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**Recording Details: melon**

**Date of Transcription: 22 October 2020**

**Transcriber: N. Brown**

**Recording Length: 24m**

ANONYMISED

Int[[1]](#footnote-1): Just to double check that you're still okay with going ahead with the study, and that you're happy to be audio recorded for this?

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

Int: Great. Do you think you could start by telling me a bit about your experience of chronic pain?

R: Yeah [*laughs*] That’s such an open question, I don't know exactly where to start.

Int: What type of chronic pain have you experienced?

R: It was the IBS pain that I’ve been having for the past couple of years.

Int: Anything else?

R: I don’t, I’m sorry I’m not really sure what you mean.

Int: That’s okay. How about if you tell me what age you were when you first started getting that pain with the IBS?

R: So it was a couple of years ago, I think I was about 21, yeah I think 21 when I first started getting it, it came on quite, it just seemed to start out of nowhere really.

Int: Yeah. Could you tell me a bit about what it was like for you when you first started getting it, maybe compared to what it’s like now?

R: Yeah. I’m one of those people that like never has time off work, like never calls in sick but at the time, I recall, I went home from work early and made a doctor’s appointment because the pain was so bad and they signed me off work for a few days, just because I couldn’t get through work because I was in so much pain. It just came out of nowhere and then to have time off work for it is like something that I would never normally do.

At the time, I felt like it was unpredictable pain and I couldn’t really control it. I’m managing it much better now, it still flares up but I can sort of manage it, hmmm well not really, kind of but I can manage it better than I was at the start.

Int: Do you still have any time off work when it’s really bad?

R: No, I probably should but I hate taking time off work, especially for something like, I just don’t feel it would be understood...

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

R: ... if I say “I’m in pain today, I can’t come in”, I don't think they’d really understand so it’s easier just to go to work and just get through it.

Int: Yeah, yeah, that’s understandable. Obviously a huge impact on your work then when you were having time off but how about any studying you’ve done outside of work, like university or …?

R: It started just after university luckily, I’d just graduated and I’d just got the job and then that’s the time it happened. So no, I don't think uni was affected by it.

Int: Ok, that’s fair enough. How did your pain, when you're having it, how does it affect your physical abilities to be able to do things?

R: Well, I don’t really want to do anything, I don’t want to see anyone or talk to anyone. So it does affect things, like I quite often flake out of things which I don’t like doing, things that I’ve arranged with my friends and sometimes I do just cancel because I’m not feeling up to it, which is probably really annoying and I get that I’m not very reliable, which I hate but yeah, it does affect like socially, definitely.

Int: Yeah - do you think you could expand a bit more on how it impacts your social life?

R: Yeah, so it’s really hard to like make plans very far ahead of time because I might be having a bad flare up of the pain and I can’t predict how I might be feeling in like a week or two, it might be a relatively good period in which case I’d make some social plans and then it comes to it and I really don’t feel up to it, like I don’t feel well at all and I just have to end up cancelling which is really annoying, I don’t like being the unreliable friend so it’s easier sometimes just to not make the plans in the first place and so I have become a bit of a recluse.

Int: That’s understandable, why you're feeling that way.

You sound, you're talking a little bit towards a feeling that you're having there but do you think you could tell me a bit more about how your pain affects your mood and emotions, even if it’s to do with the social life and then that affects your mood and emotions?

R: I guess the main way it affects like my feelings is that I feel … I don’t really talk about it with anybody because I feel like they won’t really get it or they’ll just compare it to a pain that they’ve had, but their pain isn’t like a constant, it doesn’t keep coming back so I don’t really like to talk about it with people because they don’t really get it, and then I just feel really invalidated. I guess maybe a bit like alone from it? Yeah. Maybe a bit cut off from my friends.

Int: That’s understandable, and a lot of people do feel that way, you're certainly not alone in that.

Do you think you could tell me about any advice that you have had from medical professionals, doctors, nurses, psychologists, physios, any advice that you’ve had from any of those people about your pain?

R: I don’t feel like I’ve had an awful lot of advice about it. I feel like the GP always kind of brushed it under the carpet and didn’t really appreciate that I was in pain, they just like fobbed me off with excuses and then when I saw the consultant, they tried to help ways to manage the pain and to change my diet and to manage the symptoms, and to try to stop the pain but I don’t really feel, 'cause like I do still get pain and I don’t really feel like I’ve had any input as to how to actually cope with the pain, rather than trying to make the pain not there if that makes sense.

Int: No, that does make sense. Have you tried seeing anyone else or had any advice from like alternative therapists or specialists?

R: No, I tried to, because it was getting me really down, especially last year, I was feeling really low so I tried, so I went back to my GP and said, “this is getting, I do feel quite low and down and like, is there anyone I can talk to about it?”, [voice slightly breaking] but then he said there isn’t and they don’t have that service. So I did try and see if there was someone I could talk about the pain with but no.

Int: Nothing specific to the pain, just general services did they say?

R: Yeah, general services like if you're feeling anxious and stuff but that’s not how I’m feeling, like the way I’m feeling is because of a specific thing, like if I didn’t have the pain, I would be fine.

Int: Yeah. So it doesn't sound like you’ve had the best experience with healthcare there. You said you saw a consultant - did they say anything different from the GP or not really?

R: They diagnosed it and then they referred me to the dietician to try and manage the symptoms by changing what I ate, they thought the IBS would settle, so they just referred me onto the dietician who was sort of helpful as a practical thing of like things that I could remove from my diet, which did sort of work but not fully.

Int: What about when you’ve had the pain before, perhaps when it was first starting at its worst, who or where did you turn to first? Was it the GP or was it someone else, a friend or family member?

R: I was Googling the symptoms first of all because like it just came so out of nowhere and then I saw my GP and they were just, “well, come back in a few weeks if it’s still bothering you” and then … oh, I got a really bad sickness bug and ended up in A&E dehydrated on IV fluids, then when I was there, I mentioned the pain that I’d been having and that’s when they took it a bit more seriously.

Int: Oh right - so really when you went to A&E – interesting.

R: Hmmm.

Int: You said about Googling your symptoms in the first instance, do you think you could tell me a bit more about any other internet resources you’ve used to find out information maybe, when you've been in pain?

R: Yes, so like I Googled it and the first thing it brought me to was the NHS website and then, I was trying to like match up my symptoms with what their website said but it could have been one of a number of things, so I still wasn’t entirely sure.

So then I was just like Googling my specific symptoms and I’d read like forums of other people who had had the same experience, what they said it was and how they coped and stuff.

Int: It’s interesting that you ended up on forums in the end, when you were searching the NHS website, how were you going about that? Can you describe it to me?

R: Hmm.

Int: Did you just Google and then click on a link from there? Did you go into the NHS website and do a search in there?

R: So, I Googled it first and then one of the options was the NHS website, I clicked on that one first because I tend to find it more reliable than some websites.

Int: Yeah. Did you find any other similar health advice websites like Healthline?

R: Yeah, I think I’ve probably read them all at some point, yeah!

Int: What was the experience of going through that like?

R: It was quite similar, I did just keep reading the same sort of stuff to be honest, like they were quite similar in content but at this point, I still wasn’t entirely sure, even though the symptoms were matching up, I still wasn’t sure if that was what like my problem was or like if I was making it up or exaggerating it at this point, I still was hoping it would just go away on its own.

Int: You mentioned before about treating the pain but nothing to help you with coping with it, so what is it when you're going into Google and searching, is it to find out information? Or are you hoping to find, perhaps, something else when you're looking on the internet? I know you said you ended up on the forum.

R: Initially, it was to find out information to try and understand like what was going on, then I would Google like more specific things, like how to, if I’ve got really bad stomach cramps, how to alleviate that so my searches did become more specific on how to treat the symptoms.

I’d find all the generic advice on the NHS website but it was so … basic, so that’s when I’d end up on the forum, just to see if other people have found like other, if they had other suggestions that might be more useful.

Int: So almost looking on the forum to try and find more information, it sounds like.

Those forums, are they specific forums? Did they have a link to any social media or groups like Facebook groups or anything like that?

R: I’m not sure, I don’t think so, I don’t even know now what they’re called. I think it was just other people, it was like general health ones and other people had typed questions in themselves, I don't think it was specific or related to anything.

Int: Okay. Do you have any experiences of looking for information about IBS pain on social media?

R: Not on social media, no, as I don’t want to accidentally like something or I don’t want it to pop up that I’ve been looking at … that.

Int: Not You Tube or anything like that?

R: No [*pauses*] I’m trying to think now if I did look at any You Tube videos, I might have done, this was like a couple of years ago though so I might have watched some You Tube videos, I can’t remember, possibly.

Int: It’s okay if you can’t remember don’t worry.

I’m going to go back to coping because we first skipped past it to talk about the internet stuff, I think I’ve got a good understanding of what you use the internet for there.

In terms of things you might do yourself because you didn’t seem to be able to get someone to come and professionally help you cope with the pain, is there anything that you do yourself to cope with the pain at home? Self-management type things?

R: Nothing like ground-breaking, nothing like anyone else wouldn’t already do. Not really, no.

Int: Not anything like relaxation or mindfulness or exercises?

R: No, I hate mindfulness, urgh, I just don’t get on with it at all, I just cannot be mindful very easily so it just frustrates me. I don't know if it would actually help as I don’t get on with it at all.

Int: That’s okay, not everything is for everyone.

R: I know people say there’s a link between physical and mental but like I don’t find it easy.

Int: Would you say then with the online resources, do you think that’s one of the main ways that you cope by yourself, is to look online?

R: Yes and even if I don’t write anything myself or I don’t contribute to the forums, I don’t even have an account, just reading posts from other people kind of helps and it can be posts from years ago, I’m reading stuff from like years back but it still helps because you're not the only one that like has that pain so you're not imagining it or exaggerating it and other people, even if you don't know them, they know what your experience is.

Int: Yeah, I get that. Have you had any problems when you've been going online looking for things to help you cope?

R: No, I don't think so.

Int: Okay, fair enough.

I think I know the answer to this, but which internet resources have you found the most helpful and why?

R: So yes, like I’ve been saying, the two because the NHS website has been not that helpful but kind of - I trust the information on that so I do look at that. But then yeah, just like random online forums written by random people that I don't know. More personal experience, like first-hand experiences of other people has been the most useful.

Int: Okay. Do you think that use of internet resources has changed from when you were first getting pain compared to more recently?

R: Yeah, definitely, so when I first started getting pain, I would research like most nights, like when I was awake in pain, I’d be on my phone scrolling through in the early hours just to get some understanding I guess and to try and feel less alone and now, I’ve lived with it for a couple of years, two or three years, I don’t feel the need to do that as much because I have a better understanding of it myself and I know what causes the pain flare-ups and I sort of, kind of know how to manage them or at least I know that they will pass so I feel less need to find, to search out other people’s experiences, I guess because I have my own experience now to go on.

Int: Yeah. That makes complete sense.

How about in terms of internet resources, have you found any that were unhelpful and why?

R: I haven’t found any that aren’t helpful but like sometimes when you're Googling, you do come across, so I know what my symptoms are, I know that IBS related pain but when I did my initial search, like it would come up with other suggestions of what it could be which were like a lot scarier, so it has the potential to like cause more worry and more concern but in my case, it didn’t because I don't know, I didn’t, I just sort of … I don't know why that didn’t worry me, I think I knew what it was like after researching.

Int: But you think perhaps if you had clicked on them, maybe it would have been unhelpful?

R: Yeah, I think so but I think it’s because I went to the NHS website first and I think they tend to focus on the common, every day, more likely scenarios rather than the more serious issues.

Int: So it gave you that starting bit of information that you needed so you weren’t drawn into the other …?

R: Yeah.

Int: Okay. And my last question here is - thinking about online resources, is there anything else that you think would be helpful or would have helped you in the past for managing your pain condition?

R: Yes, like I said, I feel like I’ve been given suggestions of how to treat the pain and like try and make it go away, but that’s not always successful and it’s not always going to just go away, I don’t really feel like I know any strategies or ways of actually accepting the pain and then like dealing with the pain and not just trying to make it go away or try to stop it happening because it is going to happen. I don’t really feel like I know any ways of actually coping with it. I think some more like ideas of how to accept and then cope with the pain instead of getting it to go away.

Int: Yeah - that’s really interesting.

I think you’ve covered everything here that I had on my checklist, quite naturally. Unless there’s anything else you want to comment on, I’ll draw us to a close for this?

R: That was really quick, I’m not a waffler! [*laughs*]

Int: No, no that’s okay.

Right, I’ll stop the recording and then if you want to ask me any questions off the recording, you can do.

[CLOSE]

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