

**Prepared For: Anna Hurley-Wallace**

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**Transcriber: N. Brown**

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ANONYMISED

Int[[1]](#footnote-1): So it says it’s recording now and the red light is on …

R[[2]](#footnote-2): Yep. I can see it’s recording.

Int: I’ll keep an eye on that as well. Are you close to your mic [name]? Because I...

R: Yeah, can you hear me better now?

Int: That’s better yeah, thanks. Okay so, again, just to check that you're still happy to go ahead with the interview and that you're still happy to be audio recorded for this?

R: Yes.

Int: Okay perfect. I’m going to be looking at my screen over here, my prompt questions but I’ll still be listening to what you're saying when I’m looking, okay?

R: Okay.

Int: So, do you want to start by telling me a bit about your experience of the chronic pain with IBS?

R: Sure, so. I think an element I’ve always had IBS really but as a child, I just put it down to tummy ache if you like and then as I got a bit older, my parents did take me to the doctors to make sure it wasn’t anything more sinister and they referred me to a consultant, which looked over it and didn’t find anything more problematic and for me at that time, I felt like they were sort of, “Oh well if it’s nothing… more “medical”, if you like, then they didn’t really want to know but obviously I was still left in pain.

 As I’ve got older and was taking my GCSEs and that, I did go back to the doctors because I wanted a secure pain relief in case it got, I got a bout of it during my exams and so I’ve been on Diclofenac since about 18 and that does help but obviously, it’s not a cure so I do still get the bouts of pain and I have to manage well when I take the painkillers to ensure that it’s effective as quickly as possible really.

Int: Yeah. Yeah. I’ll come back to the painkillers in a minute, but how old were you when you first started getting the pain?

R: Pain? I would say probably about 12, I could say officially it was pain, if you like.

Int: And a few years after that, you had the exploratory …?

R: Yes.

Int: Okay. What was it like when it first started compared to more recently?

R: I would say it’s probably got worse now, it’s particularly reactive with my periods as well so it’s a kind of period which I dread every month because I know that the two together will interact with each other. Although in some ways, at least I have a very regimental and fixed pain relief option now whereas before that, I didn’t. I was on commercial tablets back then, if you like.

Int: Okay, okay. And you said before about it affecting your school and work life, how has it been affecting that?

R: I think it did affect me through my university years, now I’m working it’s not too bad because I can be flexible with my working hours so if I need to take a break because of the illness and I can put it down or pick it up when I’m feeling better.

Int: Okay. How about your social life, how does pain affect that?

R: It does affect it in terms of there will be times when I don’t want to go out and because I can sort of rapidly plan it with my periods, I know that there’ll be certain dates that I get invited to, that I won’t be able to attend because I know it’ll be bad that day.

Int: So, you’re able to plan ahead a bit?

R: Yes.

Int: Okay, how about your physical abilities, apart from the pain itself, how does your pain affect your physical abilities?

R: While I’m in the pain, I can’t really move that much, I’m clenched up with a hot water bottle and not really able to help myself too much even to the extent of making a cup of tea or something. Obviously, that’s whilst I’m in pain, in the periods between pain, I’m able to do most physical things. Yeah.

Int: Okay, okay. If you're taking the Diclofenac when you're in the really bad pain, does it help?

R: It does, it’s not instant though, you’re still looking at probably an hour’s worth of pain and so I have to be quite organised, to make sure I’ve always got the tablets with me, so I’ve got easy access to them.

Int: Okay. And, what about mood and emotions, how would you say pain affects those?

R: It does bring me down obviously when I’m in pain and the days leading up to my period, because I know that I’m going to be in super pain with the two combined. But other than that, I try and be quite positive about it and able about dealing with it.

Int: So positive overall?

R: Yeah.

Int: Okay, and can you distinguish between period pain itself and the IBS pain?

R: Yeah, there’s two very distinct pains, it’s not always during my periods so that obviously helps because in the times between my periods when I’m getting IBS pain, I know what that feels like compared to the period, but I don't know why, I think there’s scientific reasons why the two combine, make each other worse, they play up against each other.

Int: Yeah, okay. How would you say it is that they are different?

R: I think one’s more an intense pain and one’s more sort of rumbling on in the background pain.

Int: Okay. Do you think you could tell me about any advice you’ve had from doctors, nurses or other healthcare professionals about the pain?

R: Obviously diet is probably the biggest advice, trying to find food that are low in fat and not too much carbohydrates and obviously, I do try to listen and take that on board. I think especially now I’m a bit older, I think when I was at uni, it’s difficult to balance everything and especially in that environment, to have good meals suitable. Yeah.

Int: And so, did you see a dietician?

R: I did, yes. And they gave me advice about what foods would help.

Int: And what did the GP say apart from the diet?

R: Not a great deal if I’m honest, obviously it explains it so there’s no cure, pain relief is an option, but they didn’t really detail too much and I’ve had to seek out, alternative therapy – they didn’t mention that at all.

Int: Sorry, what was that about alternative therapy?

R: The doctor didn’t really mention that as an option or anything at all, if I am honest!

Int: So, you haven’t had any advice from anyone like a psychologist or similar?

R: No.

Int: How about a physio?

R: No.

Int: Have you gone and sought any advice from other alternative specialists?

R: Yes, I’ve sought out alternative therapy, I’ve taken up mindfulness which helps. Yeah.

Int: Okay. How have you found that? Mindfulness.

R: Yeah, I think it helps to kind of … numb the pain if you like by putting you in a different state to receive the pain if you like, sort of get you prepared so you're not, in the moment, everything’s not consumed about the pain if you like.

Int: Okay, okay. Is that something that you do more yourself when you're at home or by yourself, to help you cope with it?

R: Yes, yeah. I come from quite a traditional background so that would probably be, might even be [inaudible 00:09:55] possibly, my parents or what have you so it’s probably something I’d do more on my own, by myself.

Int: Okay, and what kinds of other things do you do yourself to help you cope, maybe apart from the medication and the mindfulness, is there anything else?

R: So generally, a hot water bottle and I just try to relax, hot baths as well, they help.

Int: Have you used any online resources to help you cope when you're managing by yourself?

R: Yes, more to be honest with you afterwards, I’m like “right, I’ve got to do something about this” and I go off and I’ll Google the condition and what alternatives there might be, that might be vitamins or sort of… yeah.

Int: Okay, and what about apps and other social media?

R: I’ve joined a forum on Facebook, like a Facebook group, if you like, and that can be quite active because it’s so easily accessible, I’m always flicking through Facebook anyway, you sometimes just spot a post that someone’s found something, a new treatment that might be worth trialling.

Int: Okay, you said forum, sorry, or Facebook?

R: A Facebook group, yes.

Int: What pages do you follow on there?

R: IBS National UK, anyone can sign up for that and they just sort of, it’s a support group really more than anything.

Int: What do you think it is that you like about that in particular?

R: I think just the fact that it’s nice to know you're not the only one suffering, there are lots of other people out there in the same boat and just the cohesion of everyone trying to support each other.

Int: Do you use any of the other social media apps in a similar way? I’m thinking Instagram or Twitter or YouTube?

R: Not Instagram or Twitter, I do have accounts but I’d say that’s more social use but YouTube can be quite helpful sometimes, different videos of people’s experience and such, so yeah.

Int: And a similar thing, you're looking for experiences?

R: Yes.

Int: What are the sort of names of videos you watch? What do they have in them?

R: Generally, they’ll have ideas to try and help support IBS and “did you know?”, that was how I found out that the IBS was so... I mean I suspected it, but I think that’s how I found out the IBS was so interlinked with my periods and stuff, so yeah.

Int: Could you tell me a bit more about any other internet resources that you’ve used to either help you cope or to find out information?

R: I’ve used the NHS website and I think that’s probably more for the medical, sort of biology side of it, suffering from it, I was quite intrigued to know what was going on actually biologically to cause it and such.

**Int:** **Okay.**

R: And I’ve also looked up on Health MD, I think it’s called? Yeah.

Int: And, what was using the NHS website like?

R: Yeah, it was clear enough, there’s only so much information they give out, I think because the website covers every ailment and is the go-to for everything, short of a precursor to seeking medical assistance, I think there’s only a generic amount of information on it, but it is a start, you know?

Int: What about your experience of using other health advice websites like Healthline or WebMD? As you were saying.

R: Yes, WebMD, it was very in-depth, more in-depth but it’s quite commercialised I thought, there were flashing adverts and different sort of drugs that might be... it just felt not so quite official if you like.

Int: Okay, okay. With the NHS website, did you find the information you were looking for about the biological side of it?

R: Yes, I did find the biological side of it.

Int: Okay, okay. And what do you think you’re hoping to find when you're doing your initial search on Google?

R: I think two sides of it really, the information on research that’s been done on it and also it’s experience from other users.

Int: And, anywhere else that you look for the research side of it apart from what you mentioned?

R: No.

Int: Okay, alright. I’d like to go back a little bit to your treatments and self-management.

When you've been trying to find out how to deal with pain, who or where would you say you’ve gone to in the very first instance?

R: In the very first instance, I would say I’ve gone to the NHS website, I’ve read up about it and then I’d say I’ve probably gone to Health MD to get a greater knowledge on it and I think especially for like variations. Obviously not everyone’s always the same so that website had more of “this might be applicable to some people; this might be applicable to some people”. So that’s where I’ve gone for that. And then I’ve got Facebook are always on hand for support.

Int: For support, okay. Have you had any advice from your friends or family about it at all?

R: Yes, my parents and my older sister, I’ve got an older sister that’s 11 years older than me, she’s given me advice on sort of old wives tales, baths and hot water bottles and things like that.

Int: So, some of those things you mentioned?

R: Yeah.

Int: Okay, anything else at all that you use to help you cope with pain?

R: No, I don't think so.

Int: Okay. Have you had any problems with coping strategies that you’ve used,

I’m thinking about you mentioned your mindfulness and your medication and your hot water bottles and things, have you had any problems with any of those strategies?

R: No, I think now I’m getting myself more organised so like I’ll have my medication on repeat prescription, I’ve got an annual membership to my mindfulness. I think through my university years, obviously you’re so busy and you socialise, you're studying, I probably didn’t organise my prescription very well, probably skipping getting repeat prescriptions and such but now, and obviously I’ve got more money now, I think that helps sadly, I think if you’ve got more money you can handle illnesses better, I’d say I’m alright now.

Int: You said you had a subscription then to mindfulness, what is that?

R: That is Headspace.

Int: Oh, okay. Is that a resource that you use regularly?

R: Yeah, recently I just got into it for the pain relief but now I use it, there’s all sorts of, preparing for important [inaudible 00:19:31], preparing for exams and all sorts of things, I use it for everyday now really.

Int: Okay. And you say you only recently got into it for the pain side of things?

R: Yeah, yeah.

Int: How often would you say you use it for pain?

R: I’d say probably once a week for pain.

Int: What sort of thing do you do on there?

R: There’s two options on there, you can have pure mindfulness, so being encouraged to zone out from pain or any sort of feeling if you like, body sensation - that’s what I mean. And there’s also help tips, how to sort of relax and get into the mindfulness sort of zone.

Int: What was the reason that you decided to start using it in the first place? How did you find out about it?

R: I think just mindfulness became more popular and I thought I’d give it a try to see if it helps because I don't think just popping pills is always the answer, although I will take them when I need them. Yeah, I find it quite helps.

Int: You say you only used it recently for pain, so when you first started using it, what was it you were using it for, or still are?

R: I looked for options that would help me zone out of body sensations during episodes of pain – and it helps – so yeah, definitely and then I started looking around the other features of it, there’s stuff for sleep and such so yeah, now I use it for all sorts of reasons.

Int: Okay. Thinking about all of the resources that you’ve mentioned, websites, apps, everything together, what would you say you found the most helpful resource and why?

R: I’d probably say the Facebook group actually just because the element of support is overwhelming at times, it’s just nice to know that you're not suffering on your own and that there’s a whole community out there that suffers and that you're not an oddball. Together, we can share ideas and tips and new treatments so I think that sense of community has a lot to say for itself.

Int: Have you tried some of the treatments that you’ve …?

R: Yes, I’ve ordered some tablets and some powders like shakes and things, so yeah.

Int: And you’ve found those okay?

R: Yeah, yeah.

Int: Are there any internet resources or apps, websites, that you’ve come across that you found were unhelpful, and if so, why?

R: I think you have to be careful on YouTube just because anyone can put stuff up. So, they can put things up recommending cannabis oil and things like that and I think you've got to be careful not to listen to everything because not everyone’s a registered doctor sort of thing.

Int: Hmm – on YouTube you say?

R: Yep, yeah.

Int: Do you think your use of internet resources and social media for pain, do you think it’s changed from when you first started getting pain to more recently?

R: Yeah, probably increased because when I first started getting pain, the internet wasn’t that out there, I think I still had Dial Up or what have you [*laughs*] so yeah, I think it’s probably more accessible now.

Int: Are you using different resources now?

R: I think pretty much the same, it’s just more accessible, it’s on your smartphone, your tablet, yeah.

Int: Thinking about online resources, is there anything else you think would be helpful, or would have been helpful in the past, for helping manage your pain?

R: I think maybe a website or some sort of app for a younger audience, because I think there’s just a lot of generic information out there for adults as a whole, but when you're first going to uni, struggling with social life, studying, I think just something a bit more appropriate to that age bracket would have helped. Yeah.

Int: What do you think the preference would be, for an app or a website type thing?

R: If I was going to university now, it would be an app just because it’s so easily accessible.

**Int: Okay.**

R: And you can get like notifications and things like that, yeah.

Int: Is that more something for information targeted at young people or to get young people together or something else?

R: I think it can be either really, yeah.

Int: But more targeted, overall?

R: Yes.

Int: Okay, so, do you have anything else to add to anything you've said? Either about pain or about internet resources in general?

R: No, I don't think so!

Int: Okay. That’s the end of the questions, I will turn off the recording and we will do the debrief and close.

R: Okay, great stuff.

Int: Thank you.

[CLOSE]

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