

**Prepared For: Anna Hurley-Wallace**

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**Recording Details: apple**

**Date of Transcription: 21st October 2020**

**Transcriber: L Eyre**

**Recording Length: 27 minutes**

ANONYMISED

Int[[1]](#footnote-1): Okay, so it should just say it’s recording now.

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

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

R: Yeah.

Int: Great. [audio interference 00:25] That’s fine [*laughs*].

Just to say as well before I get going, my screen is over here with my tick sheet, so if I’m looking over there and not looking at you, I am still listening to what you’re saying, okay?

R: Yeah.

Int: Okay, so I know we did talk a lot about this in the screening but I’m going to go through some of that again. So, can you start by telling me a bit about your experience of chronic pain?

R: Yeah, so I’ve had pain from a very young age, pretty much all my life, but it wasn’t actually diagnosed as being hypermobility syndrome until I was 15.

**Int:** **Yep.**

R: And then along the way I’ve picked up a couple of injuries.

Int: What injuries have you had?

R: So, I’ve got cartilage damage to my knee, that was about 2015, and I also broke my back about two and a half years ago.

Int: Okay. And how have those areas been since you had those injuries?

R: They’re definitely areas that have more pain than the rest of my joints, it took them a long time to heal and settle down again.

Int: How long would you say it took them to heal? Do you think longer than normal or …?

R: Yeah, definitely for my knee it was longer than normal. And then as for my back, I still have unresolved musculoskeletal pain from it, two and a half years on.

Int: Okay, so quite a long time then. With the hypermobility syndrome, how old were you when you got diagnosed with that?

R: I’ve got a feeling I was about 15, maybe 16.

Int: Yeah. But you said it started …?

R: From a very young age, yeah. The first time I’ve got a definite memory of pain was probably year one in primary school.

Int: Oh right, so really young, okay. Do you think you could tell me about what it was like when it first started maybe compared to how it is now?

R: I think it was definitely more localised to my legs when it first started. It was often put down to just being growing pains, but these pains are still here and I’m 21 now so we know that they’re not growing pains. Now it’s more generalised, pretty much all my joints are affected.

Int: And apart from the injured areas, where are your worst joint pains, would you say?

R: Definitely shoulder because it dislocates pretty much daily, and my hands and ankle.

Int: Okay. And how does the pain affect your physical abilities to do things day to day?

R: So, I don’t write anymore because the pains in my hands just prohibit it. So, for uni work I have to type. I can’t do certain exercises, so I can’t go running because it would just leave me in bed for days with a pain in my legs. And I can’t do any strenuous weight exercises because obviously that will set my shoulder off, and it tends to dislocate [*laughs*].

Int: Anything else or is that …?

R: That’s pretty much it. I keep going through most of it, I don’t let it get in the way.

Int: Okay. And you said it affects your writing, but how does it affect your school and work and university life?

R: I definitely take longer to do assignments and stuff because I can’t sit for hours and just do work, I have to have regular breaks because the pain gets quite intense, even with typing I still have to have regular breaks.

Int: And with your academic work, have you had extra time and things like that?

R: Up until uni, no, they’ve not really been that inclusive through high school and sixth form. But university’s been amazing, they give me extra time and they give me rest breaks and everything.

Int: Okay. And do you work at all or …?

R: I’ve done part time work, I usually work as a summer temp at [company name].

Int: And does your pain affect your work in the part-time work?

R: I’m quite lucky, [company name] is very flexible with me, so rather than working on the shop floor they usually have me in the stock room or this year on greeter because obviously, Covid. So, they’re quite lenient with what I can do and they understand that sometimes it takes me a bit longer because I have to break things down into smaller bits for me to be able to manage.

Int: And how does pain affect your social life? Would you say that it does?

R: Yeah, definitely. I can’t go out as much as someone, a normal 21-year-old would, for sure, because I need to schedule in times for my body to reset itself.

Int: And what about your friendship groups and things like that?

R: I’m really lucky with the friendship groups I have at the moment, they’re so understanding. They don’t judge me, they’re very, yeah, but through high school there was definitely issues where people wouldn’t understand why I was always injured.

Int: Okay. And how about your mood and emotions, how does the pain affect those?

R: Well, I was actually diagnosed with depression and anxiety a few years ago as a result of it. It was mainly due to the fact that I had no support medically and it really got me down because obviously I was being told it was all in my head, the pain, and obviously we know now that it wasn’t, but it really does get you down.

Int: Yeah, that’s understandable. And so, I know it’s been a long road for you, but can you tell me about any advice that you’ve had from doctors and nurses or other people such as psychologists or physiotherapists about your pain over the years?

R: Yeah, so I’ve got a really good physio regime at the moment which has been a godsend. And I’ve also now, because I’ve moved to uni I’ve switched GPs, so I’ve got a GP who really has a decent understanding of hypermobility which has been invaluable. They’ve given me medications which help, they’re a lot less judgemental than my old GP, and yeah, it’s basically a lot of learning not to judge myself and just to accept my limits.

Int: Yeah. And you mentioned as well that the pain, you think, was related to the mental health issues that came afterwards, so have you had any advice from psychologists or psychological therapists?

R: Yeah, I had CBT last year at uni, through uni, which was really, really helpful. She gave me some really helpful techniques to sort of manage my mental health without becoming adverse to my physical health.

Int: Great. And do you think you could tell me about your experience of some of the treatments maybe before that, maybe more when you were in your teens and before you came to uni? How was that experience of treatment?

R: It was pretty non-existent. So, through when I was younger, they just basically were very dismissive because I was young, so young people shouldn’t have pain, and that was basically my old GP’s mindset. It wasn’t actually until I broke my back that they realised that the pain was quite bad, because I mistook it for just another flare up. So, I think that was the only time that they realised how bad the pain was getting. But then they just referred me to physio and physio told me there was not really that much they could do, and that was the end of it...

**Int:**  **Right.**

R: ... through my teens until I moved to uni.

Int: Okay, and you say you’re having physio now, or you’ve had it recently?

R: Yeah, yeah, it’s starting up again following, obviously, lockdown.

Int: Yeah - did you have extra physio for the post-injury pains?

R: No.

Int: No, okay. And have you had any advice from any other alternative therapists or specialists?

R: No.

Int: No? Okay. So, over time, thinking about the experience altogether, when you’ve been trying to find out how to deal with the pain, who or where have you turned to in the very first instance?

R: So, I didn’t really turn to anyone because my GP made me feel like it wasn’t real, so I sort of suppressed it and I didn’t really mention it to anyone, I kept it as hidden as possible. Only when it was really, really bad I told my friends, but because we didn’t know what was going on, they couldn’t really understand, they couldn’t really get behind helping me, if you kind of get what I mean?

Int: Yeah, yeah. Okay, so you think in the end maybe your friends were where you went?

R: Yeah, definitely out of anyone it would be my friends who I’d have mentioned it to.

Int: Okay, and although you weren’t too sure how to explain it to them, or they struggled with the explanation of it, can you tell me about any advice that your friends and family have tried to give you?

R: To not overdo it and to accept that I can’t do everything and that I shouldn’t have to do everything and that I could sort of ask for help from them, even if they didn’t understand why, they’d still try to help where they could.

Int: Okay, okay. And what kinds of things do you do yourself to cope with your pain, maybe when you’re at home or when you’re just by yourself?

R: Normally day to day it’s pacing myself, so I plan the week, know when I’m going to be very physically active and plan in times after that that I can recover. And then it’s just using things like painkillers and heat bags.

Int: So, you use heat packs?

R: Yeah, they’re a lifesaver.

Int: Okay, and what about things like relaxation and mindfulness, do you do any of that to help with the pain?

R: Following CBT last year I definitely do now. But before that obviously I had no idea about mindfulness. But yeah, I definitely do try to practice mindfulness now and use breathing exercises to sort of ground myself.

Int: Yeah. And what’s that been like? Have you found it easy or hard?

R: It was hard at first because I was so used to not having these sort of techniques. Planning to use them was a big change, allowing myself to sort of experience my emotions about it and not just suppress everything.

Int: So, maybe a little bit of a challenge at first?

R: Yeah, but a lot easier now because it’s been about a year since I finished and it’s definitely been helpful.

Int: And what about the other things you mentioned, medication and your pacing, what has that been like, have you had any problems doing any of that?

R: Again, pacing at first was hard to wrap my head around, but now looking back I have no idea how I coped without pacing myself, because I used to try and do everything all the time and I wouldn’t plan in times to, sort of, recover. And looking back, I don’t know how I did that, because without set recovery times now, I would really struggle.

Int: And when you’ve had issues maybe starting up with the pacing and with the mindfulness type things, how have you overcome the problems? Because you say you’re doing okay with those now, so how did you overcome the issues?

R: With the mindfulness it was talking it through with my therapist, so we introduced them quite early on in CBT, so discussing the issues with her that I was having with the mindfulness activities. She sort of explained how to stick with it, so to speak, and she explained that it doesn’t come naturally, you have to work at it. And then with pacing I feel like it just, I figured that I end up with energy crashes and I’d be in so much pain if I didn’t, that it wasn’t worth it, so it just sort of came naturally.

Int: Have you used any online resources when you were doing these coping strategies by yourself? Have you used any online resources to help you with those?

R: No.

Int: No apps or anything?... Okay.

 Do you think you could tell me about any internet resources you’ve used to find out information about chronic pain or about hypermobility syndromes?

R: So, I did the typical thing, the first thing I did was Google, so the NHS resources, and from there I found the, is it the HMSA, so the hypermobility syndromes association, and then I found the Facebook support groups, which have been so, so useful. And yeah, they were probably the most helpful resource that I found.

Int: Do you think you could tell me a bit more about the experiences that you’ve had seeking help and looking for information Facebook?

R: So, I’m part of, not one of the official groups but one that’s got quite a lot of members, people that have got hypermobility syndromes, EDS and people like that. And they have been so supportive when it comes to seeking help, and they’re often a lot more knowledgeable than regular people would be, so like my friends. So, I feel I can turn to them more when I’ve got an issue that I think is related to hypermobility but I’m not quite sure. They’re very supportive, yeah.

Int: And what do you do, do you just go on there and then …?

R: Yeah, I just usually post a message on the Facebook page and normally lots of people will answer.

Int: Okay. And, I know you mentioned Facebook is your main place, but do you go anywhere else like Instagram or YouTube?

R: No, no, I’ve only just got Instagram so I’ve not really explored yet.

Int: Okay, okay. And you mentioned as well the NHS website as being the first place that you went and then linking onwards from there.

So, can you tell me about your experience that you had of using the NHS website to find out about your pain?

R: So, for me it was quite interesting, because I didn’t at first come up with hypermobility, I think I just searched like chronic pain in joints and up came hypermobility. So, it was quite useful to be able to link together symptoms that I’d had and be able to take it to my GP and be like, ‘Look, this is what I think I’ve got’, and for them to be able to confirm it.

Int: Okay. And did you take the page literally with you?

R: Yeah. Like I say, my GP before wasn’t the best, so it was normally useful to take things with you to them.

Int: Okay. And you said you initially typed in “chronic pain” or maybe the areas you’re having pain. What were you hoping to find when you’re searching the internet?

R: I feel like I was looking for, not just obviously solutions but I just wanted answers, I wanted to know why my injury wasn’t healing, why I hurt in other joints that I hadn’t really injured. It was mainly for answers, I think, for peace of mind that I wasn’t crazy.

Int: Yeah, and then you came across the rest later, the social support.

R: Yeah.

Int: Okay, what about other health advice websites, for example Healthline, have you used any of them to find out about pain?

R: Later on I have, yeah. So, once I had the diagnosis, I wanted to know more and more about it, so I’ve gone onto various different websites, I’ve lost count of how many I’ve looked on, because I’m a scientist so I want to know about the cause and the mechanism and things to avoid and stuff like that. So, while the NHS website was a good starting point, it was a bit too vague for me, I wanted to know more the reasons behind it.

Int: Okay, so even more explanation?

R: Yeah.

Int: Okay. And how has your use of these internet resources, that you use and the social media that you use, how has it changed from when you were first diagnosed compared to more recently?

R: So, now it’s more just if I’ve got a new symptom pop up, I want to see if it’s linked. Because I know that obviously hypermobility has a lot of comorbidities attached to it, and there’s a lot of associated symptoms, so for me now it’s not so much knowing why, because I did a lot of that initially, it’s more just seeing if a new thing is related to it or whether it’s something independent.

Int: And which resources have you found the most helpful and why?

R: So, I normally go onto research papers, so NHCPI or whatever it is, I can never remember, I just Google it and it auto generates it. Just because I like to know the more precise and the more like researched answers rather than just the NHS which, again, can be really vague.

Int: If you don’t mind me asking, what area of science do you work in?

R: Well, I’m a third-year biomedical science student, with hopes to hopefully go into medicine as a graduate.

Int: Okay, yeah, just trying to get an understanding of where you’re coming from, looking at the papers. Okay, and any internet resources that you’ve found where unhelpful and why was that?

R: What’s it called, that American one. I can’t remember what it’s called. It’s where you type in all your symptoms and it throws things back at you. For the life of me, I can’t remember what it’s called.

Int: Is it WebMD?

R: Yeah, that’s the one. I feel like at first it was quite dismissive of the pain that people with hypermobility can have, so yeah, it wasn’t the most helpful website. It wasn’t always the most accurate either, so yeah, I tend to avoid anything WebMD-y.

Int: Yeah, when you say dismissive, how was that, that you thought it was dismissive?

R: It was...The way that they wrote the article related to it, I don’t know if it’s changed now, but it was like, ‘Most people with hypermobility live a normal life, it shouldn’t hold you back at all’. It’s quite dismissive when you’ve got people like me who it was starting to hold me back. It was feeling like I wasn’t doing enough to help myself. Yeah, it wasn’t the nicest article at the time that I read, so yeah, it wasn’t brilliant.

Int: Okay, that’s understandable. I’d like to talk a bit more, because you said about having the CBT more recently and the associated anxiety and depression. Do you use any online resources to help with that?

R: No.

Int: None at all?

R: No. I tend to not really talk about my mental health much because it’s not as pressing for me as my physical health at the moment, so it sort of takes a back seat.

Int: Okay, well that’s fair enough. And I suppose then, thinking about online resources, is there anything else that you think would be helpful or would have been helpful in the past online for managing [inaudible 24:33]?

R: Sorry, you just cut out there, my WIFI’s not brilliant.

Int: Yeah, it’s making a strange noise. I’ll wait for it to die down again.

Okay, so thinking about online resources, is there anything that you think would be helpful or would have been helpful in the past for managing your pain condition?

R: I feel like a better symptom checker than WebMD, so something where you can link everything together but without being dismissive of the levels of pain that you can experience with them. And also, more information that was readily available about the support that you should be getting from your GP, because I thought it was normal for them just to send you away just because you’re young.

Int: Okay, so maybe more specific to young people?

R: Yeah, yeah, definitely.

Int: Okay, anything else that you can think of that you would have liked or not really?

R: No, I think that’s about it, yeah.

Int: Okay, well unless you have anything else to add to what you’ve already said that you think, ‘I really want to talk about this as well’, that’s the end of the questions.

Do you have anything else you want to add?

R: No, I don’t think so.

Int: Okay, so I will turn off the recording and then off the recording, of course, we can have a bit more of a chat or you can ask me any questions if you want to.

[CLOSE]

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