

**Prepared For: Anna Hurley-Wallace**

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**Recording Details: lemon**

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**Transcriber: J. Mason**

**Recording Length: 16 minutes**

ANONYMISED

Int[[1]](#footnote-1): Okay. It’s started recording now. Were you just going to ask something then?

R[[2]](#footnote-2): No.

Int: Okay. So, just to double check that you’re still happy to go ahead with the interview and that you’re still okay with being audio recorded?

R: Yes.

Int: Great, okay, so I know we talked a bit about the pain condition in the screening, with the hypermobility. Can you tell me a bit about your experience of pain?

R: What do you mean exactly by “experience”, the feeling of it or…?

Int: Wherever you want to start or I can ask a different question.

R: Yeah, so it’s like I just moved to my uni accommodation and so if, because there’s a lot more walking now, after a while I think my ankles and feet start hurting and yeah, it is, makes me feel like I can’t keep up with other people as much and yeah, it is quite stressful and, yeah.

Int: Okay. And, could you tell me a bit more about the type of chronic pain that you have?

R: So, it’s kind of just, I think I mentioned it last time, just joint pain, hypermobility, yeah after maybe a normal amount of use for other people, my joints would start hurting.

Int: Yeah. And, that’s a good example, what you gave, about now you’ve just moved to uni and your ankles hurting. How old were you when it first started?

R: I think 12? Probably yeah, 12. Yeah 12.

Int: Yeah. When did you decide to go to the doctor about it or when did you get a diagnosis?

R: I think since I was younger, my parents and the doctors already knew I had flat feet so the diagnosis was quite early and I went to the doctor probably, yeah, starting 10 or something to see about maybe physiotherapy or arch support for my feet at least.

Int: Yeah, so even before that.

R: Yeah.

Int: And, do you think maybe you could tell me about what it was like when it first started, maybe compared to how it is now?

R: I think it’s actually quite similar, yeah. I don’t think there’s been a huge change. Yeah.

Int: Okay. And, how does pain affect your kind of school and college life, before?

R: Before or now?

Int: Well, a bit of both, if you wouldn’t mind talking a bit about maybe how it affected you through school, and then maybe how it’s affecting you now?

R: Yeah, so I guess in school it did make me tired easily if there was PE things as well, it was more difficult to do it and I think like I said, when I was 16 or something and I had to do GCSEs, I had to talk to like people in my school about my hand joint pain to get extra time. I think a similar thing as in university that yeah, walking to the shops but I think it’s a little bit more, it’s a little bit greater because you can’t really get your parents to drive you places, so walking to places often I think it does mean that the pain is a lot more often now. And, I haven’t started doing more studying right now so I haven’t been experiencing hand pain as much but I have spoken to my University Disability Services and they have provided extra time for me, if, when exams do start.

Int: That’s good that you’ve got some extra time and spoken to them as well. And, how does pain affect your social life or how has it affected your social life in the past few years?

R: I think yeah, it does cause you to maybe not as easily agree to going out places or to, because you feel like you might, it might not be worth the pain involved or yeah, or like just near the end of a walk with people, you have to ask them to slow down or like, yeah, so I think that’s how it’s affected it, yeah.

Int: Yeah, okay. How about your mood and emotions, how does your pain affect those?

R: I think it gets quite stressful especially when, for example moving in to uni there’s a lot of other stuff as well going on, so the pain on top of it is, does make things a lot harder and so it is quite stressful I think.

Int: The stress, okay. And, you mentioned a little bit there about doctors that you’ve seen but could you tell me about advice that you’ve had from doctors, nurses, psychologists, physios, any other healthcare professionals that you’ve seen?

R: I think it was mainly to do some physiotherapy exercises and also to wear arch supports. But I’ve found, I don’t know personally I think I lead kind of a busy lifestyle so I don’t really find, like when you’re really tired and you come home and you don’t really have the energy to be thinking about doing physiotherapy exercises and I think arch supports have a different problem, like your arch rubs against the thing and that can cause a different kind of pain, so I haven’t found them that helpful.

Int: Okay, yeah. Do you think you could tell me a bit more about your experience of the physiotherapy treatments for the pain?

R: I think they just tell you what to do and I got some, they gave me some bands and stuff to do exercises but I think if you don’t do it very regularly it doesn’t help and so I haven’t been doing it very regularly. I think some other physiotherapists that I went to just said that, “If you can’t do those then at least exercise in general can be helpful”. So, I’ve been trying to follow that rather than the specific physiotherapy exercises.

Int: Okay, okay. What about have you had any advice about your pain from maybe any alternative therapists or specialists?

R: No.

Int: No? Okay.

How about your friends and family, could you tell me about any advice maybe that they’ve tried to give you?

R: Probably just to do with the physiotherapy or maybe just to exercise more, yeah, I think that’s mainly the advice that I got.

Int: So, encouraging you to do what the doctors have said.

Okay, and in the past, when you’ve been - I know you said you got diagnosed quite early so you’ve known what the issues have been quite early - but in the past when you’ve been trying to find out how to deal with pain, who have you gone to or where have you turned to in the very first instance?

R: I think probably just my parents, nothing else apart, parents and doctors I guess.

Int: Yeah, because you were quite young weren’t you, in the first instance?

Okay. And, what kind of things, apart from the physio and the exercises that you’ve mentioned, what kind of things do you do yourself to cope with your pain? I’m thinking about things like medications maybe or relaxation or mindfulness, anything like that?

R: I don’t do anything like that, I think when I just come home I try to rest enough to recover.

Int: Yeah. So, mainly just resting and recovery?

R: Yeah.

Int: Okay. Have you used any online resources to help you cope with pain when you’re by yourself?

R: To be honest, I don’t feel like I would find anything helpful so I haven’t looked so much.

Int: Okay, right. How about, have you used any resources to maybe try and find information out about your pain condition?

R: Again, I think maybe I tried to find more orthopaedic shoes, I don’t know apart from that I don’t think I have because yeah, again I’ve always maybe just felt like I know what it is and I don’t think there’s any, many other solutions to it apart from the ones I know, so I don’t know if searching up on the internet would actually tell me something that was actually helpful or something I didn’t know.

Int: Okay. Maybe, have you had any experiences of using the NHS website at all? Have you used that for…?

R: I don’t use it for the chronic pain, no.

Int: Okay - that’s fine. How about social media? Do you use any of that maybe to seek support or not necessarily to find information but do you look at any chronic pain stuff on there?

R: No, not really, no.

Int: Or even YouTube videos or anything like that?

R: No, I think I try to ignore that I have it, to be honest. Unless it gets, I don’t know, I think I just try to deal with it quietly without, yeah.

Int: Okay.

Do you think maybe you kind of have looked at social media and then just thought, no? Is that…?

R: I think I just haven’t looked for chronic pain support in social media specifically, I mean maybe after this I might think of it, but I never actually thought of that as an option.

Int: Okay. How about maybe groups outside of that? Do you have any kind of support groups of any kind or, that you go to ask for help and support?

R: No.

Int: Okay. And I guess then the big question to ask for you is, in terms of online resources, is there anything that you think would have been helpful in the past for you to use kind of online, to help you with managing the pain?

R: No, I really can’t think of anything. No, I don’t think…

Int: That’s okay, or what do you think maybe, you said that you might think about looking in to it after this, where would be the first place you would go to look online?

R: Like when you go just on Google, it gives you really basic answers that you already know, so maybe something a bit different like Reddit or something like that.

Int: So, more drawn towards social media maybe?

R: Maybe if, yeah.

Int: Okay. That is fair enough. Is there anything else that you wanted to add to that? I know you said you don’t use online resources too much which is fine but anything else you want to add to expand on anything that you’ve said?

R: Maybe also I would think of looking at a YouTube video after this, yeah, maybe that could help, I don’t know.

Int: I suppose you don’t know until you look, that’s fair enough.

Okay, well unless there’s anything else you want to add on to what you’ve said, that’s the end of my questions anyway. What I’ll do is I’ll stop the recording and then if you’ve got any questions for me off the record then you can ask those as well, and I’ll send you your debrief.

[CLOSE]

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