

**Prepared For: Anna Hurley-Wallace**

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**Transcriber: N. Brown**

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ANONYMISED

Int[[1]](#footnote-1): Just to double check that you're still happy to go ahead with the interview and you're still happy to be video and audio recorded just for this?

R[[2]](#footnote-2): Yes, that’s fine.

Int: My interview questions are over here so if I’m looking over there and not at you, it’s not because I’m not listening, I’ll still be listening to what you're saying, okay?

R: Yes, that’s fine.

Int: Alright. Can you start by telling me a bit about your experience of chronic pain? I know you have fibromyalgia so wherever you want to start.

R: So my chronic pain is usually spread throughout my body, with fibro it’s more for me in my joints, so it’s throughout my shoulder, through down my back, my knees and then sometimes my hands. These are like a daily occurrence and it normally means that I can’t do some like day to day activities, just because it’s a bit harder when you're in a lot of pain and things like that.

Int: Okay, and how old were you when it first started?

R: I first started getting like just a little bit of back pain when I was about 14 and then I went to the doctors after that, and basically misdiagnosed until I was diagnosed with fibromyalgia at 18.

Int: Okay. Can you tell me what the pain was like when it first started compared to how it is more recently?

R: It’s definitely got worse. When I was first diagnosed, they said that the condition doesn’t normally like, doesn’t have to get worse but when it first started, it was just kind of on and off pain, I’d say it wasn’t always constant, it was mainly just in my back as well, sometimes it was in my knees but mainly it was just like back pain. But now, the pain is more severe and I’d probably say that I have like a pain scale so on a day to day basis, there’s always pain but it would be, “I can cope with it today because it’s sitting at a 3” or it gets to like a 7 or an 8 and then I’m feeling like I can’t do certain things.

Int: What are the things that you feel unable to do when the pain is really bad?

R: So sometimes I can’t get up or walk, there’s been times where like I literally am not able to move, get out of bed, things like that. I can’t wash my hair, simple tasks like that because I just physically can’t move like my arms or whatever to hold the shower head or things like that. Just like yeah, simple tasks that just fatigue you out as well, that comes into it.

Int: Do you think it affects your school or work or uni life?

R: It definitely affected my uni life when I was at uni and it does affect my work now, in terms of my job… just because, as sad as it is, I can’t do as many things that other people can do so static positions is normally what triggers it so if I’m sitting for too long, standing for too long, it then just means that I can’t do continuous things.

Int: Tell me a bit more about how it affects you at work now, aside from standing, does it affect you further than that, do you have days off and things?

R: So I’ve had a certain amount of days off for my fibromyalgia which my previous work allowed just because of my condition but yes, there are days where like an ambulance will be called just because the pain is too high, so like have the medication that I’m on, so yeah it will stop me from doing work ,there’s a lot of times where I’ve had to say for example, just go out for like an hour, have a nap, I’ve had a nap at work, taken some painkillers and then tried to like get on with my day or like be put on reduced duties and stuff like that, so I can’t do as much as other people. For example, driving, like I drive a lot in my job so I would probably be stopped from doing that and just be office based.

Int: Okay, okay. Do you think pain affects your social life? And if so, how?

R: Social life is a massive thing for me, I love going out but at the same time, I know it comes at a price. For example, if I go out say on a Saturday night, see my friends, the interaction that I would have been out for them for so long, my body’s fatigued, the pain sets in, I then will have the worst Sunday, like I won’t be able to get out of bed particularly quickly, it will take me a long time, I’ll then be on like painkillers throughout the whole day.

 So it’s just a bit frustrating because it makes you not want to go out because you know full well that you’re basically putting the pain on yourself because you're knowing like the outcome, that going out or like doing normal social activities would have.

Int: Hmm. But it sounds like you don’t stop those activities, you just kind of take the brunt of the pain when it comes later?

R: There are times where I’ll say no and I’ll know my body’s like had enough but at the same time, there’s like a point of, like my age comes into it a lot, I’m 22, I don’t want to look back and say this condition kind of beat me because I know that 10 years from now, I’ll be like frustrated that- I don’t need to go out when I’m in my 30s and 40s but that’s the time where I’ve wasted, so that’s what I kind of feel sometimes.

Int: Do you think pain affects your mood and emotions, and if so, how do you think it does?

R: I’d say yes, I was diagnosed with anxiety and depression when I was about 16, I don't know if it’s directly affected as in that’s the only thing that caused it but it definitely is a contributing factor. I think it’s really horrible, in my mood personally, when you wake up knowing full well every day that you're going to be faced with difficulty and pain and like just fatigue all the time, it’s exhausting. So yes, I get down all the time because it’s just tiring to feel like you're basically like in groundhog day, you wake up and you know it’s going to be the exact same as yesterday and you're going to have the same struggles.

Int: Yeah, yeah. Do you still deal with the anxiety and depression? I know you mentioned the depression but is the anxiety still there now as well?

R: Yes. My anxiety is based around a lot of things, the type of person I am and just things like that and simple things related to fibro, I just feel like… I get anxious knowing that there’s an event coming up or something like that because I know full well that I’m going to be in pain as a result of it and sometimes, they’re things you can’t get out of and you know full well you're getting anxious waiting for that day because you know the impact it’s going to have on your body.

Int: Yeah, yeah okay. So it sounds like potentially anxiety and depression started before the fibro really kicked off, but now the two things are influencing each other?

R: Yeah.

Int: Okay. Can you tell me about advice that you’ve had from doctors, nurses, psychologists, physios, any healthcare professional about your pain?

R: Well, there was actually conflicting opinion on that, when I first was diagnosed, they told me to stop the exercise I was doing because it would be damaging and then as time went on, they changed their opinion and said, “throughout your pain, you should always try and stay active”, I don't know why they’re correlated but they always try and say, especially for fibro pain, don’t just think it will get better by staying still, yeah stay active and things like that.

 Mindfulness, they try and say a lot of stuff to be helping your anxiety side of things and pain, psychologists, I’ve been to CBT therapy and things like that before, that have helped a lot but yeah, they sometimes say it’s mentally a certain thing and your nutrition, your diet is a lot of what they try and say to stimulate pain because some foods can actually trigger more than you think, so stuff like that.

Int: So, you’ve had a real mixture.

R: Yeah.

Int: Who told you about mindfulness, was it the doctors or the psychologist?

R: It was mainly the doctors to begin with because they recommended it and then going through like different psychologists, they were more onto that as well.

Int: Okay. Have you seen a physio at all as well?

R: I used to have a lot of physio probably when I was about, I still had physio at university, probably when I was about 20 but I haven’t seen a physio recently, no.

Int: What about anyone else, like alternative therapists or other sorts of specialists, have you had any advice from anyone like that?

R: No, not really. The only kind of thing I would say as an alternative is just like self-care, simple things like spa days can be really beneficial when you just feel like you’ve let your body relax, which is a benefit in itself.

Int: As you mentioned it, let’s talk a bit about self-care.

Do you want to tell me a bit more about what kind of things you do yourself to cope with the pain when you're on your own?

R: I’d say simple things, just like a hot water bottle, people underestimate how far and like comforting that can be, for me heat is better than ice for my pain, I always think heat is better but yeah, I just feel like trying to- hot baths are always recommended, kind of relaxing to the point where your body actually feels like it’s I don’t know, getting some help but mainly just medication as well, like I take a lot of tablets.

Int: Okay. What sorts of medication do you take?

R: On a small scale, I would take co-codamol, codeine most days and then they’ve prescribed me Tramadol for the times where it gets really bad.

Int: Okay. You mentioned about mindfulness and relaxation before as well, do you do any of that?

R: It doesn’t really work for me, like I do understand why it works for other people, I just feel like I’m quite like a… stressy person in my head and sometimes I just feel like I can’t get to the point where I can let myself get there, whereas other people quite like naturally that chill, who do yoga and normal things like that whereas I feel like I haven’t let myself get to the point where I can do that.

Int: Okay. How has it been, managing as you say, doing the self-care stuff?

R: It’s hard because I just feel like I’m bored of it if that’s the best way to describe it, I’m fed up a little bit. It feels like I want this magic cure and that’s the honest truth, sometimes I just kind of feel like I want to wake up and someone’s like, “oh by the way, if you just do this, you won’t feel any pain again” because it’s, it is really tedious to do the same things over and over again and like it might make the difference for five or ten minutes, it might make the difference for a couple of hours but you know full well you're going to be back in that same position.

Int: Mm. Do you have any other problems with any of the specific strategies you're using to help manage the pain?

R: No, not really. I feel like I’m in such a routine now, I’m just kind of used to it.

Int: Yeah, yeah. Have you used any online resources to help you cope with the pain?

R: Not to necessarily cope with the pain, I’ve looked at a lot of people’s like other stories and like what they do and things like that, and that’s probably a bit more comforting just because sometimes like when I explain to people, especially my partner or things like that, “this is how I feel”, he doesn’t actually understand what I’m saying or how I feel. So I feel like looking at other people online to see that they’ve had the same things is quite comforting.

Int: You mentioned about your partner as well there, do your friends and family give you any advice about what to do about pain?

R: I’d say no, my mum, she’s had like her own chronic pain in terms of headaches and migraines and all that, so I feel like she’s numb to other people being in pain because she’s like, “I’m in pain”, do you know what I mean? And I feel like they don’t really understand on a daily basis, so they probably wouldn’t give much advice because they’re probably just thinking, “she can have a couple of paracetamol and she’ll be fine.”

Int: Yeah, okay. You mentioned about going looking for other people’s stories online, where do you go to when you're looking for that?

R: Mainly Twitter and Facebook groups, I always look for fibromyalgia groups because that’s just like directly for me, there was even like a group that I saw advertised on like a vehicle, that they do like meetings but obviously because of COVID it can’t continue but yeah, I normally look at all the Fibromyalgia UK and all the different groups that people have put in there and blogs on stuff that they write about.

Int: I’ll talk a bit more about the fibro pages in a second, but do you have any experiences of looking for information more generally about pain on social media?

R: Not on social media as such, I’ve always looked on like Google and things like that but I feel like there’s not a lot of accurate stuff on social media about certain pain.

Int: Why is that you - I know you said the experiences of people that you're looking for - but is there any particular reason why you look some of the Facebook groups you mentioned, like Fibromyalgia UK?

R: I just think they do exactly what I want to do which is raise more awareness for the condition. On a day to day basis, I feel like I’m a broken record but it just feels like there’s not enough … like I don't know what the word is, there’s just not enough exposure for the condition, there’s loads of disabilities and conditions that just aren’t visible and because people can’t see them, they don’t understand them and I feel like by having them and sharing all their pages, more people could understand “What’s this condition, what happens? Maybe someone I know has this condition”.

Int: Mm. So it sounds like you lean towards the more promoting awareness pages?

R: Yes.

Int: You mentioned about Googling stuff as well, what other internet resources do you find, or go on, when you're searching the internet for information about pain?

R: Mainly just like accredited websites, like a lot of things that have gone into studies to do with the condition and things like that, even some pages that again like they’re not necessarily social media but they are examples of question and answers about “this has happened to me, has this happened to anyone?” or like “when this pain has happened, has anyone got any advice?”, I feel like they’re just good websites to have because sometimes you can feel like you're on your own and [inaudible 00:17:16] stuff like that just makes people feel a bit more like there’s a community or people that can help.

Int: Like the forum type pages?

R: Yeah.

Int: And, do you ever go on the NHS website to find out about pain?

R: Yeah, I think I’m probably the worst person for that because I use the NHS website to diagnose myself with a lot of things, I’m that hypochondriac in certain aspects. But yes, like there was when I first got diagnosed, I looked on the website to see what methods of treatment they suggest for pain and stuff like that but sometimes I feel like the NHS is just facts, not necessarily that helpful because it’s just telling you about the condition, not as much what can be done, what there is out there, it just lists the type of things that you can do.

Int: Okay, okay. What about similar health advice websites like Healthline or WebMD or any of those? Have you looked on them at all?

R: Probably not as much, no. I’m quite inquisitive but I just feel like I stick to more websites that I know.

Int: Mm, yeah okay. What would you say you were hoping to find when you’re starting off on your Google search?

R: Probably an easier life, something that I’m going to go “oh my God, I hope this works and I hope I can use this” and like when I go home that night and I do something that maybe someone else has done and it’s worked, I think “thank God”, like I’ve actually found something where I can take like my pain down from 8 to a 5 and I’ll be able to cope, or when this happens I know that I can deal with it, whereas sometimes I feel like because I’m not used to it or a new symptom comes up, it’s hard to cope with it sometimes so you just feel like you want to know that there’s an end goal or something that’s going to stop it basically.

Int: Do you think your use of internet resources and social media has changed from when you were first, or when you first started getting pain perhaps, to more recently?

R: Yes, as pain gets worse, I feel like I search more, it gets to a point where when I first kind of had the pain, I thought it was going to be not, I didn’t think it was ever going to go but I thought it would be manageable so I didn’t really feel like I needed any help or anything like that, but I feel like as I’ve got older and as it’s got worse, I worry, for a long time I worried that I would never be able to work or I’d never be able to have a real job so I feel like now I’ve searched more in the case of what happens if this happens to me, maybe like there’s an alternative or if I can get better.

Int: We didn’t talk too much actually about your experience of general treatments for pain, how has your experience been of treatments for pain?

R: Erm... I mean I’ve actually had acupuncture for pain and I don’t feel like it worked but I’m sure it would work for lots of other people. I feel like it has a wide spectrum of different tablets, I’ve been on most antidepressants and they are supposed to coincide with fibromyalgia, some of them because some of them can make your mood better and your sleep better which can then affect your pain.

 But I feel like I’ve had so many different things and I don’t necessarily feel like anything works, I feel like sometimes that’s me being a bit of a pessimist.

Int: When you're going on the online forums and you're looking for other people’s experiences, do you take some of the treatment recommendations from there?

R: No, I haven’t actually. There’s one thing that I have looked at which is everyone recommends CBD oil in a lot of things and that’s been one of the most recommended things for fibromyalgia. I haven’t tried it yet but that’s definitely a thing that I would try, I just haven’t, in a way, got round to it or haven’t put my mind to going, “I’m going to look at what’s best” or what people have thought about it but that’s one of the definite things that I would look into.

Int: Alright then. Overall, which internet resources would you say you found the most helpful and why is that?

R: I’d say Twitter has been the most helpful because it has the most forums and platforms and most groups and I feel like it’s got the most diverse spread, so there’s so many different types of people on there that there’s been accounts of different things and you have loads of things to compare it to, and it’s probably given me the most information.

Int: Is there anything on the internet or on apps, websites that you’ve come across, that you’ve found was unhelpful and why was that?

R: Probably not personally, I feel like I haven’t had anything that’s come across bad, especially to do with my condition, I haven’t seen anything negative. There might be things that are false on the internet that I haven’t come across but for me, nothing has been unhelpful.

Int: Okay, well that’s good.

Thinking about online resources, is there anything else that you think would be helpful, or would have been helpful in the past, for managing the pain?

R: I feel like more doctors and actual practitioners and specialists speaking out. There’s a lot of people like me and like other people who suffer, make blogs and different things and they spread like their experiences, but they’re not medical professionals and I feel like if more medical professionals spoke directly about the condition and gave advice, I feel if that was more prominent, then more people would feel they had an understanding [1] of the condition and [2] they could help others and people with the condition felt like they were listened to, and could get that help.

Int: Yeah, yeah. Anything else as well that you thought in the past you wished was there?

R: Probably not, to be honest because by the time I looked, I felt like I was able to see a lot of resources.

Int: Do you have anything else to add to anything you've said so far, either about the pain or the fibromyalgia, or about online resources?

R: No, not that I can think of.

Int: Okay, alright. That brings it to the end, thanks that was really great. I’ll turn off the recording and then you’ll have a chance to ask me any questions that you have as well.

R: Okay, perfect.

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