

Lara: My Endometriosis – part 2

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.

In this episode, Lara has really kindly recorded a voice diary, talks us through her thoughts and the process of going through treatment for her endometriosis. So, over to Lara.

Lara Cowpe:

So, it's nine days before my second operation. Sunday night, and I'm feeling a little bit anxious about the COVID test, so I have to have a test on the Friday before the operation. So, I'll go in and I'll have the COVID test and also a pre-op blood test as well, but it's just a bit anxiety provoking really because until I have the test I don't know if the operation can go ahead or not.

And although I'm being as strict as I can and being really cautious you know there's always that sort of thread of doubt that you know I could have it without knowing it, I could have already had it. You just don't know and last time - the last operation I had and had the COVID test, last time they said that it could take up to 72 hours for the results to come back and that they won't call me it's negative, so I pretty much spent like the three days afterwards before the operation like waiting to see if I was going to get the call or not.

So yeah that's on my mind tonight and that kind of adds to the anxiety of having an operation, is the whole uncertainty around COVID and of course I keep reminding myself that there could be other things that could cancel surgery anyway that, you know, I'm not in control of either, you know they could decide to stop doing the surgery because of COVID generally, so yeah so anyway so that's something that's weighing on my mind a bit. Yeah.

I'm going to be working from home right up until the date and I've been working from home since March anyway, so nothing new there and I'm trying to keep as fit and active as I can because I know that the fitter I am before surgery, the quicker my recovery is likely to be hopefully so trying to keep that up.

Yes, it's just little things like starting to run out of certain foods in the house and I'm like should we get some in because even if we did get delivery - which we would have to do because you can't go to the shop - even if you've got delivery is still like another chance that COVID could be transported into the house, so it's just things like that you know when really before an operation you know it's hard in enough as it is without all of this going on.

But I'm lucky that you know we're able to self-isolate and I've got space to work from home and I know there are people who have had to isolate either for the first operation or just genuinely had to self-isolate and they've been confined to like one room in the house and that

must be incredibly hard. I'm finding this hard enough and I can go into different rooms and things but yeah that must be it must be really, really tough.

So, fingers crossed - Friday that the test will be negative, and that I won't get a phone call about it and everything will go ahead.

Another thing about this COVID situation is that I'm a bit of a worrier - and if I were saying 'a bit of a worry' in front of my husband or my family or close friends they'd be like 'yeah okay understatement. Yeah okay'. So, yeah I'm a worrier and I'm one of life's people who pretty if there's something I could worry about, I will worry about it.

And I've worked really hard over the past couple of years to kind of keep a lid on it - not a lid on it in the sense that it will combust at some point - but I mean, getting a handle on it, and learning ways to manage my worries and anxieties.

A lot of these things are normal, you know, being, you know, worried about, you know, first day in a job or, you know, those usual like feelings that you go on a Sunday night before work and stuff like that. And if you've got a really important meeting to go to, or an important appointment or something like that, you know, it's on your mind, and then those things are absolutely normal. But a couple of years ago, I needed to recognise actually, normal situations were causing me a lot of emotional upset and causing me a lot of anxiety. And so, I decided that I didn't want to be like that anymore.

I didn't want to lose that part of me that cared. And I think for me, personally, a lot of my worries and anxieties come from, I just because I care too much, sometimes. Too much, maybe. But I just care a lot about people, about situations, about doing my best, being the best that I can be, you know, and taking care of the people that are important to me. And that's, that's all great, but I think it's important that we recognise when worry and anxiety is actually too much. And it's almost like detrimental to our well-being. And that happened for me a couple of years ago, so I decided that I was going to do something about it. And I paid to have CBT, because I just didn't want to wait on the waiting lists. And also, I felt that I you know, I could do that and potentially not take up space for someone else who really needed it.

And so had CBT. And it was quite expensive, but probably some of the best money I've ever spent in my life. Because it taught me so much about recognising your thoughts, and understanding that, you know, thoughts are, they are just thoughts, and how to stop that kind of spiral of worry. And even if you're in the spiral before you realise you are, which happened to me a lot, it's about recognising that that's okay. But there is a way to kind of stop that, stop in its tracks almost and think about something else or do something else. And that was really helpful.

But what I'm coming on to is that COVID has really challenged me in lots of ways, particularly around worry and anxiety and in preparation for this operation. It's added that extra dimension on to it, where not only am I anxious about having this operation, and all of the things that go with that, but I'm also anxious about COVID. I mean, I could get COVID before this operation, and then the operation be cancelled. But equally I could get it afterwards when I'm recovering and when my body is weaker and trying to repair and how might that be.

So COVID really is a massive, massive test. For people going through, you know what I'm going through. But people generally from different walks of life, you know, this is massively challenging for people who probably err more towards worrying anxiety and rumination. And this is just a catalyst for that really. And I'm really having to keep a check on that.

And, you know, I could probably talk about it most days, but I try really, really hard not to moan, worry and verbalise that to people because well - no one wants to hear me moan on and on and on about the same with stuff.

Also, not just that though. There is nothing I can do about it. I can only control what I can control, which is making sure that I abide by the rules and the restrictions. Anything coming into the house is quarantined in an area and sprayed and stuff like that with antibacterial stuff. And so, I can only control me, and my actions, I can't control other things. So, I need to remind myself of that and even saying it now while I'm recording this, it's, it's helping and I'm like, 'yeah, okay, that's correct'. You only can only do so much, you can only do what you can do. So, after the COVID worry has been put to one side for one moment, there's then that worry about surgery. And, again, I'm trying very hard not to ruminate about it too much, because it will send me into a panic.

I mean, I'm coming back to COVID, again, I was going to not spend most of this recording talking without COVID. But anyway, it's there again. So, let's go with it. Just the thing, like having to go into the hospital by myself. I get dropped off at the door by my husband who I can't kiss or hug because, you know, COVID. And then I go into the hospital and then I'm there, on my own, in a room until next day, when he wakes me up.

And for me, that is one of the hardest things about this experience of having an operation during COVID. And having the operation full stop is being on my own. And I know, you know, there are other people who do it. And it's great and everyone's different and a fully understand that. But for me, it's really, really difficult waiting on my own.

I've had a lot of operations, appointments in the past. And for every operation that I've had, I have had somebody with me, family member, and that's just that's just really important to me. It helps me to feel calm, helps me to feel not alone. So having to wait in that room by myself, waiting to be brought down. It's really hard. And I really struggled with that last time I was in. Just feel alone and isolated.

And I spent most of the time post-op that evening on the night speaking to people on WhatsApp, ringing my family, because I couldn't bear being in the room by myself, feeling I was in pain from the op. I was a bit tired, but I wasn't tired enough to sleep, and there were buzzers going off. And I had to have the door open even though there was noise out in the corridor, but I just don't want to have the door shut.

So yeah, it was it was really hard. So yeah. Being on your own, it's horrible. And I think to myself, I'm you know, I'm perfectly capable of entertaining myself and I've got my phone and I've got my iPad, not my iPad, my tablet thing. You know, I can call someone if I want to, but, and I've got people around me and other people, but what about other people? People who maybe don't have the means to do that.

You know, think of how many people during this pandemic have had to go through, you know, maybe more serious operations than what I'm going through, on their own, waiting on their own, coming round on their own. Coming round from the operation on their own.

And the staff are there and they're, you know, they're lovely, and they do their best and I am so grateful for that. But nothing for me nothing beats having someone you know, someone that's close to you with you. And I that's just one thing that I just don't understand. When if people's partners, or whoever is able to self-isolate with them, why can't they come in with them? Why can't they have a COVID test too? So, people don't have to go through stuff on their own, it's so hard, so hard.

Music plays

I want to talk about menstrual well-being on the national curriculum. This is something that, I'm going to be honest here, is starting to really, really frustrate me. And it's very, very irritating. That basically in Wales, the Senedd continuously votes against amendments to the education bill, to include menstrual well-being on the new curriculum. And the thing is, that England and Scotland have included it. Also, if you're following any of these sorts of topics in the news, you will know that Scotland is the first UK nation to pass a bill to end period poverty. And so, I just don't understand why Wales is failing, our young people and why it's being continuously voted not to make menstrual wellbeing, compulsory, within the national curriculum.

Now, the types of feedback that I've had from letters that I've written to my local Senedd member and getting a response from the education minister is well, it's a very detailed letter. In summary, it's saying that, you know, the curriculum gives schools flexibility, which is fine. But to me, and to lots of us, menstrual well-being needs to be compulsory in the curriculum. And schools need to be given guidance on how to address it because menstrual wellbeing generally is still a massive taboo. And when I considered doing this, what I'm now calling my endo diary, I had really big reservations about doing it. And deep down I know that those reservations are down to, you know, societal views, opinions, or behaviour, I guess, around menstrual and women's issues.

You know, these are very, very personal things. And they're not talked about, they're not discussed. And ironically, the only way they are discussed is in a way that normalises the pain, and discomfort and distress that we go through, you know, month after month, after month.

Normalising the pain, you know, that this is just a period. This is what everyone, every woman gets. And it's not right. And in this day and age, just think for a moment. Think for a moment what it is like for someone living with a condition where pain is normalised. Like how is that, how is that appropriate? How is that even possible these days?

So yesterday, the Senedd voted against an amendment to have menstrual well-being included in the curriculum, I believe that another amendment is going to be taken forward. So, we will watch this space and live in hope that Wales will basically wake up and stop failing us, stop failing our young people. Young people need to understand, need to be taught how our bodies work, and how – in inverted commas - they 'normally' work.

And to be in severe pain, every time you have your period, to have, you know, horrendous bleeding, to the point where you feel like you can't leave the house. You know, this is something that someone women. You know, being sick, you know these sorts of things need to be investigated.

From my experience, I am sure, if I had had, if I'd been educated about menstrual well-being, I am sure I would have questioned some of my symptoms a long time ago. Even if not the period symptoms, but the other symptoms with regards to pain and discomfort down below.

You know, that's not, that's not normal. And when I say that, I mean, pain and discomfort during intercourse. And this is something that I just thought was normal for, you know, your first time. But for us, it became apparent that it wasn't getting any better no matter what we did. And then becomes a problem of well, if that's not going to work, then how are we going to start a family? And it was only through a GP questioning my tolerance of a routine smear test where the issue finally got brought to light. And I know that if someone said to me, 'yeah, no, that's not normal for it to be continuously painful, intolerable, etc.', I would have, I would have questioned things a lot sooner.

And so, what I'm trying to say here is we need to stop normalising painful periods. We need stop normalising the, often debilitating, symptoms that women get around their cycle, their menstrual cycle. And we need to teach our young people, boys and girls, about how their bodies work and what to expect, and when they need to seek support.

I can't tell you why this amendment continuously gets voted down in Wales. I just don't understand. So, let's hope that Wales will do the right thing by our young people. Follow the example of our neighbouring countries in the UK, other settings, and in Scotland and place menstrual well-being on the new curriculum in Wales.

Music plays

An update on the topics covered in the previous recording, which was recorded on 29th of January 2021. On the second of March 2021, the amendment to make menstrual wellbeing education mandatory was not passed in the Senedd, with 26 votes in favour and 28 against. The Education Minister has instead committed to including the topic in the statutory code underpinning mandatory relationships and sexuality education. Both Fair treatment for the Women of Wales and Endometriosis UK have maintained that periods / period health, are a health and well-being issue rather than sitting within relationships and sexuality. This stance won't change, but they will do their best to ensure that wherever the topic is covered, that it has a health focus, so that all pupils know what is normal, and what isn't. And are empowered to seek medical attention when necessary. To find out more about this, please follow Fair Treatment for the women of Wales and Endometriosis UK.

Music plays

It's the morning of my operation and just to update you on what's been going on the last couple of days. So, it's Tuesday morning today. On Friday morning, I went to the hospital to have my COVID test. And also pre-op bloods. So, I think they do a full blood count, a blood typing test, so they know what my blood type is. Renal function, I think was another one. And

there might have been something else, I can't remember now what that was. They also did a 12-point ECG this time, which I didn't have before. And I did ask the nurse. And she said sometimes they ask for it. Sometimes they don't. So anyway, that was done. And that was all fine. And a couple of days before that I'd had a telephone call. And they'd gone through the pre-op assessment form with me. So, asking all about my medical history, any allergies I've got, how I was feeling about the operation, who's bringing me into the hospital, things like that.

Also on Friday, I had a Zoom consultation with my gynaecologist. And we went through the pre-op consent form online and had a discussion about that together. And we also discuss that today when I go into the hospital they'll sort of recap the consent form today as well.

Because I've got a gynaecologist and a urology surgeon present today. I also had a telephone call in the week from the urology surgeon, and he was just explaining to me his role in the operation. So, he's involved because the endometriosis that I have is, the urology surgeon is involved, because my endometriosis is quite close to my bladder, and potentially the ureters as well which are the tubes leading to the kidneys. So, his role in the operation is to insert a camera into the bladder, and then identify the two ureters and insert tiny little stents into the ureters. And what this does is it identifies them for the surgeon so that they can see where they are because they're quite difficult to see. They also help to protect them during the operation. And I was told that the stents light up. So, my ureters will be effectively glowing today and then at the end of the operation, the stents come back out again. So that's what the urology surgeon is there for.

And then the rest of the operation will be led by the gynae surgeon who will be excising my endometriosis. There's, I think there is debate about excision versus ablation. Ablation is where they like burn it away. And excision is, I think both have benefits but, for in my case excision, the benefits outweigh the benefits of ablation. So my endometriosis, will be excised today. And it will be the endometriosis around, near my uterus, bladder, rectum, and underneath my ovaries, as I understand it. And so, my, my understanding is the endometriosis is in the space between these organs. And so hopefully it will be relatively straightforward to remove today, although it will be quite delicate surgery.

So, I'm just I'm just getting ready to leave for the hospital. I've got my, my overnight bag pack, just had a shower and washed my hair because I'm not going to be able to do that for about 10 to 14 days until my dressings come off. So yeah, so I've done that.

I last ate something before 6am this morning, and I can drink water until 10am and then I need to I need to stop having any water then. Yeah, so, I'm just going to get ready. And I might be able to do a recording when I'm in the hospital when I'm waiting but, if not, I will speak with you on the other side.

Music plays

I'm back in my room after the operation. I probably sound a bit groggy because my mouth is a bit dry from the anaesthetic. I think I was in theatre for about three to four hours. But apparently it's gone well. The gynae surgeon is going to come and see me later. That's what he said anyway, so I hope so. So he can tell me what went on. I haven't got a catheter or

anything. So that means that from an urology point of view, it went okay, hopefully. Yeah so I'm just laying here now trying to feel a little bit more awake.

I've got TED stockings on and little inflatable booties on my feet and I've got a fancy new thing on my head. This little sticker on my forehead which is attached to a line, and it continuously measures my temperature. So that's quite a new thing. I've never had that before. And I don't think they had it back in October when they had my last operation so, so that's interesting. And I'm attached to a drip which is giving me fluids, I believe. And I've been given quite powerful pain relief. I have been assisted to the toilet because they want me to try and pass urine. That hasn't happened yet. So, I am waiting patiently for my body to wake up and allow me to pass a bit of urine. So that will good.

I've had a phone call with my husband to let him know that I'm back in the room, yeah and with my parents. So that's nice that I've been able to speak to family.

So, yeah I'm just I'm just waiting here now. Might put a put of music on my phone and just, probably keep closing my eyes a little bit because I am quite tired. I'll check back in later.

Music plays

It's about half past one in the morning and I've probably woken up every 40 minutes or so. My little inflatable booties which seem to be inflating every 10 seconds, as pleasant as it feels, they are little bit noisy. I don't know if you can hear in the background. So yeah, but I am sleeping a bit better than I did last time I was in, so that's a bonus. I think you don't really tend to sleep very well in hospital really, particularly after an operation. And I keep needing to go to the bathroom, I have finally been able to pass urine, which is great, but it takes a while. I have to sit there, and the nurses are being great. So, I need to be helped to the toilet and the moment and they wait outside. Yeah that's okay. I have felt a bit sick as well so I've had to have some anti-sickness medication and some additional pain relief and maybe as you can hear my mouth is still quite dry from the anaesthetic.

I have managed to eat something in the evening, no right now, it's very early in the evening, but last evening I did have something to eat. So that was fine and then I'm just keeping on drinking water because I need to keep hydrated and I need to keep going to the toilet. And also helping my mouth not feel so dry.

The gynae surgeon did come to see me last evening and I'll tell you a bit more about that in the morning.

But he said the surgery went well from his point of view so that's great and I'll check back in in the morning.

Music plays

It's quarter to seven on the third of February and I have been home since mid-morning and I'm really, really glad to be home sat on my own sofa, and just having my feet up. I said that I would let you know about what the gynae surgeon told me after the operation. So, he

explained to me that my endometriosis is quite widespread. So, he has excised it, removed it from various areas of my pelvis including under my ovaries, and various parts of the peritoneum, near the bladder, ureter, rectum, pouch of Douglas, and near my uterus and ovaries as well. He has taken a small area off a small part of the rectum as well and that went fine and the urology surgeon was happy with my ureters, so they were, they inserted some stents into my ureters and then they light up to help identify them and protect them during the surgery. So, they're still intact and the stents were removed so that was good. So, everything went really well from the gynae surgeon's point of view.

The only, the only other thing is that we already knew that there was an area of endometriosis on the terminal ileum, so the end of the small bowel, just before it joins the large bowel, and we knew that that was there. But some of the pictures from the surgery show the endometriosis almost it's within the ileum muscle, the tissue of the bowel, and it's like puckering the tissue and it looks as though it is constricting the ileum and narrowing it. So, although I don't have any symptoms that I can particularly note from that, it is something that needs to be thought about. I think anyway, if it is narrowing that section of my, my small bowel. So, what we're going to do is we're going to compare the images from this surgery, with the images from my surgery in October. And see, hopefully, they might give an indication of whether that area has changed at all or remained the same. And also, we will speak to a gastroenterologist and see what their opinion is on that on that area. So that's the one area that hasn't been removed or anything done with it. So yes, we'll have to wait and see what happens.

But at the moment, I just had my dinner, my stomach is really quite swollen, of course because they've filled me with quite a lot of air in order to do the surgery. So, my stomach is very swollen and bloated, and I'm really quite sore. So, when I walk I'm needing to hold on to my husband's arm for a bit of support. Yeah, so I'm just taking it easy. And I'm probably going to have an early night because I keep nodding off.

Music plays

It's the 6th of February, I am four days post-op, just to give you a little update on where I'm at. So, I able to stand a bit taller when I walk. I'm not sort of, kind of, hunched over trying to sort of protect my tummy. So that's good.

I've got some bruising coming out on the right-hand side of my stomach so that worried me a little bit this morning. So, I've messaged my consultant about it. And I had some other bruising I noticed two days ago on my back. And it seems that it's just post-op bruising coming out. So that's good. But yeah, it's always a bit disconcerting when you get new marks appear. And you're like, 'Oh, you know, should I just monitor that? Or do I need to do something about it?' But I haven't got any additional pain there, so I guess I'm just going to keep an eye on it.

What else has happened today? Yes, going to the toilet is still a bit of an ordeal because it really burns when I wee, which is not conducive to trying to empty your bladder because your body wants to go 'No, no, no, no, no, don't let any more come out because it hurts'. So yeah, you just have to sort of sit there and just breathe.

Yeah, and every time I think it's getting better the next time it gets worse again. So, but I did have a catheter in during the operation, so I understand why it is sore. But I guess I just need

to keep an eye on it and hope that it continues to get better. But I'm trying really hard to make sure that I'm emptying my bladder fully each time I go to the toilet. Because, you know you need to do that otherwise your bladder is going to become irritated and, you know, you could get further problems. So, if that means that I have to sit there for a little bit longer than that's what I need to do.

So, so yeah, otherwise pain is doing okay. I'm on still on the paracetamol, making sure I'm taking that regularly. And yeah it's fine. Yeah it's a bit uncomfortable at night at the moment. I did try lying on one side last night, but I can't seem to do that for very long. So, I have to spend most of the night lying on my back, which is okay but it's not great staying in one position and I don't know if it's because of the swelling or just because I don't normally sleep on my back but my lower back gets a bit sore.

So, by the time it's like 6am, I'm like 'right I need to get up because I've got to move'. But yeah, otherwise, touch wood, I'm pleased with how I'm doing at the moment and comparing to last surgery, which was similar, but not the same. I seem to be doing well. So yeah, I'm really pleased about that. Yeah, it's good.

Today, I put a post on my Facebook about this second operation and about endometriosis generally, and how I feel about talking about it. And I was in two minds about doing it, which I kind of still am, as I'm recording this and in two minds about whether I want to go through with this or not, and I'm kind of battling with myself about that. And I think what it comes down to is the topic really. Your menstrual well-being and reproductive issues are just not talked about and even now I'm sitting here are I'm feeling a bit awkward about it. If I'm honest with you. You know those feelings, like I said in my post, is why should I talk about it? Why do I need to do that? Why should I put myself through that?

You know, it's really difficult. Who's going to want to listen? What will people think, or people say? You know, and a lot of the stuff that I'm talking about and I'm telling you about is quite personal. And it's topics and things that we just don't want to talk about. It's embarrassing. Yeah, it's just not done. It's not the done thing. And a lot of these things still seen as to be as taboo. But, as difficult as I'm finding this, there is a stronger part of me, that is telling me to just do it. Because this is exactly what I needed. You know, well I need it now, but I needed it before. My husband needed it, when we were having difficulties, and all the symptoms I was having, and we'd say to each other 'is there anyone else going through this? Are there any other couples having to do what we're dealing with?'

And so, it's those things that I remind myself of, which pushes me to do this. Pushes me to put this out there and talk about these things, because they happen, they are real. And unless we talk about it, people aren't going to know about it, people aren't going to want to talk about it. And then people aren't going to get diagnosed. And they're going to go on and on and on. Not knowing what is wrong. And people not understanding what is wrong. So that's what is continually pushing me to do this and push me to put that post out there today.

Because I want to raise awareness. And I want to do something to try and help to make a difference. And I know that's not going to happen overnight and this probably isn't going to change a lot of stuff. But you know, even if it helps one person. Even if there's one person listening to this thinking that this resonates with them or someone's listening to this thinking

that you can feel like you have a little bit more understanding of what people are going through then that's great. But yeah, it's not easy to do. It's not easy to put that out there. But so yeah I did that today. I'm glad I've done that. I've had a lot of comments. Okay they are family and friends, I've had a lot of comments you know encouraging me and wishing me well and you know, that just again, that just reminded me that people are kind. That people do want to know and try and understand and they recognise what I'm trying to do here. So that's great. So, if any of you guys are listening to this, and if you remember my post, just to say thank you very much. You know, those comment, and those little likes, they really mean a lot. They really do.

Music plays

I just want to mention briefly here about the wonders that are compression stockings. Now, those of us who have heard of them will probably know that there is research to suggest that they help prevent DVT post-surgery. And I've been advised to wear them until I'm fully mobile. So, I am doing as I'm told, however, I have to say they are one of the most difficult garments to actually get on your feet, particularly if you've had a surgery, which means you can't really bend very well, at your midriff, which makes reaching your feet quite tricky.

Also, you're already tired, and you kind of need all the energy you can muster to try and get these things over your toes, and then over your heels and pull them up your leg as far as your knee. They are incredibly fetching; I have to say. The other thing is that they aren't that warm so one likes to wear socks on top of them which then leads to the problem of toe comfort. So, I don't know if anyone out there is in agreement with me that the placing of the toe of the sock, is very important and if it's not quite right it drives you a little bit stir crazy. So, it's quite difficult to get a sock on top of a compression stocking, and then get the toes to have enough wiggle room. So, it's probably taken me about 10 minutes to both my compression stockings and then my socks on top to the point where I actually feel comfortable and can carry on with my day.

So, I think it just makes me wonder how people manage with these things. It's one of those things where we're told we should wear them and advise patients to wear them. But actually, the logistics of actually getting them on and off is really quite difficult. If I'm honest with you, they're not really something I would choose to keep on, you know, more than one day really because you know they're not that comfortable on the knee and they are a bit itchy as well. So, it's not really something I choose to keep on my feet without changing them, so yeah but I guess that's just one other thing to ponder really, thinking about, you know, the precautions and the advice that we give patients, particularly with things like this which are actually quite difficult to put on and off even for the most able people person. Yeah, so there we are, hoping I don't have to wear them for that much longer. But I am wearing them for now.

Music plays

Today is day 10 post-op and today is the day that I removed my dressings. So that went fine. It took a little while because they're quite sticky and it's quite sore. And there were five of them altogether. But I had a little moment where, when I remove the dressing covering my belly button, in that my belly button may no longer be present, which I was not expecting. Yeah the belly button, or the navel, I once read somewhere is the first scar that we have and as we

know is where the umbilical cord was connected when we were babies and I guess for most of us, we probably don't focus a lot on our belly buttons.

But yeah, I, yeah, I was not expecting it to look how it looks at the moment. So, I'm kind of hoping that my tummy is still quite swollen from the surgery, which may be contributing to how it looks at the moment. But yeah, I was a little bit taken aback. And I was also taken aback by my reaction to it as well, because but it's a belly button. But I guess it's one of those things where you're expecting something to look how you expect it to look, how it's always looked, and then when it doesn't look like that, it can take you aback and take you by surprise. And yeah, I guess that's what happened to me today. And so, I know it's just a small little thing and in the grand scheme of life, it's fine. It doesn't matter. At the end of the day, what it looks like, because I had to have this operation. There was no option, so in the grand scheme of things it's a teeny tiny thing. But yeah, it just goes to show sometimes how sometimes something can take you by surprise and you can react in a way you weren't expecting so yesterday was one of those days where something happened, I wasn't expecting it and yeah. I was a bit sad. I've got to say, but it'll be fine.

My scars are healing well, otherwise. And hopefully when my tummy stops being so swollen, my belly button will still look a little bit like it used to look, maybe not the same. And in any case, it just is part of my battle scars I guess. And every scar tells a story.

Music plays

Today is two weeks post-op, I can't believe how fast it's gone. It's quite mad really, how quickly time can go by. So where am I at? I am, I think I'm doing well and I'm still with walking with my husband. So, it helps him to have him – not lean on, a lot – but to support me when I'm walking.

So, I've been trying to do that each day, I think there has been the odd day or two where we haven't been for a walk. But I think that's okay, you know, it's important that I listen to my body so yeah. So, I've been walking each day, some days the walks are shorter than others but I'm starting to notice a difference in the pace that I'm able to walk. So, to start with it was really, really slow and what I was finding was, when we'd get to a certain point and then we'd turn around, so I didn't have too far to turn back. And on the walk back I would get this, sort of, overwhelming feeling of tiredness and that's slowly getting better but still there a little bit.

So yes, I'm pleased that I've been able to do that. We have a dog who comes with us for a walk. But I'm not yet able to hold her lead yet because she does pull a little bit and I'm just not feeling very confident. So yeah, so I'm trying to walk a short distance each way with support. Um, what else? My pain. My pain is getting better. I'm still taking pain relief regularly each day and I do wake up in the night, if I'm trying to sort of turn in my sleep. I am sometimes waking up because my stomach muscles are so aching, and I remember that from my last surgery. And so yeah, obviously so still recovering there.

But yeah, the pain is manageable and under control. So that's really good. Otherwise, mentally I think up and down. So, I'm having days where I'm feeling really good in myself, and then days when I'm feeling a bit down just about the surgery and everything that's going on with regards to having endometriosis and fertility and all of those things.

So yeah, I think a bit up and down. And I'm also noticing things like concentration is still not quite there. So, I'm kind of struggling, I've got loads of books to read but I'm kind of struggling to focus. And also, if I'm reading I tend to get very tired. So, I'm looking forward to that coming back a bit, and I'm also forgetting things as well. Just little things like, like, me, my husband having a Zoom call with our parents, or his parents, and I forget that we're doing that. Until he comes into the room and is like, 'right so we're going to speak to my parents now' and I'm like 'are we?'. So yeah, just little things like that. So yeah, but again, you know, I recognise some of this from before, and just, it will, it will come, and I think the tiredness and fatigue has a lot to do with that.

Otherwise, I don't think there's anything else to comment on really, other than I spoke to my GP today, because the hospital where I had my surgery, they provided a sick note, but just for two weeks. So, I spoke to the GP today, and I'm having, I've got another sick note now for another six weeks, which to me feels like a long time, but as the GP said it does go by quite quickly. And she said that we can always review things. So yes. So, I've got that. And one of the things that the neurologists suggested pre-surgery was to have a renal function test post-surgery. So just to check that that's okay. So, I need to go and have that done and a blood test at the doctors. So, we need to go and have that done at some point soon. So, today is one of the good days, so I'm feeling upbeat and pleased with how things are going far.

Music plays

It's day 25 post-op and I'm recording this because, well, I wasn't going to record this now, I was going to talk about this in more detail in my final interview with Ricky, but while I've been thinking about it, I feel like I really need to, I should probably record this now. Because I don't want to forget the message that I want to get across here.

So last night, and just as I was getting ready to go to sleep, I said to my husband, 'do you know something? The one thing from my cancer treatment as a child that had a big question mark over it for years, and years, and years, was fertility, and if my fertility had been affected by that and what a horrible twist of fate – if I can call it that - that my fertility has not been affected by a potential life-threatening condition and the toxic medication that I had to take to get rid of it. But by a completely separate condition, that is chronic and that I have to live with for the rest of my life. And it really struck me, that was the first time I thought about that in that way, and it has really kind of smacked me in the face, I guess.

As a cancer survivor, and if wants to hear more about that story, you can listen to my, the other podcasts that Ricky has recorded and released previously on this podcast channel, I can only speak from my personal experience, but I, you know, I wouldn't be surprised if there are other people who maybe feel this way. As a cancer survivor, I often feel like I can do anything. I think back to that time, and I think, I had cancer, I had stage three or four cancer. I had a tumour in my chest, the size of a grapefruit, which is massive anyway, but particularly for a seven-year-old. I had chemotherapy treatment for two years, and I had follow-up until I was 16. I went through all of that, and it went, it's gone. And I didn't have any lasting effects or late effects - that I'm aware of anyway.

And so, there is a part of you that feels like you could do anything. Like you, you fought cancer, it's gone. And, and you were a child at the time. And, you know, there's something pretty, I

don't know, there's something quite sort of phenomenal about that. Having gone through all of that, not just for me, but for my family and our friends that were around at that time. You know, you know, everyone's kind of going through it with you, everyone's kind of got their own journey of it, if you like. I got through it, and they got through it. And so, there is a part of me that feels like, 'well anything's possible', within reason, but, you know, anything's possible.

And also, part of that comes down to my upbringing as well. My parents have always encouraged me and my brother to be the best that we can be. And if there's something that we want to do, then you know go for it, if there's an opportunity, you should grab it with both hands. And if it works out, great. If it doesn't, that's fine. We'll just pick ourselves up, dust ourselves off, and we'll find another way.

And, you know, so there is that that really quite strong part of me. But then that is countered, or constantly fighting, with another part of you. Which I guess can only be described as the fear of something bad happening. And there is nothing really that you can do to kind of get rid of that feeling because you know what it's like to go through something that horrendous. You know what it's like when things go wrong. And you know, how quickly your life can change.

And coming back to endometriosis, you know, this journey is really hard. And there is that part of me that's like, 'right, you know, I can do this. I will find a way, I'll find a way to live with this' and I will, and I am doing that. And but there is also that fear that I can relate to, of 'you've had this surgery now and it's good, but it's still there and it could grow back'. It could grow back in the places that it was, it could pop up somewhere new. You have no idea. I don't know what that looks like in the future, this is new territory and I guess it will always be because you can't read the future.

And coming back to fertility, you know, I need to draw upon the strength and resilience that I have from my past experiences, my upbringing, life in general, you know all aspects of my life really and I need to remember that feeling of hope that I have that anything is possible. And, in the end, it will be okay.

And even if our experiences of a family is not how we imagined to be, that will be okay, because it will be what it will be. And however, we have children, they will be our children and to me that will be okay. That will be okay.

Music plays

I'm mindful that my last two recordings have been heavy, shall we put it, and in some ways that's okay because these are really important issues that need to be talked about and these are things that I haven't wanted to talk about, and I felt very uncomfortable about talking about. And, you know, I've talked about this with Ricky when we were planning this, you know, this experience is very personal and a lot of the things that I've covered throughout this podcast are very, very personal things, very, very private and normally they're not really things that I would want to talk about to people. But I'm doing it because this is something that I lacked in the early days of my journey, is hearing from somebody going through what I was going through and, you know, it doesn't really matter how many people say to you 'oh

I understand how you feel', they don't until you have actually been through exactly what you're going through. And that's no disrespect to anybody and, you know, we'll always be grateful for any support that we get. But there is a difference between, you know, hearing directly from someone who has been going through it.

So, I'm just aware that my last two recordings are quite heavy going. And they are important things that need to be said and I know there are going to be people out there who will, you know, this will resonate with unfortunately. You know, the recording I did about fertility, it's really, really difficult, it's really, really hard really, really hard, very hard to talk about. But unfortunately, it happens. And so, what I wanted to do here is just kind of change the tone a little bit, because there are going to be down days and in the past I've always tried to like not to dwell on them and to do whatever I could to either not dwell on it or not think about it or try and make light of it and actually that's quite a lot of pressure. And I've, you know, I've had people say to 'oh you're always so upbeat and always smiling' and things like that, and I am. I'm glad that people see that in me but, you know, I have my moments, and everybody has, and I just want to say that that's okay to have those moments.

And I think the important thing is to not sit there for too long. You know, sometimes we need to sit with those moments and accept that things are really hard, or today is a bad day, and have a moment. But it's also really important to not sit there too long. And when that becomes a habit, or those days are becoming more frequent, or you're finding yourself unable to maybe get out of those feelings and emotions, you know, as quickly as you might normally do, or you're really struggling to see your way out of it, that's when it's important to seek some support. Now that can be anything from, sometimes we can manage that ourselves by just trying to do something different. So, you know, getting outside for a walk, trying to change up our routine a little bit. Give ourselves some headspace almost. Or it might be that we need to speak to somebody, so maybe pick a friend or a relative, someone that you feel most comfortable with. Speak with, speak with them.

If that doesn't work, then it might be time to seek some professional support through a GP or, you know, other services, depending on what the issue is. So, if it's endometriosis, it could be Endometriosis UK. If it's to do with fertility, it could be Fertility Network UK, there's also an organisation called Fair Treatment for the Women of Wales who would be able to signpost you to various resources as well.

So, yeah, it's okay to not be okay. But it's also important to seek support, if we need it. And I just wanted to share with you something that really spoke to me over the weekend. So, something that I haven't spoken about much, or at all actually, is faith. And I know that faith isn't for everybody and that not everybody has a religion or a faith. But a lot of people have something within them spiritually, that drives them, that motivates them. And, for me, that comes in lots of different ways and one of the things is my faith. And yesterday I was taking part in a Zoom mass online and the sermon or the homily was about life, really. And some of the things that I noted down from it, to remind myself is that life is sometimes a mountain to climb. It's difficult, and we can lose sight of things, we can lose sight, we can lose our way. And sometimes we need something to hold on to steady ourselves. Now that can be a person, that could be a hobby or an interest. It could even be a faith, I guess. And all of us in some way or another will be visited by adversity during our life.

And one of the things that was talked about was the old-style radio clocks, when the radio clocks were brought in, they were publicised as being completely accurate, because they were continually being adjusted by the signal to make sure that the clock was completely accurate. And what the priest was talking about was that it's sometimes the same for us. That we can receive signals in our life, when we're lost, when we've lost our way, when things are hard. Even when they're not hard, actually, and we're having a good day. We can receive a signal. And sometimes that can just happen in the blink of an eye and it can be over as quick as it arrived, but it can happen in the blink of an eye. And all of a sudden, things make sense, and these are quite precious moments, and they can give us an inner conviction.

I've had those moments along the way. Not just in my recovery from this surgery but along my whole journey gynae wise and in other aspects of my life. And don't know really, maybe that is my faith. Maybe that's something to do with me as a person. I don't know, but you know there are those moments where things seem to make sense, or you get that moment where you think to yourself 'everything will be okay'. You can't always say why, or why you think that, or why that came to you, but you do get that feeling that things will be okay, or this makes sense, or now I understand why I was feeling like that. And I don't know if this is right but, for me, it is that kind of glimmer of hope that it will be okay whatever happens, I'll be okay. My husband will be okay, and we will get there.

I don't know how that's going to look right now, and sometimes that doesn't sit with me very well, it doesn't sit well with me because I like to know. And I think a lot of us would like to know, you know, what's going to happen, but we don't. But yeah, there is that hope. So even when there are those down days, there are good days and those moments - those precious moments - and those that glimmer of hope that we will get there, and it will be okay.

Music plays

Ricky:

So, a massive thank you to Lara for recording those voice diaries. Just to say that we're planning on releasing an extended version of them in the near future. If you'd like any more information on endometriosis, please go to endometriosis.org or the NHS website. In the next episode, we'll be talking to Lara about her experience further down the line postoperatively. Thank you for listening.