

**Prepared For: Anna Hurley-Wallace**

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**Transcriber: J. Mason**

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ANONYMISED

Int[[1]](#footnote-1): Okay - have you got a notification saying it’s recording?

R[[2]](#footnote-2): Yeah.

Int: Great, so just to double check that you’re still happy to go ahead with the interview and that you’re happy to be audio and video recorded for the purpose of this?

R: Yeah.

Int: Great. And, just a note as well, so my screen is over here with my checklist on, so if I’m looking over there, I am still listening to you.

R: Yeah, no worries.

Int: Let’s get started then, so could you start by telling me a bit about your experience of persistent pain?

R: Yeah, it’s hard work! What kind of stuff do you want to know?

Int: So, let’s start with what type of chronic pain you’ve been experiencing.

R: So, it’s usually just stomach ache, back ache, the typical stuff that kind of comes with a period except it’s like all the time.

Int: Yeah, and that’s due to another condition, isn’t it?

R: Yeah.

Int: Could you tell me a bit about that?

R: Yeah of course, so I’ve got endometriosis which is a hormone condition, it causes extreme amounts of pain, like not just at the time of the month but throughout the month as well, so yeah, each day can vary, sometimes I can go a bit of time without pain but the majority of the time I am in pain, yeah, it’s very uncomfortable.

Int: Yeah, I can imagine. And, how old were you when you first started experiencing that pain?

R: I would say I was around 13/14 when I started going to the doctors with it all. But, I only got diagnosed two years ago, so it was a while before they actually took me seriously.

Int: Could you tell me a bit about what it was like when it first started, the pain?

R: Yeah, it was, so I think obviously because you’re so young as well, you just think, “Oh it’s normal” and I think you’re just brought up with it being normal and that’s reinforced by the doctors as well like because they’re saying, “Yeah, it’s normal to be in pain with your period” but I was like, “It’s not though, it’s like around my period too” so it was just frustrating because you’re just not taken seriously and I think a lot of people are just like, “Oh you’re too young and it’s just period pain, it’s normal” and I think because it’s so normalised from everyone, you just kind of accept it and get on with it.

Int: Yeah, and how about, could you tell me about what it’s been like more recently maybe since you’ve been diagnosed?

R: It’s not really been much different to be honest because there’s not really any form of treatment or cure for it, it’s just a case of trial and error with medication and stuff because obviously everybody’s different. But, I still kind of feel like people don’t take it as seriously as it should be. And I’m still in pain and I think I will be for a long amount of time, but it’s just trying to find that right thing what will help me manage it.

Int: Let’s talk a bit about how you were diagnosed, could you tell me a bit about that?

R: Yeah, course, so I was going to my doctor for years and he was just like, “Oh it’s just normal period pain, IBS” they gave me all the tests and stuff but obviously you can only get diagnosed with endometriosis with a laparoscopy but they kept saying I was too young for that. So, I went and got another opinion from someone else and they were like, “You need to demand to go and see a gynaecologist” so I did. It took them about five years to say that I could have the operation, they just kept saying that I was too young and there’s no chance that it would be endometriosis at my age, which I think is stupid because people can get it at any age. So, yeah, it was hard to get diagnosed with it.

Int: But eventually you did have a laparoscopy?

R: Yeah, you just have to keep persisting.

Int: Who did you get a second opinion from, [Name]?

R: So, I went to, it weren’t even like a doctors really, I don’t know whereabouts you live, whether it’s similar, but I went to you know like a family planning service?

Int: Oh, yeah.

R: So, I went to one of them and I just explained the situation and I just, because they was the majority females, so I don’t know about yourself and I’m not judging but I think obviously women understand what it’s like to go through periods and when stuff isn’t going right. And I think they’re more sympathetic to it all as well, I think they can understand and take you more seriously because all the doctors that I saw were male which I’ve not got nothing against, but I think it’s easier for women to sympathise because they know what it feels like and I went speaking to them and they were like, “You need to go and see someone” because I’d only been in there five minutes and they said, “It sounds like endometriosis to us” which I’d never even heard of that word before. So, they insisted that I went to gynaecology, so I did do. But, even then it took a few years to get the ball rolling with that.

Int: Okay, yeah, so quite a different experience with the second opinion?

R: Yeah, definitely.

Int: Okay. And, in terms of your pain then, how does it affect your education or school and work life?

R: Yeah, it does affect my education but I’ll still get all my work done. Like with uni, I’ve always had my essays in on time, I’ve never got like extensions or anything, I think it’s kind of been my motivation really. It does affect it in the terms of like I have missed days when I’ve not been well. Concentration, it does take me a while sometimes to get motivated, especially if I’m in pain, sometimes I’m like, “No, I’m not doing anything”. So, it’s affected it in that sense, it’s not affected like my grades or anything, or like me handing stuff in, deadlines, I’ve been able to attend all exams but in a sense of like missing time, yeah, I have missed quite a bit of time due to it. But, I think doing work and that’s helped me, really, you know sometimes just to take my mind off it, if that makes sense?

Int: Yeah, and do you work at all as well or…?

R: No, I did do, I’ve always worked, since I was 16 throughout uni, I was recently a carer for my granddad but he’s just passed away so at the minute I’m not in work, I’m just concentrating on my PhD.

Int: Yeah. I’m sorry to hear about that.

R: Thank you.

Int: And, in terms of maybe your mood and emotions, how does your pain affect those?

R: It just gets me down quite a bit, I think like because no one has really heard of it, no one really knows what it’s like, if you get me, which sometimes it’s hard to talk to people about it because I think some people are just like, “It’s just a painful period” but it’s not, it’s more than that, like I’m tired all the time, like I’m exhausted and I think people just think, “Why are you so tired all the time?” [*laughs*] I think it’s hard for some people to understand and obviously it would be, I’d be the same if I were experiencing it, I think it would be difficult for anyone who’s not going through it to understand.

Int: Yeah. And how does that affect your social life? Does it affect your social life?

R: Sometimes, yeah, so I kind of have to plan things around especially that time of the month. Even though I’m in pain quite a bit, it’s the majority like that time of the month, so I will try and plan things around it like holidays. I do, I am still sociable and I will go out but sometimes I have to cancel plans last minute when I’m in pain.

Int: Yeah. Is that because of your physical ability to be able to do things or is that more to do with something else?

R: It’s just, sometimes I’m just in so much pain, I just want to lie in bed, like it just hurts, like your whole body aches and sometimes I think I just used to force myself to do it but now I just think if my body needs to rest, I’m resting.

Int: Yeah, so does it affect your physical abilities would you say in that sense, your pain?

R: Yeah, not a lot but it does in a sense, like I don’t know, it does, like when I’m in a lot of pain I’ll be like, “I’m not moving because I can’t”. Like me and my partner love going on walks but there’s times where I’m like, “No, I’m not even risking it”.

Int: Yeah. That’s understandable as well, that you feel that way sometimes.

Do you think you could tell me about any advice, I know you talked about kind of your diagnostic route then, but any advice that you’ve had from your doctors or nurses or any other healthcare professionals that you’ve had about the pain?

R: Yeah, so there’s not much really, like after my first operation they just put me straight on the menopause which wasn’t really dealing with the situation, it just kind of masked it. But, I was still in a lot of pain because the endometriosis caused like a disease to some of my muscles, so I got another opinion and he said like the menopause won’t help at all, like it’s done damage that needs to be dealt with first. Pain-wise, I’m under a pain clinic but all it is they’re just like, “Oh you need to go on the pill” but I just, I don’t like that and I think it’s just masking it instead of dealing with it. I’d rather learn how to manage my pain than just cover it up, but I do have painkillers. I try not to use them as much but if I’m in a lot of pain, I will do.

Int: And, in terms of the pain clinic that you’re under, what kind of healthcare professionals are in there, is it a mixture of people, or who do you have?

R: I only really see the doctor who did my surgery, but every time I see someone else, it’s just something different all the time. So, like my first doctor who did the surgery, he was the one who put me on the menopause and he didn’t get rid of any endometriosis but then the surgeon / doctor who I’ve had this time around, she was like, “You shouldn’t have been put on that menopause injection, I would never give it to anyone your age”. So, I just feel like there’s no set like recommendations with it, like everyone’s doing what their opinion is, so I just kind of feel like I’m getting passed around, like some people are like, “This’ll work” and then everyone’s like, “This’ll work” and I’m like, “Why can’t…?” I don’t know, I feel like with other illnesses, you just get a set treatment and I know this illness is different for everyone but I just feel like there’s no, I don’t know how to explain it, do you know what I mean?

Int: So, having lots of different opinions?

R: Yeah, I don’t feel like there’s nothing solid, like set in stone on what to do.

Int: Okay, and is that pain clinic, is that just a pelvic pain sort of clinic, just specific to that?

R: Yeah.

Int: Okay.

Can you tell me if you’ve had any, about any advice you’ve had for your pain or your condition from any other alternative therapists or specialists, anyone like that?

R: No, I’ve only really spoke to my GP, the people at the family planning and, like I said, under the pain clinic now but that’s it really. I’ve asked, I said to my surgeon like would there be a chance that I could go private and see someone who’s a specialist, like I would, I’m more than willing to pay for that but they refused. They said that, basically, to go and see someone like that, because once you’ve had so many operations the scarring can cause your organs to stick together, so basically they said they only send people privately when that happens, so yeah, that’s another dead end [*laughs*].

Int: Right, and in the pain clinic or even before you were put in the pain clinic, have you ever seen a psychologist or a physio or anyone like that about it?

R: No.

Int: Okay, okay.

So, when you’ve been trying to find out how to deal with pain in the past, who or where is it that you’ve turned to in the first instance?

R: So, like when it first started off or…?

Int: Well, whenever you’re having pain, where is it that you kind of go to your first…?

R: At the beginning I did kind of rely on the GP, obviously I was quite young then as well and that was probably before you could just get your laptop out and Google stuff like now. So, a lot of it was GP but then I think obviously when I got to an age where I was like, I feel like no one’s taking me seriously, you do have a look online don’t you and you start having a mooch but I try to avoid that because I think you can scare yourself sometimes and diagnose yourself with something that you’ve not got. But, once I got, once the family planning said, “Oh we think it might be this”, I did do a lot of research on it and I’ve got some books about it to just get some more information, to see if there’s any like tips. I have joined some groups online, where people post advice and stuff, so yeah just that really, I just relied on doctors more but obviously had a look online but when I’m looking online, I’ll stick to like NHS websites, like proper websites and just reading really.

Int: Okay, and you said you read some books on it as well, are they books that you’ll get yourself?

R: Yeah.

Int: Do you buy them?

R: Well, the hospital provided me with one after my operation which told me a bit about them and then I’ve just had a look in some groups online and you know like to see if they recommend anything what’s helpful and giving you tips and like I don’t know, just to help you deal with it because it can be quite isolating as well, so yeah.

Int: Yeah, and you talked a bit about your online use there, and that you don’t kind of use it too much, but you did mention the NHS website, so do you think you could tell me about any experiences you’ve had of using the NHS website to find out about pain? What’s that been like?

R: Yeah, I think it’s kind of useful because [inaudible 0:16:45] NHS website, I think sometimes you’re kind of made to feel like it’s not real what’s happening and you’re not in pain, so I think like seeing it there, it makes you think, “Right, someone actually understands it”, seeing the symptoms, it kind of like normalises what you’re feeling as well, if that makes sense?

Int: [Phone connection problem until 0:17:40 – *asked interviewee turn off video to help recover audio – continued without video*]

I think you were just saying it’s nice to be able to see it all on the NHS website.

R: Yes.

Int: Have you used any other similar health advice websites like Healthline?

R: No, I’ve not looked at that. Like I said, I try and stay to an NHS website because I know that it’s accurate information and myself, I don’t know what other websites to look at really. I’ve used like the endometriosis organisation, like their proper website as well but I try and stick to reliable websites, well what I know is reliable because I think sometimes you can just get led astray with stuff.

Int: Yeah, so do you have any experience of looking for information on social media or not really?

R: Like I said, like there’s a couple of pages probably on Facebook that I’m in, I don’t write on them but it’s just nice to see like other people’s experiences as well and to think, “Oh, that’s happening to me as well”, like it kind of like normalises what you’re going through, if that makes sense?

Int: Yeah, that does make sense and I know you said, that’s one of the beginning things you said about joining the groups, you know even if you don’t participate.

How about other social media resources like YouTube or even Instagram and things like that, have you looked at those…?

R: Yeah, I don’t really use YouTube but again, there’s some groups on Instagram, a couple of people who kind of do blogs about themselves and their own experiences. So, there’s that, the odd few that I follow. I try and not to follow so many because I think sometimes, like, it can put fear in to you sometimes because I think obviously everyone’s experiences are so different and I don’t want to spend time just worrying about things what don’t relate to me, if that makes sense?

Int: Yeah, so kind of a bit choosy maybe about what pages you follow and…?

R: Yeah.

Int: Yeah. That’s interesting about blogs that you said there as well. Do you go on them a lot, blogs, or not really?

R: No, not really, it’s just a couple who are kind of linked through Instagram. Obviously, they post videos about their own experiences, about when they’ve been having operations and stuff, so I just, sometimes I think it’s helpful like especially when I was quite nervous about having operations, it’s like quite calming to listen to other people’s experiences with it.

Int: Yeah, I mean when you’re searching the Internet, what, you say you’re starting off with Google, what is it you’re hoping to find? What are you hoping to find when you go off on a search or does it change?

R: I think like with Instagram, like it’s more for like people’s experiences with it. Whereas like Google, it’s if I want any information about it, so maybe if I’ve been recommended a medication or something, like I’ll look in to it that way. Like if I’m feeling a certain way then I’ll check it on the NHS whether it’s a symptom or not, it’s just some more information really because I don’t feel like you get that from doctors. Even when you’ve been diagnosed, like I don’t feel like they give me that much information, I mean like they give me a book but that’s not them telling me anything.

Int: Okay, so using maybe sort of NHS website and Google for different things to what you use maybe your social media platforms for?

R: Yes.

Int: Okay - and, I’d like to go back a little bit.

What kind of things, is there anything that you do yourself when you’re at home to cope with your pain? Things like exercising or relaxation and mindfulness, any of that?

R: Yeah, well like I said, me and my partner love walking everywhere, we’re always going on walks, just little things like if I am in pain I’ll try and manage it my best, I’ll have like a hot bath, water bottles. I do try and just get on with it but I do know like sometimes if I am in so much pain, like I do need to rest, like I’m learning to not force myself to go out when I’m not well.

Int: Yeah, yeah - and, have you used any online resources to help you cope with pain when you’re by yourself or at home?

R: Not really, like I said if I see on Instagram people will recommend stuff but I just think everyone’s different with stuff and what works for them might not work for me. Like I saw stuff about, “Oh don’t eat gluten” and I tried it and it didn’t help me, so everyone’s different. Like I do try and stick to what the doctor recommends me, even though he’s not really that helpful, but I just kind of feel just a bit in the middle. Like, I just feel like I need someone proper to just sit down with me and be like, “This is what you need”.

Int: Yeah - and, with the sort of strategies you use when you’re at home, I know you mentioned walking and exercise, that kind of thing, have you had any problems kind of managing the pain by yourself?

R: No, I think like I’ve kind of grown and learned how to manage my own pain really because I’ve had to do it for so long.

**Int:** **Yeah.**

R: Like I said, I have got painkillers but I try and not use them unless I’m in a lot of pain, I’ll just have a hot bath or a hot water bottle. So, yeah, I do think that I can manage it because I’ve just had to, I’ve had to learn to manage it and cope with it, obviously before I got diagnosed as well. So, yeah, I don’t really think I’ve got any problems as such. For me it would just be like, I’d rather not have to deal with the pain and manage it, I’d rather them tell me something what could help get rid of it but it’s just one of them things.

Int: Yeah - and, in terms of this internet resource use and the social media use, how has that changed from when you, maybe from when you first started getting pain compared to more recently?

R: I think obviously it’s better once you get a diagnosis because when you, obviously I was a lot younger and like I said, there probably weren’t as many resources available as now but when you’re just searching like “pelvic pain”, “bad periods”, everything is coming up, it’s like, “You have cancer” and everything and you’re like, “Oh my god!” but now you actually know what it is, it’s a lot better because you can like search around your diagnosis, where before I was just typing in my symptoms like and everything’s coming up and then you end up getting anxious and worried, like you think you’re dying but obviously once you’ve been given that diagnosis, you know what to search so yeah, it’s a lot better.

Int: Yeah, so you think you’ve got better at doing your internet searches and finding what you need?

R: Yeah, definitely, and I think as well, like you’ll know yourself, being at uni helps because you can only use reliable sources when you’re writing essays, so I think that’s helped me so much as well because I’ll look at something and I proper analyse it, like, “Is this a safe website for me to go on? Is that actually true information?” where sometimes you look at websites and you’re like, “That doesn’t look reliable”, like especially some websites where they’re telling you all these ideas of treatments and I think the doctors, the NHS, don’t even know any treatments, so that’s why I tend to stick to their page because I think if anything does come out, that would be the first place, the first type of people what would tell us that.

Int: Yeah, that makes sense. Okay. So, then I guess which internet resources have you found the most helpful and why?

R: To be fair, I do like being on Instagram and the select people that I follow on it, the groups, I like that because like some of them will take questions so people will ask questions, so it’s like I know kind of what applies to me and doesn’t, like so sometimes it might come up and I’ll be like, “Oh I was thinking that”, “Oh I thought that just happened to me”, like that’s good and I like that, I do like listening to people’s experiences because I don’t know, it just helps you feel like you’re not alone with it, because none of my friends have this, no one I know has it, so I think like following someone on Instagram, you feel like you know someone who’s going through what you are. So, I think I do like, I probably would, out of anything, prefer Instagram. But, not for like actual reliable information as such, more for like the experiences and feeling like you’ve got someone there if you get me?

Int: Yeah, and you said just then about your friends and family, have you had any advice from your friends and family about your pain and about the endometriosis?

R: They’re all really good with me, like they’re all understanding but I still think it’s hard to explain to someone who’s not going through it because they’ve not experienced it. Like they’re all amazing with me and they all know me better than myself like but I just think, I don’t know, I think sometimes it’s hard to explain to people because to explain it is just like, “I’m in pain quite a lot of the time”, that’s it, there’s not much more to it than that but it’s how it affects you. I don’t know, yeah, they are really good with me but it’s, I just think it would be nice to have someone to talk to who’s been through it.

Int: Yeah, yeah.

Okay, well that was me just going back to that point because we didn’t talk about it before. My other question is which internet resources have you found maybe unhelpful, and why?

R: I don’t know [inaudible 0:30:35] such but I can imagine, like I said, I try and stick to reliable websites but obviously if you just type in “endometriosis” on Google, how much stuff comes up, so I can imagine there’s a lot out there and there’s a lot of websites, like I said, “Don’t eat gluten” and stuff like that, there’s a lot of people who are probably trying to be helpful with stuff but it’s not going to help everyone and I feel like if people are going out there thinking, like you might get some more vulnerable people who are like, “Oh I’m going to do this and everything’s going to be okay” and then if it’s not working like it could affect them even more, like, “Why is this not working for me?” So, I do think there’s quite a few bad things out there, but I think it just depends on what you’re searching and what you’re reading yourself.

Int: Yeah, and you said before that you think because of your education, you’re a bit more informed with that, maybe?

R: Yeah, because like yourself, it’s like when you’re searching articles, journals, like I think you look at it a bit in more detail of where that information is coming from, and like who’s telling you and giving you that advice. Like is it coming from doctors or people at a professional level or is it like someone like me who’s just wrote online saying, “Well this helped me”?

Int: Yeah, and I suppose then thinking about online resources, is there anything else that you think would be helpful or would have been helpful to you in the past for managing your pain condition and the endometriosis?

R: I don’t know really, I don’t think there’s anything different but I just feel like, I don’t know, I can’t explain really. I just feel like it should just be considered for younger people as well but I don’t really think that’s anything to do with, well to be fair, even if you go on NHS websites it says that it’s a condition what affects people in their 30s and 40s but it’s not, do you know stuff like that? Maybe people should, like the NHS should address that and look and maybe, because me at a younger age probably looking at that would think, “Well I can’t have that because I’m not in my 30s or 40s”. Like my doctor even said to me, “You’re too young for it” but I’m not and I know that there’s a lot of other people out there my age and younger who’ve got it. So, I think stuff like that, maybe they should address it more to younger people and it might help a lot of people pick up on a diagnosis earlier.

Int: Yeah - that’s a good point, thanks for that. Is there anything else kind of about the condition that you’d want to talk about that we haven’t covered or about online resources?

R: I don’t think so, unless you’ve got anything else you want me to mention?

Int: No, nothing I want you to mention, just if you had any other thoughts.

R: No, I’m happy with everything.

Int: Okay, so that brings it to a close then, that’s the end of the interview. So, what I’ll now do is I’ll stop the recording and read a debrief to you. And if you‘ve got any questions that you want to ask me off the recording, then you can do as well.

[CLOSE]

1. Interviewer [↑](#footnote-ref-1)
2. Respondent [↑](#footnote-ref-2)