

Lara: My Endometriosis – part 1

Behind the health statistic podcast

Transcript

Ricky Hellyar:

Hello, and welcome to Behind the Health Statistic. My name is Ricky Hellyar, and I'm lecturer at Cardiff University School of healthcare sciences.

In this three-part special, we'll be exploring the topic of endometriosis with my colleague, Lara.

So, what is endometriosis? It is a long-term condition where tissue similar to that of the lining of the womb grows in other parts of the body, such as the abdomen, the ovaries, fallopian tubes. We're not really sure of the cause, but it seems to be linked to genetics or a problem with people's immune systems.

Endometriosis costs the UK economy around about 8 billion a year in treatment, loss of work and health care. Symptoms include often severe abdominal pain, terrible period pains and pain or discomfort during, and after, sex.

Treatments for the condition include painkillers, hormone medicines, and surgery to remove endometriosis tissue. And we think there are around about 150,000 women in Wales with endometriosis, that's equivalent to the population of Swansea. Average GP visits to diagnosis is 26 compared to 20 in England. The average time it takes to get a diagnosis is nine years in Wales compared to 8 in England.

Women in Wales, with endometriosis, are more likely to be unemployed due to symptoms than women living elsewhere in the UK and around about 43% of endometriosis patients in Wales purport to be in poor health or very poor health compared to 30% elsewhere in the UK.

As you'll hear in the interview, one of the first indicators of endometriosis is abnormal periods. 49% of pupils in the UK have missed school days because a result of their periods and 1 in 4 girls and young women across the UK said, said they felt unprepared for the start of menstruation.

Organisations such as Fair Treatment for the Women of Wales seek to address issues such as this, and we'd really like to thank them for their contribution in making this podcast. So now over to the discussion.

Hiya, so I'm here with Lara today, who's kindly agreed to talk to us about her experience of having endometriosis. Hiya, Lara, are you all right?

Lara Cowpe

Hi Ricky, yeah I'm good thank you.

Ricky:

Ah good thank you. So, should we just start then? Can you tell us a little bit of background, how you found out about endometriosis and just tell us a little bit leading up to diagnosis and identifying that was a problem for you?

Lara:

Yeah sure. So, I think I had some awareness of endometriosis. I'd heard the term but didn't really know kind of what it meant.

But for me, probably, my journey started about four or five years ago now, which is when I was first referred to gynae [gynaecology]. But prior to that, I'd always had like painful periods, and smear tests were awful.

So, I always, I always took the double appointment, whenever I needed my routine smear, because I knew it was going to be painful and that I needed extra time and that's what I've been advised to do by one of the GPs was to book a double appointment with the GP to help with my smears.

And I just thought that was normal, you know, because everyone says smears are uncomfortable and nobody likes having that done, so I just thought that this was normal, and the same with my periods, really. I always thought that what I experienced was normal, it was something that I just had to put up with.

Ricky:

With your periods, what were you experiencing?

Lara:

So, the main thing for me was quite severe abdominal cramps and lower - what I now know is pelvic pain, that I just assumed was just sort of global stuff stomach cramps, really. And so, my periods are quite heavy, but not again as heavy as other people get as well.

So, yeah. So yeah, painful periods, quite heavy, they would last, my periods will last about sort of five days maximum, the first two days would be the worst. And like day one, day two. Yeah, stomach pains, to the point like when I look back, where I have like, I thought like nausea, I was never sick, but I had like nausea, and it probably would have been better for me sometimes to just curl up on the sofa.

And, but I, as I say, I just thought this was normal and not something that I could really complain about so I would just power through. So, I never had a day off school due to my periods or menstrual wellbeing. I never had a day off work or uni [university] either. And yeah, and as I say it's just something that I just sort of powered through with.

When I was about 19 or so, I did have a random appointment with a gynaecologist, which was a bit out of the blue. I was having some scans for back pain and they thought they saw

something on my ovaries on the MRI, so they referred me to gynae, and they didn't really find anything which was good, but it led to a conversation about my period pain.

And the gynaecologist said to me then well, you know, if you get painful periods, and you're finding it difficult then you know you could probably consider going on the pill. I've never wanted to go on the pill, I personally don't really like taking medication unless it's absolutely necessary. And it just wasn't something that really worked for me. I didn't have a sexual partner either, so it didn't occur to me either, from like a contraceptive point of view. So, I really wasn't keen, but I was persuaded nonetheless to give it a go. And that pill did help. It helped to kind of make my periods very regular, so I knew exactly when they were going to be, and it did make them lighter. It didn't always get rid of the pain, altogether, but it did help.

And so, I was just on yeah I was on the pill for a good number of years then, until about two or three years ago when I was suffering with migraines and they thought it would be best if I came off it.

So, sorry. I lost track Ricky.

Ricky:

That's all right. I find this, like, sort of really interesting. About pain and it's a case of, I don't know, it feels like in other aspects and areas of life we seem to sort of want to get rid of pain in certain ways, but it almost feels like.

I suppose the two questions really for you is sort of: why is it, do you think, that we accept that women can be in pain? Which I'm not entirely convinced, as a man, in men's health we'd accept that. And two, because it's such a personal thing, I suppose, at what stage do you go from 'this is a normal acceptable pain' to 'this is abnormal'? Do you know what I mean?

Lara:

Yeah, exactly. I think that's probably one of the difficulties not just with endometriosis, but with women's health issues, generally.

It is very much like periods are not pleasant things, but *everyone* gets them and they're painful and they're annoying. Yeah, so, you know, it's kind of normalised, if that makes sense.

But in some ways, by normalising it in that way - I mean I never talked to my friends about my periods, even though, you know, most of us have them or all of us have them. And so, you know, I can't remember any conversations with people my own age about my periods other than 'oh my gosh, I've just come on, have you got a sanitary towel I can borrow?' and, you know, that kind of thing. And I, you know, I do remember things like being in lessons at school knowing that I needed the toilet, but not wanting to put my hand up to go.

Even though I know, no one's going to know what I'm doing, but it was just that feeling that I'm on my period. It just makes you feel very self-conscious, I guess. So yeah I yeah, I do think that periods and having pain during periods and discomfort, it's been, it's normalised in

society and it's like, seen as acceptable for women to put up with that. And I think that then becomes very difficult then to identify when something isn't normal.

Ricky:

Yeah, yeah.

Lara:

And in some ways like, we can argue 'what is normal?', as well. Yeah, so yeah for years, I never thought there was anything wrong, if that makes sense. I just thought, this is just what periods like for me. And I just, I just put up with them. And unfortunately for me, I have an allergy to certain anti-inflammatory medications, so the only medication that I'd take was paracetamol which, for me, didn't take the edge off enough, but it just about did enough that I could sort of manage.

Yeah, I do. I did and I still do function as normally as I can when I'm on my period. But yeah, looking back, I know that that's not normal and I did, and I have, struggled for years without realising that there was something not right.

But for me, like, difficulties down below have been something that I've had since being a kid. So, from the day that I was toilet trained, I was unable to control my bladder, if I was laughing.

Ricky:

Yeah

Lara:

So, I used to completely wet myself which was a little kid that's fine, and as I grew up it just became something that me and my best friend would laugh out if I went to her I would take all of my knicker drawer with, because I knew I was going to have fun but I also knew I would end up working myself, and probably about the age of 14 or 15 when I had an incident in town with a group of friends where I lost complete control of my bladder. That was the moment where I thought I need to do something about this because it can't carry on. It's incredibly embarrassing.

So, I did have women's health physio when I was in my mid-teens. They said that I had something called pelvic floor dysfunction, or a weak pelvic floor. And so, I was given like the pelvic floor exercises and that sort of thing. So, I had seen sort of women's health professionals, I guess, at certain points in my teenage years, for different things that may be, may have been unrelated but in some ways they, they might have been in other ways.

But even, you know, even with having that input, which I did, and I know there are probably other women that never had any input and still they were referred later on in life to gynae. But even with that it never occurred to me that there was something else going on.

Ricky:

It's bizarre isn't it? That sort of normalisation of two things really - the normalisation of discomfort and pain, you sit through it, and almost the normalisation of not discussing it, is that we don't talk about it. And I suppose in your case, your diagnosis of endometriosis came from almost an incidental.

Lara:

Yeah, yeah, absolutely. So, where are we now? Yeah, so just over a year ago. I had a lump in my, in the right side of my groin. And this lump - when I look back - the lump has been there, on and off, probably for about a year or 18 months. But it always sort of came and went, and the pain was very much like a muscle strain. And I had gone to the GP about it when I first developed it.

And because I'm a runner, I run, you know, we both thought that that's what it was, it was a groin strain and because it kept going away, for months at a time, there was no kind of other pattern to it and that's what I kind of put it down to - oh I've just got a bit of a weakness there. But as I say, yeah just over a year ago, the lump came back, and it didn't go away.

So, by this point, I'd already been under gynaecology for about 3 years, and I was referred to them by my GP following one of my painful smear examinations and the GP was very taken aback at how painful I found the examination, and afterwards she me down, she, she said I'm going to ask you a personal question. I said okay. And she said she first of all she said, have you always found smears, painful? And I said, yes, and I'm thinking to myself, but doesn't everybody? And then she said to me, do you have pain in other ways, like during intercourse? And I said to her, yes I do. But again, I thought that was normal, because I only had one sexual partner, and everyone said it's going hit the first couple of times. So, you know. And she was like, right, she said I'm not convinced that this is actually normal. And I think that there's maybe something else going here we need to we need to refer gynaecology.

So, I came out of the appointment thinking, okay, well, that's fine. Let's see what gynae say. So, I was seen by the gynaecologist, and as I say, we're back talking three years ago, at this point. And they, they weren't really sure what the problem was. I couldn't tolerate a physical examination at the time, so they couldn't even examine me properly. And the gynaecologist said to me he said right. He said we could do something called the laparoscopy, which is where we would insert a camera in through your belly button and have a look around and see if there's something going on.

However, it's, you know, that's going through surgery, and we might not find anything, so he went through the pros and cons with me. But he said, what I can tell you is that there's actually something going on with your pelvic floor muscles, which may or may not be related. And so, you know, maybe that's something that we could look at first. So, having had women's health physio before, I knew what to expect and I said yeah, let's go down that route first before we look at any kind of invasive procedures.

So, I was under women's health physio, for about 18 months. And that was very hard going, and the first appointment I had she said to me, you need to be prepared that you're in this for

the long run. This is not going to be a quick fix. And she was right. It wasn't a quick fix, I had to do a lot of exercises, pelvic floor exercises and other strategies in that area. Yeah, it was very, what's the word? Very demoralising, at times the progress has been slow, but she would say things to me like this is a muscle, that we're trying to not only retrain because my pelvic floor muscle wasn't actually working, how it should.

So, it was involuntarily tensing, and I couldn't tell the difference between relaxed and tense, and then also on top of that, then I had the pain cycle, where now I associated other things down there with pain. So, you try to overcome that as well where your body, your mind is associating pain with that area. And that was very slow, but it did, it did help, I was able to sort of progress with that.

But coming back to the lump in my groin. As I say it had come back, and it wasn't going away. And so, I went to, I had actually had, by coincidence, a gynae review. And I said 'oh while I'm here, I've got this lump in my groin and it hasn't gone away. Would you mind having a look?' So, she examined me and she's like 'so I'm not really sure what this is. But I think you know you should probably go to your GP and get certain tests done'. So, I went to my GP, and it was a male GP. I don't think, I don't know if that matters really, but I just think it's worth pointing out, but it was a male GP I was seeing.

Ricky:

I was going ask you, does it make a difference?

Lara:

For me, it doesn't make a difference. I have in the past, when I've had a male GP when I've asked questions about women's health related issues that he has himself suggested that I see a female GP, which is fine by me, and I'd rather that they say that. And, but it doesn't matter to me. Really, whether it's male or female, but what matters to me is that I'm being heard.

And, and so, yeah, it didn't matter to me that I was seeing a male GP, and as it turns out I thought I was just going for a groin strain. So, I hadn't even thought about it being women's health related anyway. And maybe if I had, I might have been requested a female but anyway, I was seeing this GP, and he was extremely thorough. He thought it was a lymph node. And so, he did an exam, of my groin, under my arms, my neck and all the areas where they examine for lymph nodes. And because of my medical history of cancer, so he was aware of that, and so, he wanted to opt for a bit of a 'watch and wait' approach. And let's leave it a week or two and see what happens.

Ricky:

So just to add in, for people listening, you had a cancer as a child, didn't you?

Lara:

Yeah, yeah.

Ricky:

Sorry, sorry, carry on.

Lara:

No, no that's fine, thanks Ricky. So, he wanted a 'watch and wait' approach so I said, we can do that, but how about we don't? And how about we do bloods now, so he agreed. He sent me for blood tests and gave me an appointment the following week for a review.

So, when he was sending me out with my bloods appointment for blood tests I said to him 'could you, could you refer me for an ultrasound?' And he was like, 'why would we do that?' And I said, 'well, I've got a lump that's painful and it hasn't gone away and my medical history. I'm very much of the opinion that, if this is going to be something that we would probably do at some point, then could we not do it now, instead of wait?'

So, I don't really know why, but he didn't want to do it then, he wanted to do the bloods, so I said 'okay fine, let's do the bloods' and let's wait and see. So, I left there very much thinking, as soon as I get these results, I am going to ask again, for the ultrasound.

So, I remember getting a phone call from him to say that he got the blood results. And they were normal. There was nothing, nothing of concern, which was good. So, at that point then he referred me for an ultrasound, so I was seen probably about within a month of that, which was good, for the ultrasound. And the radiologist, the first thing he said was when I pointed to the area. He said, 'I don't think that's the node. It's not quite in the right place'. So, I'm thinking to myself, 'well what is this then?'

So, anyway, he did the ultrasound, and he said to me, he said, 'right, I don't think this is the lymph node. The lymph nodes in that area are a little bit inflamed but that's not surprising, there could be something else there that's irritating them'. He said, 'I think this is some, this is something called the thrombophlebitis, which is like a swelling in a vein - not a DVT [deep vein thrombosis]. And he said it can be caused by trauma or injury to the area such as if you're running. So, I was like okay great, that's good. He said, 'I want you to come back in a month. We'll do the ultrasound again, see if it's changed', so I said, 'okay fine'.

I went back in a month. It hadn't changed. Now at this appointment, it was the same consultant radiologist, which was good because for me, I'm very much for continuity. But he had a member of staff, observing that day. And so, while he's doing the ultrasound, this lady's chattering away to me and asking me all these questions about this lump and when I noticed it and stuff. And I happened to say to her, you know something funny about this, but I've noticed over the last month or two, that it becomes more painful when I'm on my period. And I just, I hadn't really thought about it until that moment. And I didn't think anything of it and just carried on chatting to her. The radiologist then said to me 'look, it hasn't changed, which is neither a good nor a bad thing really. But rather than send you away and bring you back again, would you consent to a ultrasound guided needle biopsy of this lump now, and we can send it off to test, and find out exactly what it is?'

So, I said, 'yeah, let's do that, crack on'. Yeah, having a needle in your groin is not very comfortable at all. But he was very gentle, and he explained exactly what he was doing as he's doing it which was good, and he did warn me when he was about to take the biopsy sample because it makes quite a loud clicking sound, and it's like a punch isn't that really, like a holepunch I guess. So, he did warn me when he was about to do that which was good because otherwise I probably would have jumped a mile. So, he took a couple of samples and he said that they were really good samples, which was good.

So, he said to me afterwards he said 'right, I'm sending these off, as I said to you before, I don't think it's a lymph node, but we will put query lymphoma down to make sure that they pass that. And he said, I, 'I really think it's a thrombophlebitis' or something else, I can't remember what the other thing was. He said, 'but I noticed you just said something about it being painful, more painful, when you're on your period'. I was like like 'yeah?'. He said so 'I'm going to put on here query endometriosis'. And I said, 'right okay'. He said, 'I don't think that's what it is, but I have seen people with it in random places like their belly buttons'.

Ricky:

Yeah.

Lara:

So, he said, 'I don't think that's what it is, but I think it's worth putting it down'. So, I said, 'yeah okay, fine'. So, I came out of there thinking, right, best case scenario is it's this thrombophlebitis thing that will go away by itself. Worst case scenario is I've got cancer again and I need to figure that out. And then somewhere in the middle is this endometriosis, which, by this point I, as I said at the start, I had heard of it, but I didn't really know what it was. So, at that point, to me, that was quite a good outcome. But also, I was thinking, it's not that – it can't be that it's not that. So then, so then I just went about life as normal, and then the results took a while to come back because they were querying a lymphoma and the results go to the all-Wales lymphoma panel. So instead of taking sort of a week to 10 days to come back, it was more like three or four weeks. But that was fine, because I'm glad they were being thorough, so yeah so I got a call from the GP, which was the same GP that I've been seeing for this lump in my groin.

And he said to me 'I'm ringing with the results of the biopsy'. And I said okay, and he said, 'right' he said, 'the first thing is good news, it's not a lymphoma'.

And I was like, 'okay, that's great, fab'. He said 'it has come back, surprisingly, as endometrioses.

Now by this point I'd had a month or so to look at what endometriosis is. And funnily enough, it wasn't actually the positive outcome that I thought it might be, if that makes sense.

Ricky:

Yeah.

Lara:

So, you know, the GP was quite right, it's not cancer and that is pretty good, but at that moment I was being told that I have - or have had - a chronic condition that has no cure. And that was what was in my head was, okay, I know what it is, and I'm really glad to know what it is, but I did have that overwhelming feeling of - there is no cure for this condition.

Ricky:

Yeah, yeah.

Lara:

And so, he was being very positive on the phone and I said to him, I am really honestly really pleased that it's not cancer, but I do now have to get my head around that I've got this chronic condition. And also, I need to get my head around how that's going to impact on, like my life and also my plans with my husband and stuff like that. And so, we had a chat, and he was saying he'd been very, very emphatic all along, I was really grateful for that. He let me know the GP in the practice that had like a specialist interest in endometriosis, which was good to know as well. So yeah, so that takes us up to about a year ago, when I, when I got that diagnosis.

Ricky:

So, when you got the diagnosis. It's interesting. It's like, I try to put myself in your position thinking that you think, 'oh great, it's not cancer', and to most people that would be amazing, amazing news, but actually, like you said it was a diagnosis that was going to sort of impact for the rest of your life.

So, when you thought about that. How did you discuss it with your husband? How did you envisage that, your life would be impacted by it?

Lara:

Well, I think I just couldn't believe I had a chronic condition. And I would have had it all my life. From what I know of endometriosis, it's something that, you know, you're born with. And it doesn't manifest until you reach, you know, reproductive age, really - adolescence. What's it called?

Ricky:

Puberty

Lara:

Puberty, yeah that's the word. So yeah, so it doesn't manifest until that point. So, I couldn't believe that at the age of 31, I was having this diagnosis, when I had it all this time and not known about it.

It started to raise questions to me then. Could I have known about it sooner? Have I missed something? And it's certainly a conversation that me and my mum had. My mum would accompany me on quite a lot of appointments and stuff and, obviously, not obviously but I have quite a close relationship with my mom, and it's something that we talked about, like, could either of us have known and could we have done something sooner?

And I know those kinds of thoughts don't help because you can't go back in time, there's nothing - you can't change what has been, but you just can't help you there when you get something like that, particularly something that is, that has always been there. Yeah, so.

Yeah, after I got over the 'great it's not cancer' thoughts, which were very much there and it was then replaced with this feeling of disappointment, anxiety, really around having endometriosis and what's going to happen next. Because yeah, it wasn't the quick, it wasn't the quick fix, diagnosis, I was hoping it was going to be.

Ricky:

Yeah, it sounds to me even getting to that diagnosis that it took a lot of tenacity to get there you know, and you've really had to - for a number of years - and from what I've read, that seems to be consistent with a lot of women that are often they lived with the condition for a long, long time. And they had to take a lot of, I suppose to fight actually, to find out what's going on with them in the end.

Lara:

Yeah, I mean, for me, my GP practice is brilliant, and you know all GPs there are great, and I'm really, really grateful for that and so, the appointment from discussing about the lump in my groin and the next steps and stuff, I've felt able to challenge - challenge is probably the wrong word because I wasn't having an argument with him - but I felt able to say, 'but hang on a minute, if I need, if I'm going to have an ultrasound at some point then can't we just crack on and do it'.

And, but you know I've got a healthcare background and a lot of my friends and family, work in healthcare and I did send messages to a couple of friends before I had my GP appointment saying, 'just double checking, GPs can refer for ultrasound can they not?' And so, you know, I did do a bit of research about what I was entitled to have. So, that if I had to make my case that I would be able to.

And I think some of that comes from my experience of, like, having medical appointments and stuff and also the way that I've, I've been brought up as well. I've been brought up to like question things and ask questions and, you know, don't leave an appointment with a question. You know, because you'll regret it afterwards.

And so, I guess I kind of been brought up that way, but yeah you're right. A lot of the stuff that I read as well about other people's experiences of endometriosis and women's health issues, and women do have to be prepared to fight in some ways. And that makes me feel quite angry at times, because we're already putting up with a lot. And most of us, only go to the doctor

when we absolutely really need to. And so, we shouldn't really have to fight I don't think. But again, maybe that comes back to what we were talking about before about how women's health issues, particularly around menstruation, obviously it is like it's normal to put up with pain and discomfort and all of those things.

Ricky:

Absolutely, absolutely. So, when you've got your diagnosis and you've got this sort of label for what's going on you know what's going on with you now. How did that change your view? Or did it change your view of health? Of relationships? Of the future?

Lara:

I think it, I think suddenly things become a bit more urgent.

Ricky

Yeah

Lara

In the sense that, so for example, this journey of me being under gynae and things, and me and my husband had been trying to start a family.

Ricky

Yeah

Lara

So, by the point of diagnosis, we'd been trying for about a year, 18 months or more. And we've been able to try more because I'd had women's health physio and that had helped with that with that. So, we've been already trying for a year without success. And I'd had, by that point, two miscarriages. And so, we knew in the fertility department, if you like, that maybe things weren't going to be as plain sailing as one might hope.

And again, we just thought it was just going to take us time and because we've had so many difficulties with having intercourse and the pain and discomfort anyway, we just thought it was all sort of tied into that really. So yeah, so getting this diagnosis was really like. 'Right, okay, we have this diagnosis, that explains a lot and, okay, so this now maybe helps to explain why we've struggled to conceive and now it puts a bit more pressure, time pressure I guess on, you know, when we, you know what we're going to do fertility-wise and trying to start a family and things.

And I think again, thinking about society views and stuff, I think we're kind of brought up to expect that, when you decide to have children and start a family, it's just going to happen - you just decide, and then quite soon you'll then get pregnant.

And what I found since getting this diagnosis and I think, be more open about it. Speaking to people, I found a lot of people actually struggle to get pregnant, for different reasons. But nobody ever hears about it, nobody talks about it, but we all say the same thing - that we all thought that this would just happen for us.

And for me, I was very much like 'right I'm going to go to uni, and I'm going to get a job, and then I'm going to do all of this stuff, and then I'll get married, and then I'll start having a family at a certain point, and you just kind of expect that it's going to happen and then now knowing what we know now - with my diagnosis - it does make you think to yourself, I do think to myself - if I'd known this earlier in my life, when I was younger - it probably would have changed my thoughts around family and life plans and stuff like that, because it does make it a lot harder to get pregnant.

Ricky:

Yeah, yeah. And it's one of those things - going back to the how people speak - isn't it, it's, it's one of those topics we can't talk about. It feels like something we can't talk about fertility - in one way - but in another way, it's normal for somebody to come up and say 'when are you having kids? Are you having kids?' I find that really odd, it's a weird thing.

Lara:

Yeah, absolutely. Yeah, like expected. You know, people expect that people at some point are going to have kids. And you know, it's like one of those questions that you ask when you meet people like 'so, where are you from? Are you married? Have you got kids?'

You think to yourself, it's only since we've had difficulties that those sorts of questions become very difficult to answer. And, and yeah, it's something that I talk to people that I've spoken to who have similar difficulties around fertility. You know those are very difficult questions. But yeah I know, the diagnosis did it start to change our plans going forward I guess.

Ricky:

Can I ask you a question about, so, what support was there for you when this happened? Because these are a big sort of like perceptual changes about how your life might be different to how you envisage. So, who did you have to reach out to? What sort of things? And I suppose, as well, you know, I know your husband's not here today, but as a unit, you know, as a team, between you and your husband - where could you both go for support with this?

Lara:

So, when we got the diagnosis - and I say 'we', my husband says 'we', you know it's me, but it affects both of us.

So, when we got the diagnosis. I had my husband and my parents and friends, but I was kind of, I felt like I've kind of been left, if that makes sense.

So, I got the diagnosis from the GP. And one of the next things I did was to ring my gynae consultant secretary and request that you can check the clinical portal, because even though I went to gynae, this did not happen through gynae, this happened through the GP. So that was the next thing I did was request that my consultant check the clinical portal, and could they get back to me, and he did very quickly get back to me and request that I have an appointment for review. So that was good.

But in terms of support. Yeah, I didn't really know where to go. We didn't know anyone else, at that point, anybody that was having problems that we were having. I didn't know any other women that were experiencing the type of things that I was experiencing. And I didn't know anyone that had had women's health physio. I didn't know anyone that was struggling to conceive. I didn't know anybody that was having pain during intercourse. I didn't know anybody, and I did not know who...

As I say, I could talk to friends and family, my husband, and that for me that was a really good help, but nobody really knows what it's like, unless you're going through it. And so, like the miscarriages, for example, I didn't speak to anybody about them, and again who do you talk to? So, what did I do? I actually turned to my gynaecologist. I asked him, I said 'right, I need resources', I'm someone that likes to know the facts, I like to do my research, to me, knowledge is power, although sometimes knowledge is pretty bloody frightening at times. I need resources and I need reputable ones, and what can you suggest, and so he came back to me with Endometriosis UK and Fair Treatment for the Women of Wales.

And so those were the places that I went for information. Endometriosis UK website and Fair Treatment for the Women of Wales, I joined them. I think membership was about pound or something. And theirs is the only forum I will follow. So, they have a public Facebook page, and they also have a private group page for members. That is the only forum I will follow.

I know people take support in different ways, and there's probably lots and lots of blogs out there I know there are blogs - I've seen various blogs and things. And I think can occasionally dip into blogs or Instagram stuff, but I don't join groups or forums that are not - I say, like kind of reputable and are managed in the way that Fair Treatment for the Women of Wales one is.

So that's kind of where I went, and I was just kind of a bit of a silent member for a while. Just sort of reading people's advice and links and stuff like that. And, you know, kind of just over a year on now, and now and again I do comment and make suggestions for others, because I feel like I'm able to do that now. And so yeah, that's kind of how I found support really and how I research things.

Ricky:

It sounds to me. You know the words you were using - 'I didn't know anybody, I didn't know anybody who had this, I didn't know anybody experienced in this'. And the word as you were saying - the word in my mind was - forgive me if I'm wrong, you sounded quite isolated, you know. And I don't know if these, these mechanisms, these support groups helped?

Lara:

Yeah, you're right, I definitely felt isolated. I knew, I knew that there must be other women go through this. There had to be. If one in 10 women get endometriosis, then I couldn't be the only person - we couldn't be the only couple - having to deal with what we were having to deal with, with sex - which everyone talks about it and it's supposed to be really pleasurable - and I find it, you know at times really difficult. And it's like, we can't be the only people in the world, going through it and I knew that, but definitely felt isolated, because these are things that nobody talks about, and you find advice online and you've got to be careful what you search.

Ricky:

Exactly

Lara:

And also, I do want to find stuff that is, as I keep saying the word reputable but that's the only thing I can think of.

I want to find the advice that I need for me. I want it to be based on something, and I want to know that that is the correct advice or whatever. And so, when it comes to like the condition, treatment options, stuff like that, I want to make sure that that is all - you know - the right information.

But when it comes to support. I mean, I talk, I'm happy to talk about things but I wasn't, I wasn't at a support group of people. I didn't know, a group of people. I didn't, I wasn't ready for that. I just wanted one person, just somebody who I could trust and build up that trust and repour with quite quickly, and just talk about these things and hear somebody else say, 'yeah, I've had that. I've been through this. Have you tried this? Have you tried that?'

I mean, I go to the GP for advice about like intercourse and stuff, and they wouldn't be able to help me, and you come out of there come out of the GP appointment in tears. I was so embarrassed. I had psyched myself up to seek advice. And I come away without any advice, being told to look online, and I felt ridiculous. It sounds, and I'm saying it now and if anyone said that to me, I would be saying to them 'you're not ridiculous, not ridiculous at all'. But again, that's the thing, you know you psych yourself to try and get advice and then when you can't get it, you're still feeling where you were, which is kind of lost, without any kind of advice and support really.

Ricky:

It's funny, isn't it, you know, in my career as a nurse and as a lecturer and things we talk about like, sort of, you know with activities of living, in what people do every day and the important things that happen in people's lives and it's funny how that is so important. We talk about work, that's fine, to some degree, people are happy to talk about religion and spirituality. But the two topics that people, you know, I think sometimes health professionals struggle with - sex and death - is the things that we really struggle with, you know.

Lara:

Absolutely. And even now, like talking to you about it I'm having that unnerving feeling about it, and I feel embarrassed to talk about it but, like, you know everyone must have some thoughts or questions about it and yet nobody talks about it.

Ricky:

But it's important. It's one of those things. And I think that's one of the things that I think I'm grateful for and I'm sure people listening to it will be really grateful for - is the fact is that we should be having these things, these conversations, you know. I think we're better than we used to be, you know, I look back to, you know, growing up in the 80s when you had, you know Mary Whitehouse. The word sex was almost banned from television, or it was a uproar when somebody kissed and stuff like that, you know, we are moving on. It's just odd that we still find it so difficult for what is such a natural human thing, process, you know.

Lara:

And like you say, when it's something that people seem to expect that people couples are going to, you know, have children. But the fundamental part of that happening. And yet, people so easily seem to talk about, you know, 'have you got children?' or having families and stuff like that but nobody talks about the things that happened around that.

Ricky:

To get those children! Of how those children are produced. Yeah, it's almost like we'll talk about the kids - we don't want to talk about how they got there.

Lara:

Don't talk about that yeah. Exactly.

Ricky:

So, you've got this diagnosis now, and obviously there are treatments available. Like you said it's non-curative, but there are treatments available, you know. Later on, we'll find out a little bit more that you're due to undergo an operation, for your endometriosis. How did those sort of treatment options come about?

Lara:

So, my diagnosis, as we know, was kind of an accidental. So, normally, endometriosis - the only way to normally to diagnose it is through a laparoscopy. Which, you know, I think it's incredible, really, that there is no other way to diagnose this condition without surgery.

So yeah so I kind of went about it the wrong way really, because I had this diagnosis, but I don't. All I know is that there's a little lump on my groin - I don't know where else it is. And that's the thing about endometriosis.

The other thing about it is that it's very individual, to each person who has it, so no person will have the same, the same symptoms, and you could be riddled with it and have very little symptoms. Or you could have a little bit of it, and have really difficult symptoms, so your symptoms don't really correlate to the extent of the disease.

So, what happened next was I had my appointment with my gynaecologist, and he was like 'right okay, so we now have this diagnosis, lump in your groin, very interesting'. He said 'right, so treatment options were as follows: either hormone treatments like the pill to manage the symptoms like the abdominal pain and period pain and regulate periods and stuff like that, or surgery'.

So, for me, the hormone treatments weren't an option because they're counterproductive to trying to conceive. So, and also by doing that, I still don't know the extent of my endometriosis. Yeah, so we were like, we agreed that we would go down the laparoscopy route.

And by this point, so this is about, sort of – I got the diagnosis in December - so we're now in sort of January, February, March, - January, sorry. And so, I was listed for laparoscopy on the NHS on the routine list – which was fine.

So, then the problem then came the waiting lists. So, the waiting list was insane. I was on something called 'referral to treat pathway', which means that the clock begins from that referral for an investigation. So back in September / October time when my GP referred me for an ultrasound. That starts the clock ticking, and so on the 'referral to treat pathway' at the time I should have had my surgery within 36 weeks.

But having had conversations in sort of February / March time about roughly when might I be expecting to hear about the operation, it became apparent very quickly that I would exceed the 36 weeks wait from the start. So that didn't sit well with me. You know, to me, I was very much like 'well, surely this highlights a bigger problem that we, if the waiting lists - if you're predicting a breach already, what is there being done about that? But that's a wider question which we can think about later. So, so I was like, right, okay, so here I am now with the prospect of not having this surgery within the nine months. Is it nine months? 36 weeks is 9 months? Yeah?

Ricky:

Yeah

Lara:

Sorry my maths is appalling!

Ricky:

I'm trusting you to work that out! I'm trying to work it out in my head!

Lara:

To me, nine months is a hell of a long time to wait, particularly for something that is affecting fertility - which we all know women have a biological clock.

So, this didn't work for me very well. But I sat with it.

Then come March 2020 and we are in the midst of a global pandemic, and in lockdown and everything is kind of, everything is now off the table pretty much, because nobody knows what's happening.

So, round about the summer of 2020, spring / summer, having had conversations with my husband, and my family, I decided that I would opt for private treatment under the same consultant luckily, but privately.

And luckily I'd already had private medical insurance for a long time. And so, I was able to, to use that and again I'm really, really grateful for that. But again, with COVID happening, there is still no definite plan for surgery.

And in the meantime, in February of 2020, I had another miscarriage again so I was now three miscarriages, having tried to conceive for - I can't remember how long exactly off the top my head - and waiting for a surgery to finally - although I knew I had endometriosis - this operation is now going to tell us exactly where it is and what it's doing.

And so eventually I had the laparoscopy in October 2020 privately and that was interesting having to self-isolate before surgery and everything.

And it turns out that my endometriosis is quite widespread. So, there's little bits pretty much everywhere in my abdominal cavity, a little bit on the bowel, little bits on the small bowel, little bit under the ovaries in the very small space, little bit between the bladder and the uterus and another little bit between uterus and the bowel.

And so, my consultant described it as one of the most interesting presentations of endometriosis he's ever seen. I think having spoken to him and I had a colorectal surgeon I had to be present for the operation as well. Speaking to both of them. I think they seemed a bit surprised with how extensive it was.

And so again, I got a very big sense of relief when I heard exactly where it was because now I know exactly what we're dealing with. But also, I can't believe that it's in all of those places. And by this point, you asked me before about my symptoms, by this point I'd started to realise that I did have a lot more symptoms than I realised.

So, I have problems with bowel and urgency to go the toilet. Intermittent between constipation and latency. So, all of these little things that I just thought were normal, were now kind of coming together in this picture of 'actually, these could all be related to my endometriosis'. So, the difficulty conceiving, the bowel problems, the painful periods, the

pelvic pains, the pelvic floor problems. All of these things were now coming together and creating this picture of what endometriosis was doing inside me, without me knowing.

That bit of it I really struggled with - was the fact that I had a disease condition that I don't know, I did not know was there. It feels a bit strange really, that I can't see it.

Ricky:

Yeah, yeah

Lara:

I really struggled with all of this is going on inside my body and I didn't know about it for years. And even though I know now. Not really many options for dealing with.

Ricky:

Yeah, there's a lot of literature about like hidden disorders and the hidden body. Certainly, when it comes up. Do you know what, some things struck me as you were saying those things then about putting everything together? Is again, they're all the things we find difficult talking about. And I think, you know, hopefully, you know a lot of students listen to this, you know from healthcare, whether it's nursing, OT, medicine, physio, whatever. I think it demonstrates, really, that there shouldn't be barriers to these conversations, obviously they've got to be done in a sensitive way, and obviously done it the right way, but avoiding these topics is not the right thing to do. You know that, like you said, if we get bigger picture what's going on with people.

Lara

Yeah, and I think, you know, sometimes, sometimes that's about giving people a chance to speak about things that are maybe on their mind and they're worried about. But for me, a couple of these things being symptoms - I didn't realise that that wasn't normal. And I mean, who talks about their bowel habits? Like, I come up with strategies. So, I knew that in the mornings is my worst time so I had to time that my journey to work and I had to get up early, in order to give my system chance to get going, so that I wouldn't get caught short somewhere. You know, things like that, but I just sort of just did, and then actually now. It's now actually I've got that gynae saying to me, 'well, you've got endometriosis in this area, that would probably explain that problem with your bowels, and things like having pain when you're trying to go to the toilet'. Like, again, coming back to what's acceptable.

Ricky:

Yeah

Lara:

I just thought it was normal if you had a bit of a difficult bowel movement that you're going to have pain with it, you know. But you know, that's not normal, like if that's happening a lot, like consistently, and if you get in a pattern – that's not normal. Yeah, so yeah it did - that surgery did. It did answer a lot of questions, and that was the first time since I've had the diagnosis that I had a sense of relief I think – because I finally had answers, like proper answers.

Ricky:

Yeah. So, you're due for surgery soon?

Lara:

Yeah, So, I've got a follow up surgery in a week's time. So yeah, the last one was an exploratory laparoscopy. They did do a little bit of excision where they take away some of the endometriosis. So, they did that in some areas of the bowel, because they had the colorectal surgeon present.

And but there was too much for them to do in one in one sitting, if you like. So, yeah, so my next surgery now is what they tend to call excision surgery where they're going to now remove as much of the endometriosis as they can.

The aim of that for me - so, it's different for different people - but some people, they have the surgery, for symptom management and pain management. For others, it's around fertility and for me it's about fertility. So, so yeah, so that is a week's time. So yeah, gearing up for that.

Ricky:

And you've kindly agreed to keep an audio diary. So, people listening to this will sort of be able to hear your journey through that surgery then.

Lara:

Yeah, yeah. I will do my best to keep an audio diary of sort of what goes on, and yeah, and how my recovery is.

Ricky:

Okay, well. Best of luck with the surgery. And what we'll do is we'll catch up with you, and listen through your diary, you know which like you say, you've kindly agreed to share with us. And we'll chat again, on the other side. All right?

Lara:

Yeah, that will be great.

Ricky:

Thanks so much for this Lara, I really appreciate it.

Lara:

Thanks Ricky

Ricky:

In the next episode, you'll hear Lara's journey through hospitalisation, and she goes to treatment for endometriosis. And in the meantime, if you'd like more information on the condition please visit the Facebook page for Fair Treatment for the Women of Wales, as well as organisations such as Endometriosis.org. Thank you.