sort of, your first couple of entries. You talk about being a worrier, and things, and could you just go over a little bit about

what you're worried about. You talked about COVID and, and there's some things I want to, sort of, like, ask some questions about if that's all right?

Lara:

Yeah, yeah, sure. You know, I just thought it was important to sort of acknowledge I guess, for people listening. That I do acknowledge that I'm one of those people that does, you know I do worry about things. Like I think I said in that recording that because, you know, I care a lot, I want things to go well and want to do my best. But yeah, I've always been a bit of a worrier and I talked about a number of years ago where I took part in CBT as a way of, you know, that was just me acknowledging that actually, everybody gets worried and anxious - that's normal, but what was happening at that time was that it was impacting my life negatively. And I decided that I needed to do something about it. A bit like you would do if you had something physically not right.

So yeah, so it just kind of really helped me to, work through how to manage your thoughts on things. But I think, you know, things like having surgery and particularly during a pandemic as well, you know, those are things that I think generally people would worry about anyway even if you're not, you know, one of life's worriers or whatever.

So yeah, it was just the thing, like, you know, hoping that me or my husband wasn't going to get COVID before I had the surgery because it's going to push it back and because of this situation you don't know then how much longer we need to wait.

And then my surgery was a bit more complicated because it needed two different consultant surgeons. So, I knew from my own health background that that requires a lot more organisation than if you just have one surgeon. So, I was kind of aware of that and then also just aware more generally of all of the organisation going on in the background because of COVID.

You know, it's not like if my operation's cancelled - I imagine, I'm not entirely sure - but I imagine it would be unlikely they'd be able to get someone else, another patient in, because of COVID, because you have to self-isolate. So, there's all those kinds of thoughts that you're trying to do everything that you can, but then acknowledging that there is only so much that you can do. There's only so much that you can control and so, you know, I think I did sort of say, in one of the recordings that I did kind of talk myself around in the end. Like, I can only do what I can do, and just hope that it all goes okay. Yeah.

Ricky:

I might be wrong with this right. When I was listening to it. When you first mentioned COVID, and please correct me if I'm wrong, obviously everyone's worried about COVID as a disorder in its own right.

Lara:

Yeah

Ricky:

But I started to get the sense from you that obviously the endometriosis is such a big part of your life, that was less about COVID as being a disorder in its own right but that it was potentially going to be a barrier to you, that's what that was. Is that right, I don't know?

Lara:

Yeah, yeah that makes sense. Yeah, I think I was more preoccupied with the, yeah, barrier to my treatment and surgery, than actually COVID itself. Which, you know, I was worried about getting COVID and I guess if I thought about that as well, then that would have been even more to, like, fry my brain. But yeah, no getting COVID is a concern. Obviously you're going into hospital and you're having an operation so you're more vulnerable, your body's more vulnerable to infection anyway, and then we're in the middle of a global pandemic. Like, how much more can you, kind of, take? Do you know what I mean?

I mean, but yeah, no I was concerned about it becoming a barrier to my surgery, because I've already waited so long.

Ricky:

Yeah.

Lara:

I'd waited so long already. And nothing was certain. So, you know, and I know that, you know, even without COVID, that you know, operations can change, schedules can change, and things happen and there's nothing you can do about them and that sort of thing. But obviously then COVID is just an added element of challenge for everyone involved - from the patient, to the hospital, the consultant, etc.

Ricky:

And it's one of those things isn't it? I think COVID has had lots of impacts on people's lives, but I think when, you know, when you think about anxiety, lots of the sorts of anxiety is uncertainty. And I think sometimes that COVID, you know, it sounded like that COVID being there - it was almost giving you a bit of uncertainty about whether things were going to go ahead and it's almost like an extra layer of anxiety, having to deal with stuff isn't it, you know?

Lara

Yeah uncertainty is a really big challenge. And I think with this condition anyway, because you don't really know what it's doing, until somebody goes inside and looks in surgery. So, yeah, so I think it is a condition, to me, that's surrounded by uncertainty and there's only so much that you can do or whatever to try and address it I guess. But yeah COVID again, you're right, was adding another layer another, layer of uncertainty and stress in an already stressful situation.

Ricky:

Can I ask you, like, about something else is that really came across like really powerful in it and I was thinking about a lot as I was listening to it. And there's something I suppose that's been on the news about things, is about that loneliness of going in, by yourself. And that like you acknowledge in the podcast, in the diary though, it's not everyone, but I think I would certainly feel the same, the loneliness of going in, by yourself, the loneliness of going through this process by yourself. And I sort of, I know this sounds like a really odd question, and it seems really obvious but, but why, why is loneliness such a worry? What, what is it about our family and our loved ones and our partners that we need in those times? It might be difficult to articulate, but I just thought it was, what is it actually trying to get, trying to get to the nub of it? What is it we need from them and why is the loneliness a problem, you know?

Lara:

I think for me, it's more about, the kind of, the comfort of having someone with you and having someone that knows you, with you. So, you don't, I don't have to put on a face 'oh yeah, I'm fine. Yeah, I'm glad to be here'. I didn't say that, but you kind of, you know, you go in and you try to be upbeat and everything.

So yeah, having, having someone with you that knows you that just, it's distraction as well. From the waiting to go down to theatre. You know, I mean I was first on the list that day. So, it actually ended up being very rushed. Literally, I arrived, and then I was seen by this person, this person, this person, this person and this person, and get changed and it was very, very quick. Whereas the last time in October, I had to wait about, sort of, two, two and a half hours or something. And sometimes the waits can be longer, you know, you never quite know what's going to happen.

So, and that's just a long time particularly at the moment with COVID, you know, I think I've mentioned before that my surgery was done privately, so the hospital that I was in, you're in your own cubicle, your own room, which is lovely, but that door shuts and you're by yourself. And for me that's really hard. I'm not used to being by myself, when I've had, every appointment, I've been to in the past, most of them, when I have had operations in the past, even in my early 20s, I've always had a family member or somebody with me. Literally, until the moment before I've gone down to theatre. And they're not allowed any further. So, yeah, and it feels weird because I'm like 'I'm in my 30s you should manage' but for me, it that was really hard. That was one of the, one of the worst parts of the experience I think, was being dropped at the door.

Ricky:

It came across as well. I really felt for you. I really felt for you and, you know, it almost felt like sometimes when I was listening to it that the loneliness seemed to worry you more than the surgery itself, I might be wrong, but that's a sense I got of that.

Lara:

Yeah, and I think maybe I was in that position because I know my consultant already and I trust that they're going to do a good job. So, I wasn't overly worried really about the operation itself, I had in-depth conversations with both of the consultants who were doing the operation, and even going through the consent procedure with them and they tell you all the awful things that might possibly happen. You know, and I was able to have those conversations and talk about if this happens, this is what I would want, bladdy blah, etc. So, from that kind of view. I was, as kind of comfortable as you can be going into surgery. But yeah, being on my own was the hardest part. Not having a familiar face, really.

Ricky:

Yeah

Lara:

Just having someone that talk to you, while you're waiting for this to happen.

Ricky:

Yeah, exactly, you know it's you know, for patients, and for people in hospital, you know, we seen these hospital programmes and stuff, but hospitals are really boring places, really boring places to be, you know.

Lara:

Yeah and especially if you're in a position where you can't really move really well and you can't get up and do stuff for yourself. Like, yeah.

Ricky:

I suppose what it shows though is that you said that trust in, you know, your healthcare practitioners, I suppose. It emphasises to people how important that is, isn't it, you know?

Lara:

Yeah, it's so important and the nurses that was on duty on the day I was admitted, was on duty when I was in before. And the first thing she said when she opened the door was 'we've met'. And I, I felt awful because I was like 'I'm really sorry I can't remember your name', but I recognised her. And straightaway I felt myself like breathe a bit of relief, because I would like 'right'. At least there's somebody on this ward that I've met before, because obviously I've met the surgeons but I'm not really going to be able to see them very much. But there's someone on this ward who I've met. So that, that was, that was a really nice surprise actually, yeah.

Ricky:

Yeah, lovely. It was, it was something obviously like, I know, like, you know from us speaking and from the diaries, you know, how much, you know, perhaps I don't know how much you know I can't put myself in your shoes but obviously endometriosis has a huge impact on your life and I know you're really passionate, sort of, about helping other people who were impacted by endometriosis, I know that means a lot to you. Leading up, so it's always there in your life, but leading up to, sort of, before you had the operation, you did a diary entry where you spoke really passionately about health, particularly around about things like menstruation and young women's health and I just wonder if you want to, if you wouldn't mind just tell us a little bit about that and what you were thinking at the time. And what you still think now maybe, you know?

Lara:

Yeah, I think, is it the recording about menstrual wellbeing in education?

Ricky:

Yeah. So, there's been a lot going on in Wales particularly, about menstrual wellbeing being included in the new curriculum. And there's been a big campaign about it led by Fair Treatment for the Women of Wales and Endometriosis UK to try and get it included in the curriculum. And there's been a couple of votes, I can't remember how many now, and they've all been voted against it being included, and a lot of the sort of feedback was that the new curriculum was sort of designed to be flexible, or aspects of it.

Sorry, I don't know the ins and outs of it. But schools were given the flexibility around this and maybe other topics. And while I think that's in some ways it's lovely that there is flexibility and sometimes flexibility is needed. But with, with a topic like this, which is very much taboo, and we talked about first interview, didn't we, about society views of women's health and menstruation generally. And I just think, I think the feeling is and I agree that it needs to be compulsory. So that it has to be taught, and it needs to have a health focus and schools need guidance on how to do that. And, you know, it would be age appropriate, and all of those sorts of things.

And so, my understanding is it's been included in, in some aspects of the curriculum, but not exactly where, you know, the campaign wanted it to be. Which is, it's a shame but I guess we have to take the positives from that, that it is going to be there somewhere and that the two organisations that I mentioned are going to still keep working with the Senedd on it.

And I know that there's definitely one MP, not MP sorry one member of Senedd, if not a couple that are really kind of driving this forward. So, yeah. Hopefully it is a light at the end of it. But yeah, it's really, really important. And the more that I think about it, the more that I think to myself, if I hadn't constantly been told that period pains were normal, then I might have thought there was something wrong sooner and maybe I would be further along the line than I am now.

Ricky:

Yeah, I've got a feeling, in some sense, that you felt that maybe the lack of this in the past has let you down, has been a bit of a let-down for you. You know?

Lara:

Yeah, and I think it's frustrating for me, personally, because I'm quite aware of, like my, my body and how it works like I've always kind of like I've understood about periods and menstruation and all that stuff. And you know I've got a lot of friends and family members that are in health - different types of health professionals - so it's not like I don't know what I'm trying to say here, I guess I feel like maybe I should have been in a better position to have picked this up sooner, and you start thinking to yourself, what, what should I, what could I have done? Should I have done something different? And then I'm like, actually, when you're constantly told that it's normal, and that everyone gets everyone gets period pains and yeah, you know, you just go on a pill and that will make it better. Like, you believe those things because you don't hear anything different.

And actually, like, since this surgery. I've had two periods, and I don't have abdominal cramps. I still have some, like, lower pelvic pain and everything, but I don't have those cramps, it's very, very, I'm very aware of that. And that just makes me, I'm glad that it has worked in that way, but I feel sad, at myself, that I've had, like, all these years, of having them, thinking it was normal and actually it's not normal. I didn't need to have it. And also, like, having endometriosis, as I said before, even though it's been removed now.

There's still that feeling in the back of my mind, 'oh it might come back', so there be a time where I do get those symptoms again, but for the moment, you know, that's one of the good things that's come of the surgery is that I don't have that particular symptom at the moment.

Ricky:

That's good news isn't it, that's really good news. And the other thing is I've sort of like thought about is, like you said, you know that, in some respects, you know, that you were in a position where you did have people that, you know, with healthcare backgrounds and stuff like that and eventually got there.

But what worries me, I suppose, as a healthcare practitioner myself, and, and this obviously somebody with you know with the autism, it just worries me and I think there's a lot of girls and women out there with the potential that this, this education is not going to be there, and they will get missed. You know that does concern me, you know.

Lara:

So that's why it's important that, you know like I said, Fair Treatment for the Women of Wales and Endometriosis UK they're going to keep with the Senedd to try and get this somewhere in the curriculum. So that, you know, young people learn about these things and learn what is normal and what's not normal. And not just that, but when and how to seek support.

Ricky:

Yeah, absolutely, absolutely. Hopefully this podcast will help a bit as well.

Lara:

Yeah I hope so.

Ricky:

So can I take you back to, sort of, the day of operation now. Is that I really got a sense in there that there was almost like a sense of relief in your voice that it was going ahead, and I don't know whether I was, I didn't know what I was expecting, but there was almost like in your voice was very positive. You seem very positive about the day, you know? About that everything was going ahead. Is that right or?

Lara:

Yeah, so like on the morning of it, and I haven't had a call to say that my COVID test is positive or that my surgery's been cancelled or anything, so yeah, it's happening, it's happening. And then, as I say, when I got there one of the first things that they said to me was that you're first on the list. The theatre lists.

So, I knew that that meant that things would probably move quite quickly. I don't think I've said that in the recording, but one of the things that I was getting a bit wound up about, but you try not to, is that when the gynae surgeon had gone through the consent form with me, prior to the surgery. He'd said 'so, we'll see you on the, on the day and we'll go through it again', because you've got to go through it again, you've got to like physically sign consent, 'we'll go through all this again, so if you've got any questions, you know, make sure you've asked me' he said, and then he said, you know, you'll have an enema, and then we'll come and get you. And I was like 'hang on, sorry, what! I'm having a what now?' He said, 'oh yeah, you have to have an enema' and I was like 'why?' He said, because of where we're operating, we need the bowel to be clear, or that part of the bowel to be clear.

And so, I got myself right wound up about having his enema and I've never had one before, and it's so private and I said like 'oh no, there's no dignity anymore' and all of this. So, again, that was something else that was kind of distracting from worrying about the fact that I'm having an operation, going under general anaesthetic and stuff. So, I was like 'right, I've just got to get that out of the way'.

So, so yeah, no, it was, it was fine. That was fine, had that. But again, it's all those little things that you have done, these procedures that are very, very private and very personal areas. And I think that's the whole thing with the surgery I'm having, it's all very private.

Yeah, so once all that was done, and then they were like saying to me, 'right, you're going to be called, someone will kind of get you and take you down to theatre'. So I was, yeah, I was quite positive then. I was like, 'right, it's going to happen. They're going to go in there and they're going to take that out and hopefully nothing will go wrong'.

And then going down to, like, the anaesthetic room. I think then, again, I started to get a little bit anxious again then. They're very busy, there's quite a lot of people around you and everyone's lovely and they're trying, you know – I know everyone's trying to keep you calm – but yeah there's lots of people around and they're trying to put like, I don't know if it's the ECG monitors on you, and they're trying to get a vein and stuff and you're like 'aghhh'.

Yeah no, they were, they were nice, and they were like 'you're shivering' and I was like 'yeah, I'm really cold' and they bought this like hot heated blanket thing to try and keep your body temperature where it should be. So yeah, they were very nice. Yeah, and then I just drifted off. Yeah.

Ricky

What I found really bizarre, and I wrote in my notes is that, listening to it, is that when you come around and you do your diary entry, is how observant you are of everything that's going on, the attention to detail and sometimes we think people sort of being drowsy, after an operation stuff like that, but actually the amount of detail that was being picked up was, was, was, was surprising for me to be honest.

Lara:

Yeah I think I've always been a bit like that. Like I said, I've had operations in the past and certainly the ones I've had as an adult, I can remember coming round after. And I can remember the conversations that I have with the staff in the recovery suite. Yeah, so I remember that, and the first operation that I had in October, the gynae consultant came to see me in recovery, and he told me how the operation had gone, and I remember everything that he said. But I think that's partly me, I don't want to forget what someone's said, what I've been told, you know. And also, I'm probably a little bit, I don't know if 'wired' is the right word, but I seem to be a bit wired when I come around from surgery. So, I'm sort of between nodding off and falling back to sleep and then being like quite alert, and chatty.

Yeah, and I remember when they took me out recovery. I must have nodded off and I could feel the bed moving, and I like opened my eyes and I can see the nurse and the ward, and I say, 'are you taking me back to the ward?' and she said 'yeah', and I said, 'can you please say thank you to the recovery nurse for me'. I felt like that was really important and I could hear her like running back and saying, 'oh she says thank you' and I could hear them going 'oh that's really nice'. It's just like little things like that, I remember. Yeah, yeah, yeah.

Ricky:

It's crazy really, isn't it. I want to ask you actually about the nurses. You mentioned about the about the importance of relationships early on, and, when you're talking about quite soon after the operation, you know, you're talking about these things you have to do you. You know, you've got to go to the toilet. And you say the nurses helped you, they were great. This is hard to sort of captures, I suppose, but what made them good? What made them good in those instances for you?

Lara:

I think it's their manner really. And I guess that's quite hard to bottle that, I guess, and sort of explain it. But I was, so I've been quite aware that I'm, you know, young patient maybe and normally able to look after myself. So having to ring the bell every time I needed a wee, or try to wee, that was the other thing. To go through all of the effort to get out of the bed, and helping me get to the bathroom, and then nothing happens. So, I was just sort of very, like, aware of that and I think that was just, yeah, maybe just me, you know being independent, you want to do stuff for yourself, and I just, you know.

I've worked in the NHS, it's just what you do. You're there to support and help the patients, but being on the other side of that, you still feel like a bit of a burden. And there's nothing that they did to make me feel that way, it's just how you feel. And so, you know, I would just ring the bell and they would come on and they would ask me like 'are you okay or is there something that you need' and I would say 'oh I need to go to the toilet'. So, they would just help me and this time I had the inflatable booties on my feet, and I had this funny thing attached to, a sticker on my head that was measuring my temperature, so I had these attachments that I didn't have last time.

And last time I physically struggled more. I still struggled this time physically, but it was definitely different. But I couldn't actually detach myself from like the boots and stuff, even if I wanted to. So, they had to do that and then, yeah, they helped me to the toilet. And particularly after the anaesthetic, I tend to get a bit, feel a bit sick. The first couple of times I get up, so it wouldn't have been very good if I was on my own, because I might have got dizzy or whatever.

But yeah, no, they were just kind, and just asked me what I needed and just helped and then they had to wait outside, and they said to me 'don't rush' and that was important, because I would have wanted to rush and I couldn't rush, because my body's still waking up, so I needed just to be in the bathroom a bit longer and stuff like that.

The fact that they just say, little things like 'don't rush'. 'There's no rush', or 'I'm not in a rush'. That helped me. Yeah, and even down to the little thing, Ricky, like when they offer you food after surgery. I don't really want to eat, but I'll have, I think I had toast and then they want to you drink as well, so I don't drink tea or coffee so I was just saying 'oh I'll just have the water I've got, it's fine', and they asked me a few times and eventually I said, 'I don't drink tea or coffee so I wouldn't have them anyway'. And then they should 'do you want a hot chocolate instead? And I was like, 'Oh my gosh, that was like, amazing - it's the best hot chocolate'. That was so like nice that they could offer me that. And it's just a drink. And I would have been fine with just having water. But the fact that they were like, 'oh do you want to try this instead?' Little things make a massive, massive difference.

Ricky:

Yeah, absolutely. So, if I talk a bit about the recovery now, if that's all right? And it was really interesting listening. So, your diary entries about recovery and you talked - there are a couple of things I want to ask, actually, you mentioned things about, sort of, I remember the bruising coming out, and you remembered about how it was difficult, going to the toilet, that it burned

and things like that. Were those expected or unexpected or what were your thoughts when these were all happening?

Lara:

So, I expected the discomfort passing urine, because they'd said that, I know they'd put a catheter in during the surgery. And just because of all the discomfort I get down below anyway, I kind of expected that I was going to have a bit of pain or burning sensation or whatever so that was that was, that was fine, I just you know, knew that that was going to be sort of short term while I was recovering. And the bruising that came up, so I had a bit of bruising on my back, lower back, and on my right-hand side of my stomach, which I wasn't expecting. And I didn't have it last time. So, I was a bit like 'what is this?' So, yeah, but I just got in touch with my consultant, and he reassured me that it was just normal coming through from the surgery, either from the actual surgery itself or like fluid or whatever. Yeah, so that, again, just reassures you 'that's fine, you don't need to worry about that, it'll go away'.

Ricky:

Yeah, yeah. I want to ask you about. I've noticed, different ways in which you describe pain. Okay? And what I've noticed is that maybe in the first recording interview we did and maybe before the operation. I know this sounds obvious you talk a pain as been something really unpleasant, and really, you know, not nice, debilitating, but it's weird and this ties in a little bit in with the really interesting stuff you say about scarring as well. I don't know, I got a sense of a different context of it, that you were actually, when you were talking about pain, you're almost like, yeah, I think you even used the word 'this is fine'. 'This is fine now'. And like the scarring you talk through it, and it started off, and I was thinking, you know, you went the scarring's there and I could see there was a sense of, you know, that there's a negative to it, but you were going 'oh it's fine now, it's fine now'. And it's almost like two different contexts, it sounds weird when you talk about pain and it's a negative context. Again, you almost talk about it in quite a positive context, I don't know.

Lara:

Yeah, so I think with the scarring first of all, so the scarring, I knew what to expect from previous surgery but what I talked about in the recording is my belly button scar. And, yeah, I almost didn't record that, because I was thinking, 'why are you so upset about what your belly button looks like? This is really silly'. But I was like actually 'no, at this moment, this is really important to me'.

And what happened was, when I took the dressing off, it looked like I didn't have a belly button anymore. I didn't have. It was just flat, with a scar. And I wasn't, I wasn't expecting it. I thought it was going to look the same as it did last time they did the surgery, which is still having a belly button, with a scar below it. So, I wasn't expecting it and also because my stomach was still quite swollen as well it looked quite distorted. And I think, yeah, just generally, it was only 10 days post-op as well, so I was probably in a bit of an emotional place and I was just like 'oh my goodness, what's happened to my belly button?'. And my husband was like 'it's okay, it doesn't matter what it looks like'. And I was like 'I know it doesn't matter' and I know that, and I knew that, but I just wasn't expecting it to look that way, and it has

gotten better it looks, it looks better than it did. But, you know, even though I was a bit upset about it, I feel okay about having scars, because they just tell a story. So, it's just part of what I've had to go through to get where I am. So that's kind of the scars I guess, and there are things that you can do, like I do, I'm doing like, scar, what's the word, you can do like gentle message and putting creams on them and making sure you do what you're supposed to do. So, I know that over time they will, they will change. Scars do change, they look different, and they will fade. But they probably won't go away. And I know that in some ways, I don't mind if they don't because it just is what it is.

But yeah, with the pain, yeah, so pain is an interesting thing. And something that even over the last week, Ricky, I kind of have been learning more about my pain. So, so I started back at women's health physio and one of the things that we've been talking about is chronic pain, and I did say to her 'I know a bit about chronic pain'. But I never thought I had it, because I thought chronic pain - you had to be in pain all the time. Even either the same pain or different pain and I don't have all the time. It kind of comes and goes and it's in different places and stuff. But actually, some of it is chronic pain. And I know that now and again it's kind of getting your head around that.

And I think the important thing about pain, for me, is understanding it. And I've only been able to really understand it in the last year or so, from having the diagnosis of endometriosis. And through, you know, like the education from my consultant and from women's health physio and research that I've done, and even just having this operation and seeing the pictures because they showed me the pictures of where my endometriosis was and what it looked like. And then after they'd moved it and it's just kind of seeing that and understanding that, so I think that's quite important with the pain.

And some of it is, because the way the endometriosis is, it's causing that pain, and discomfort and inflammation etc. But some of the pain I have is not, is not reflective, shall we say, of what's actually happening. And so, it doesn't make it not real. Because that's the other thing, and I think that's some of the things that women hear or get told a lot, that it's in your head. And that's not true. Like this pain is real. And some of the particular pain that I guess, it's real, and it feels a certain way, but it doesn't, it's not an injury if that makes sense? So, it's about kind of, I guess, that's where some of the CBT comes in as well and it's retraining your brain to understand that *this* pain is this, *this* pain is not quite what you think it is - it's there - but it's not exactly what you think it is. And it's trying to sort of tame it, I guess.

And there's a professor, I think it's based in Australia, I've forgotten his name now. But he's done research into pain. I think he's got this programme called 'taming the beast'. And I watched a short clip on YouTube and I was like 'oh my gosh, That's my pain'. Yeah, yeah, it's been a learning experience and well as recovery, physically.

Ricky:

Yeah, yeah. Can I ask you about something? In the first interview, and obviously the diaries, you've mentioned your husband.

Lara:

Yeah

Ricky:

Can I ask about, obviously he's not here to speak for himself, but what do you feel, what's your husband been through, throughout all of this?

Lara:

Yeah, yeah, I think it's difficult for him. I mean, we're quite like chalk and cheese as people. He's quite laid back, I'm maybe not so much. And so, he's very good at keeping me calm, and supporting me. He's got a lot of patience and a lot of understanding, and he's been like a rock through this. I can't remember if I've said this before, but it very much feels like we are going through this, rather than me, just me. I know he's sort of there. So, I mean, I mean for him, he'd never heard of endometriosis before. Like I said, I'd heard of it, but I didn't know what it was. He'd never heard of it and he had no idea what it was. And even, like, trying to talk through with him. [Phone rings]. I'll wait for my phone to stop ringing.

Ricky:

That's all right, that's fine honestly.

Lara:

So even like talking through it with him, you know I think. I have asked him about it and it's difficult for him to understand because he's not going through it. It's not happening to him. But, you know, he can see what it's doing to me and it did make him feel sad, like he said that, it's sad to see what it's doing to me in regard to, so the pain and the discomfort obviously, those symptoms. But also, he notices things like, you know I get quite like emotional, like I said some days I'm up here and other days I'm like 'today's a bad day.' And you know, he sees that, because he's my husband and he sees that more than, like everyone else. So, yeah, so I think it is difficult for him. But, you know, as I said before we support each other, we're a team. That's what he says. I think the hardest part that he's found with it, as I say, is the impact on my and the pain. The fertility difficulties that we had, he found very difficult. We both have really.

Ricky:

Can I ask you about that then? The fertility issues and sort of the impact that's had on you and how you, you know, you speak so passionately on that final entry. You know that final diary entry. I just want to know, sort of, how, I want to explore it a little bit really, if that's all right, you know?

Lara:

Yeah, yeah, that's fine. I think, I still don't fully understand endometriosis affects fertility. I don't get it. I've read up on it, but I don't understand. Physiologically, biologically, whatever the word is, I don't fully understand why it affects it.

In our situation, we've had fertility tests and there's no problem with our fertility, so that's good. That's really good. But it feels like, in some ways, that our fertility is taunting us a little bit. Because it's like, everything's fine here, but there's a reason why we're not pregnant and haven't had children yet.

And, you know, I've had three miscarriages and I think that the miscarriages, is one of the hardest things I've ever gone through. And even though, through this process, I'm feeling very able to talk about things, the miscarriages are one thing that, it's still difficult to talk about. And, yeah, nothing prepares you for that happening. And again, that feeling that there's nothing you can do about it when it happens. And you, you know, they were all quite far apart, so there was a year between the first two and then six months between the second and the third. But yeah you don't really forget that.

Ricky:

Is there support out there for you?

Lara:

So yeah, I was talking to my mom about this, about a week or so ago and it was like the first time I said to her, I didn't have any support. So, like the first one we were on holiday, and it was very early, between sort of four and five weeks, and we didn't have access to any tests or anything like that. So, it kind of just happened. You know, and then it was just at the end of the holiday, we were back at the weekend. So, the Monday, I rang up the GP, because I'd started to get abdominal pain and it wasn't like a period. And they said it sounded like a miscarriage and I could take a pregnancy test to see, but the chances were that the hormone levels would've fallen by now, so it wouldn't show. And I think I did take one, but it didn't show that it happened.

And then the second one was, I'll never forget, well I'll never forget any of them but, the second one actually happened at a fundraising night that I was hosting. And I was getting ready for the event and I was at the venue and I was getting all ready and doing my hair and stuff and went to the toilet and there was blood, and I was like 'right'. I think I probably went into a bit of, sort of, autopilot mode. I was like 'right, how'd you feel? I feel okay, what do I need? I need sanitary products and I need to tell somebody, because I don't know how this is going to pan out. So, I told my husband and my mum, but I didn't want to tell anyone else because I was like 'I need to focus' and I don't want this. You know, I couldn't deal with any of that, I just need to do what I need to do. And at the time, we rang 111 and they said that it sounded like a miscarriage and the best thing to do was to be at home and rest, this was like half one in the morning after this event. And, but if you're worried, go to A&E and I was told I would be assessed by the gynaecology team. So, some of the symptoms did change, so we did decide to go to A&E in the morning. And I was screened, like they screen you, like they do in

A&E triage. And I was told to go home. And I wouldn't be seen by gynae team. And that was really difficult because I'd been told one thing and now I'd been told something different and apparently the pathway had changed very recently. And so, they have this new system, and the answers that I'd given didn't indicate that I needed to be seen by the specialist team. And I found that really difficult because, as I say, that's what I was expecting. And I was also, it's frightening as hell and they booked me into the early pregnant unit. This was a Saturday, and the appointment wasn't going to be until the following Wednesday. And I was sent home and you feel very alone and isolated, and you just have to wait for it to happen. And the other thing that was happening around the time of that one was this lump in my groin had come up. And I was thinking 'this is happening, and I've got this pain and lump in my groin, what on earth is that?'

On the Monday, I rang my gynae consultant secretary and explained what had happened. I didn't know what else to do and I said I didn't want to wait until the Wednesday to be seen and they managed to get me in sooner, the early pregnancy unit. That was hard, you have to wait to be seen and they do, they did a pregnancy test which was positive. And then because it was positive I had to have an internal ultrasound which, with all my history, was very unpleasant and with everything going on, was very unpleasant. And I explained that I have pain, below. And that was negative but because the pregnancy test was positive and that was negative, it was an inconclusive result. So, I had to have the blood test that they do where they take your blood and then you have to go back 48 hours later and have a repeat blood test to check your hormone levels. So, through all of that, and again, the hormone levels had fallen, and it was a miscarriage.

And then the last one was, yeah, as I say, sort of six months after that. About a year ago now. And again, I went to the early pregnancy unit and yeah, miscarried. And I wasn't, I think they gave me a leaflet and I was given some contact numbers. But I didn't. I didn't have. I didn't really feel like I had support, really. And I didn't know where to go to get it. And I didn't know that I, if I should Because it's common. Again, you hear this stuff all the time. It's common.

It happens a lot in the first 12 weeks and I think, from the fertility side of it, that's one of the hardest things about that has been other people's reactions, and the things that other people say. And I think we talked in our first podcast didn't we, about the questions people ask, you know, they ask 'are you married? Got children yet?' But then if you say things like that you've had a miscarriage or not yet, because you're trying. You know people, I know they want to help, but everyone's got an opinion and advice from 'oh you shouldn't really talk about that' or that 'it must be awkward to talk about that' or 'you should talk about it more or said something sooner' or 'it'll work out, it'll be okay, keep trying' or 'I know so and so, a friend of mine, they had IVF, and then they conceived naturally' and 'have you tried this?' and 'have you tried that?'

It's really difficult sometimes, because I am positive and I hope that one day it will be okay, like I said in my recording, but you don't know that, and actually sometimes it would just be lovely for people to say, 'I'm really sorry for that'.

Ricky:

Yeah

Lara:

Sometimes that's all you need. And I think, you know, that's another reason why talking about it, even though it's been difficult at times, it's important because unless we talk about it more, people aren't going to, they're not going to talk about it, it's still going to be a taboo and it's still going to be difficult for people to discuss.

Ricky:

Yeah. Obviously, I am no expert on women's health and this process has been a big learning curve for me. And one of the things that I picked up is, it seems to be common, you know, from this and from what I've read around, is women's health 'oh it's normal, it's common, it's common, it's common'. Whether it's abnormal period means, whether it's miscarriage. 'It's common, it's common'. But that doesn't mean it's any less important to the person who's going through it and, and that's something I'm struggling with a little bit, to be honest, you know, as I listen to it.

Lara:

Yeah. And there's an added element, for those of us who've had a miscarriage in the first 12 weeks, or at whatever stage, is you have nothing, there's no baby.

Ricky:

Yeah

Lara:

So even though you lose a baby, you have nothing, because there's nothing. It's too small. You know, so that's hard as well. Yeah, I found that, you know, I don't know. I guess I wouldn't have thought about it unless it's happened to me but that's an added dimension to it. And I don't know if that makes it harder or makes it easier, I have no idea, but it's just like an added element to it.

I've been thinking about what would've helped. Like I said, I didn't have any support, what would've helped? And I think, for me, what would've helped is having some sort of service where so many weeks after you presented with miscarriage, you get a phone call from somebody. Somebody that's trained and rings you and says, 'I'm ringing from this service because we recognise that you recently had a miscarriage' and asks if you want to talk about it. And I probably would've done that if somebody had reached out to me. A professional had reached out to me and I would've grabbed that opportunity.

But otherwise, you know. And I talk a lot – as you can probably tell! But with this, I didn't know, I didn't know where to go, I didn't know if I wanted to go there. And even if I did, I wouldn't have known where to go. And it's only in the last couple of months really that I have reached out to organisations, so Fertility Network UK is one of them and they offer one-to-one support and also group support. So, if you prefer group situation, you can access that, but if you'd rather have one-to-one then you can have that as well.

They've got resources and things like that and, you know, maybe I'm ready for that now. Maybe I might not have been ready sooner, but I do think it would've helped me and I would've benefitted from it if there'd been some sort of service to reach out to women, reach out to me. Who've miscarried even early, like that.

Ricky:

I'm sorry, Lara. But like you said, hopefully, like we said that even discussing it will offer some guidance and some thought-provoking stuff for other people. Maybe you know, that can help them.

Lara:

I was just going to say, I think it's important to say as well that, in some ways, there's a feeling not to talk about things and then in other ways there's also a push to talk about things as well. But it's very individual, and I feel that, you know, people shouldn't be, they need an opportunity I think and then they can say 'yes please' or 'no, thank you'. So, I think that's just important to say as well, like you know, that people can feel like they can talk when they're ready. But I do think that some of it comes down to having the opportunity. And when you go through something like that you're not always in a position to find that yourself.

Ricky:

So, I want to ask you just a couple of last questions because I know you've been so generous with your time and everything. After everything you've been through with the endometriosis, with your history, what's the future hold for you? What do you envisage happening?

Lara:

Well. In the short-term, I'm hoping to go back to work soon. And yeah, that'll be good, and I think I've said before I've got a really supportive team which has been amazing. And I know that Endometriosis UK are running, are raising awareness about endometriosis in the workplace because, actually, a high percentage of women don't want to tell their employees that they have endometriosis.

And so, there is a campaign with them, for employers to take part in. So that's been quite interesting to sort of learn a bit more about that and how work can support women. But like I said, you know, I've been supported. So, in the short term, it's going back to work. Get back a bit of normality I guess. Hopefully being able to get back to things like running, which I love. So, I'm really excited about that.

From an endometriosis point of view, I think the main thing is I don't know and that's the problem, that's the uncertainty. And this could be it, and I might not need any more operations. Or I might need an operation in five years, I could need an operation in a year, you don't know, you just have no idea. I have no idea what my endometriosis is going to do next.

So, from that point of view I didn't know. I do have a review with a different specialist, a gastroenterologist, for one of the bits of endometriosis that's on my small bowel which they couldn't remove. Sorry, it's not that they couldn't, they decided not to, at the moment, because it's not really showing any symptoms at the moment. But we're just getting another opinion on that. So, but it's looking like that will be left alone as well at the moment.

And then, fertility wise, they say the next sort of six months to a year is the, I guess the crucial point really. Where, I guess, my endometriosis is as good as it's going to get. Because, you know, they've removed as much as they can do. So, we're just hoping that fate will be on our side and it will all work out naturally and if it doesn't, you know, we're exploring referrals to fertility services, so there are options. Like I was saying in that particular recording, there are options, and I don't know which, or what's going to happen in future, but whatever happens, you know we've got this far, you know, and it'll be okay. I don't know! It'll be all right in the end and if it's not all right, it's not the end like they say. So yeah. Hold on for that I guess.

Ricky:

You say that 'in the end' and I think that was the bit that got me when you go on, 'it'll be okay, it'll be okay in the end'.

So, I want to ask you one last question, if that's all right? And, you know, I'm so grateful for everything you've done, Lara and I'm so grateful for how open you've been, I'm so grateful for the time you've taken. I think it's been so important to students; I think who listen to this. I think it's so important to members of the public and I think it's so important to people who are going through, maybe not exactly the same, but similar set of circumstances as yourself, and honestly I can't tell you how grateful I am for that.

So, the one last question I want to ask you, is through all your experience and there's probably so much more you could say, but if you could offer one bit of advice or one sort of pearl of wisdom or something to healthcare professionals. What do you think it would be?

Lara:

I think it's to say to listen to your patients, and obviously I'm speaking as a woman, and for men endometriosis doesn't affect them, but we know our bodies best and if we say there's something wrong, then there probably is something wrong. And I think that more needs to be done to recognise women's health issues, particularly endometriosis. It is so under-funded. Services are so unfunded, and endo research.

There has been little movement in the last 10 years, or more even, very little, for a condition that affects 1 in 10 women. It's so common. And so, I say healthcare professionals to, you know, take that on board really. But it's not just down to healthcare professionals, you know, it's down to services and governments as well, to invest in the services so that healthcare professionals can do what they need to do to support patients and offer that service to them.

And I also think to be emphatic to your patients. Unless you've been through exactly what someone's been through, you can't really understand. So, it's not about saying 'I understand', but it's about being empathic and listening to people I think.

And I think for anyone listening to this who thinks that this resonates with them or anything that they're going through, to go and seek support and go to your GP. And if you don't get an answer with that GP, go to a different one. And I would also say as well, I just want to acknowledge that my experience will be very different to other women's experiences of endometriosis. It is very, very different for each person that has it.

And I recognise that I have an excellent GP practice. And I have an excellent gynaecologist, and other professionals that have worked with me. And I say that because it's important to acknowledge that. To acknowledge when it works out, but also that that isn't the experience for everybody, unfortunately.

And so, but hopefully this gives some idea of what it is like to live endometriosis, live with a chronic condition, and some insight into treatments and the experience that goes along with that really.

Ricky:

Yeah, thanks so much for that Lara, I really appreciate it, like I said.

Lara:

And thank you for giving me the opportunity to speak as well.

Ricky:

Absolute pleasure. Absolute pleasure. So massive thanks to Lara for giving these insights. I'm sure people find them really insightful, thoughtful and it will really help students with their practice.

I'd also like to thank Cardiff University School of Healthcare Sciences' Pete Smith for producing these episodes. And if you'd like more information on the topics covered, please look at the Fair Treatment for the Women on Wales's Facebook page. Please also look at Fertility Network UK, who've a website, information, groups, one-to-one support, miscarriage support groups also, Endometriosis UK and Endometriosis.org. Thanks again for listening.