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**Recording Details: cherry**

**Date of Transcription: 19 December 2020**

**Transcriber: N. Brown**

**Recording Length: 46m**

ANONYMISED

Int[[1]](#footnote-1): You should have a notification just saying it’s recording now.

Just to double check that you're happy to still go ahead with the study and you're happy to still be audio and video recorded, just for this?

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

Int: Great. My screen’s over here, that’s where my question prompts are, so if I’m looking over there and I’m not looking at you, I’ll still be listening, it’s just I need to refer to that. Alright?

R: Yeah.

Int: To start off with, I know we discussed some things in the screening as well but there might be some repeats and that’s fine. Could you tell me a bit about your experience of chronic pain with the hypermobility?

R: Yes, so, I guess as a kid, I was probably experiencing chronic pain but it was written off as just being one of those kid things, like over-exaggerating, but then it was probably significant by the time I started sixth form, so when I was 17, my joint pain was bad enough that it was unusual and it wasn’t, like before I’d had quite bad back pain and that had been written off by as something to do with my [inaudible 00:01:34] stuff, I don't know but it was in my hands and stuff so it didn’t make any sense really.

Yes, and that didn’t really get resolved. I kept going back and they didn’t really give me anything useful and then this year... kind of at the start of this year, I got diagnosed with PoTS because my heart was going crazy and stuff and then I think they made the connection that maybe my joints stuff was kind of a thing and I got referred to the physio. The physio picked up, like the fact that I’d been diagnosed with PoTS, the physio that up and actually saw me this time, so yeah, if that’s what the question is aimed at! [*laughs*]

Int: That’s fine! So, was it the physio who then assessed you for the hypermobility?

R: Yeah.

Int: And that was the first time you had that sort of assessment was it?

R: Yeah, before I’d been to the doctors a bunch of times and they checked me out, I think they were checking for arthritis, swelling and stuff but yeah, we didn’t do any hypermobility stuff and I kept being referred to physio but they never actually got to the point of seeing me, like they would just send me information packets that weren’t helpful.

Int: With the PoTS, was it the GP who noticed that …?

R: Yeah.

Int: Okay, alright. Can you tell me about what the pain was like when it first started, maybe compared to more recently?

R: I think when it first started, it was like less than it is now but also it was like, I didn’t have any techniques for dealing with it at all so it would just hurt [*laughs*]! I’d just have to deal with it, and it was in different places, it was often in my wrists which I found quite hard because it’s like … I don't know, it was a different kind of pain, now I get it a lot in my legs and stuff, but it was a weird - I would describe it as like a bone pain which nobody knew what I meant but it felt like the inside of my bones hurt. But it was like written off as “[name]’s just always in pain.”

Int: Okay, and how about now? How does it compare to now?

R: So now, to some extent I have less, like the specific joint pain feels less important to me because I’ve got more other different symptoms now, that kind of affect me more I would say so … yeah.

Int: Which symptoms would you say affect you more or the most?

R: So, migraines, quite bad. Problems with my stomach, really bad because you know, it affects your whole relationship with food and eating and it’s like such a big part of your life that you know, that’s probably those two are quite bad.

Int: Okay. How does pain affect your academic life, thinking about school, college, university?

R: Especially when I didn’t really know what it was and it was in my hands and stuff and I’d find it quite difficult to concentrate and write, because it was like my hands hurt so much. It makes me more kind of worried about being able to deal; I’m more worried about being able to cope with like knowing I have a bunch of essays because it might be really bad at different points. And how will I deal with that at that point when it’s really bad and I still need to do an essay, if that makes sense? In terms of planning stuff is harder.

Int: What about your social life? Does your pain affect that, and if so, how so?

R: Yeah. I’d say as like this year, as my health got worse and stuff, basically I started university last year and didn’t really, I left after a couple of weeks of my course, and I’ve come back this year. And so last year, when I didn’t know that my pain was like, I didn’t really have an understanding of my health and I just did what everybody else said and Freshers Week like went hard and you know, kept up with everyone else and I was just seen as like everyone else and partying, clubbing and stuff at the same level.

And this year, I’ve come back and this time I’m using a cane, and the people who I was with friends with last year are all around me, and they … see it and because none of them are disabled, they see it and nobody really wants to talk to me and obviously, I don’t really want to go out drinking and stuff, especially in coronavirus times, I’m like aware of how it would affect me probably way more than other people.

I don’t want to... I feel as though I’ve just changed my social life, but it’s meant that all my friends now, like most of my friends now are disabled as well, which is really cool because they get it.

Int: So, you’ve got a different social group now?

R: Yeah.

Int: Okay. How are you feeling about all that? Having deferred last year and then come back, how are you feeling about it now?

R: To some extent, it’s better because now I know and I planned, like I got in touch with all the right people, disability stuff and also like you know, like I understand about like pacing and stuff now, all these things are actually, even though my health is probably worse, it makes me feel like I have some control over that. Yeah.

Int: You mentioned as well that you're using a cane now, how does pain affect your physical abilities, aside from just the pain happening itself, how does it affect you physically?

R: Yeah, so, when I get pain, especially in my hips and my knees, especially in my knees, my knees buckle quite a lot, I find it quite hard to … and I find it very hard to stand like in place so especially with queues and stuff, I really can’t stand without much support for that long or else my knees just buckle and also my hip pain is really, I can just feel it, press it, it just feels like I’m pressing down on my hips and knees and using a cane has meant that I have something to lean on when my knees feel shaky and it takes a bit of the pressure off my legs, which has really helped my pain.

Int: What about your mood and emotions, how would you say your pain affects those?

R: Yeah, I go through kind of phases because obviously there’s the whole thing about your mood can, like the way you think about pain can also change it and stuff so I try to be like, I need to be happy! Because then it will all like go away, yeah. I guess I was having quite a difficult time just before I got to uni, you’re feeling the grief of this is this pain is here forever, that’s quite difficult to deal with.

Int: So, a sense of grief?

R: Hmmm.

Int: You mentioned a few things about advice that I know you would have got from some healthcare professionals, but I’ll talk a bit more about that.

Could you tell me a bit more about advice you’ve had from doctors, nurses, psychologists, physios that you’ve seen?

R: Yeah. To be fair, I’ve got a lot of online resources that I was sent by the physio department about pacing and living well with pain and stuff. Depending what mood I’m in when I’m reading them is how I interpret them because sometimes they just feel like they’re being like you need to be really positive and if you think, like there’s this one about ‘tame the beast’, some thing, and I’ve watched the video a couple of times and the first time I watched it, it seemed to be like “if you think about your pain differently, then the pain goes away” but I just didn’t really get much out of that one.

I think there’s an emphasis on mood affecting pain and stuff, which to be fair I do kind of... I understand and it feels worse when you're sad and you're in pain but I don't know to what extent the connection is there.

Int: It’s a very difficult one, for sure. Those are the things you got from the physios were they?

R: Yeah.

Int: When did you start your physio? Have you ever had it face-to-face or has it just been online stuff?

R: I had an appointment with the physio where it got assessed and stuff and he did all the kind of like tests and stuff, so that was face-to-face and then I’ve had, they’re spaced out, I think I’ve had a couple of phone conversations and they sent through web resources afterwards.

Int: Okay, so on the phone and then sent the resources to you after.

You mentioned about the relationship between your mood and emotions and the pain being explained by the physio, but have you ever seen someone more like a psychologist about that?

R: Not about the relationship, not somebody who is specifically there, like I was working with, I have seen a psychologist, but it was for mental health - it wasn’t related but I did mention it was about my health stuff getting worse, but we just talked about it as rather than talking about my health, it was just talking about my health as another stressor, if that makes sense.

Int: Okay, okay. If you don’t mind me asking, what was it that you were seeing a psychologist or therapist about before, or if you still are seeing them?

R: I’ve stopped seeing them now but I had like a psychotic episode and so it was about that.

Int: Okay, okay. With regards to the pain then, have you ever sought advice from other alternative therapists or specialists that you can think of?

R: No, I don't think so. No.

Int: No? Okay. Do you take any medications, did the GP give you anything?

R: I take a betablocker for PoTS and I take something for my stomach, I also have a, like I’m currently taking sleeping medication.

Int: Yeah. What was your experience like of talking to the GP about those and getting prescribed those?

R: For the betablockers, it was what he offered when I got diagnosed, he said “this will help and this is pretty much what we can offer you to help” [*laughs*] and for the stomach thing, it was like “okay”, like he offered it as a, I’d basically been having stomach problems and stuff and he was like really, I was obviously being quite concerned because I know there’s lots of overlap, people have stomach problems and then … the GP was kind of like really dismissive of the fact that I was concerned about it, like “it’s not cancer, do you think it’s cancer?” and I was like “No, I don't think it’s cancer, I think it might be something related to this” and he was like, “I don’t think that causes any problems [*laughs*], just take these.”

Int: Okay, okay. But you did take the advice in the end?

R: Yeah, I’ve been taking them and I’m just waiting for the time period he said to come, he was like “come back in a few weeks”, in nine weeks.

Int: Alright. In the past then, when you’ve been trying to find out how to deal with this pain that you're getting, who or where is it that you’ve gone to in the very first instance?

R: I guess first I’d go to my parents, I guess letting them know I’m in pain and being like “help!” because when you're little and you're like “my stomach hurts” and they give you Calpol, it’s fine. I’d go to my parents and then probably look online because you don’t want to go to the doctor without an idea of what you might think it might be, obviously it’s not your role as the patient but to have some sort of idea of what you need to mention.

Int: To have an understanding before you go to the appointment?

R: Yeah, I do find it quite helpful to know what I need to mention that will trigger them thinking whether it might be something else or not because you know, especially when you have a bunch of overlapping stuff, you're like “which symptoms are related to the current problem?”

Int: A couple of things you mentioned there, I’m going to ask about friends and family first. Can you tell me about advice that you’ve had from friends and family, parents you mentioned, about the pain?

R: My mum was always like, “you need to go to the doctor” and we’d go to the doctor and then they would give some stupid advice, well not stupid advice but like the physio people, whatever, would send a stupid information pamphlet and then “if it persists”, it did persist and we would be like, “let’s go back to the doctor”, and my dad was always like, “Oh, I had the same thing as a teenager, I always had growing pains, I had back pain, I got joint pain”, basically most of the health problems I would talk to my dad about, he’d be like “I have that as well, it’s normal”. And I’m like “okay!”

Actually, talking to my grandma because she has chronic fatigue, she was the only person that I mentioned the bone pain, how I described it and she was like “I know what you mean, I have the same thing as part of chronic fatigue”. But that sent my mum off on a big spiral because she was like “Oh no, you don’t have chronic fat-“, I was like “I don’t have chronic fatigue” and she was like “No, I don't think you have got chronic fatigue, you can’t have chronic fatigue”, so yeah.

With friends, I had a partner who actually had EDS and this is before I’d ever heard of EDS and I would constantly be, they would be like “oh this hurts” and I’d be like “Oh yeah, yeah I hurt like that as well”.

Int: Okay. When was that, if you don’t mind me asking?

R: I was with them between when I was like 18 and 19, I think. Yeah.

Int: Okay. You mentioned as well about going onto the internet before you go to the GP, can you tell me a bit more about internet resources you've used to find out information about the chronic pain?

R: I think I guess I would just start by Googling, like sometimes you just put in all the stuff and see what pops up and generally using the NHS sites and also WebMD – that’s probably one, I guess. But before it came to this year, where I suddenly got everything kind of became clear, before that point, it was just nothing seemed to match me at all. And, yeah.

Int: Okay. And what about the experiences you’ve had of using the NHS website?

R: Yeah, it’s been, obviously they’re very easy to read pages and they’re quite simplified so once, if you want to find like more health advice, it’s often more helpful to go somewhere else but if you just want to know the diagnostic criteria of a condition, it’s quite good to use.

Int: So, using, you mentioned WebMD, with that to help you.

R: Hmmm.

Int: How do you find the WebMD website?

R: That’s also alright. You kind of trust it slightly less than you trust then NHS one, but it does have a bit more information and there’s also the symptom checker, which honestly, I’m a slight hypochondriac [*laughs*] and it never brings up anything useful but yeah, it’s quite a nice tool I guess.

Int: When you're initially searching Google, what are some of the things you are putting in? Are you putting in symptoms or something else?

R: I would put in symptoms and especially if they’re like, so if you put in joint pain, most stuff comes up like arthritis but if you put in joint pain and then you put your age and clicking joints, that kind of thing, I just throw those in there.

Int: Okay. What do you think you're hoping to find when you search the internet?

R: I guess it’s like “that’s me”, you know what I mean? “That sounds like I reasonably fit those symptoms” and let’s go to the doctor and be like maybe that’s what I have or, because often, I’m always quite wary of going to the doctors and being like, “I think this is what I have” because I feel like they won’t really, but kind of going with an awareness so that when they mention that, they’ll be like “oh I heard of that” and you kind of know they’re doing the right kind of test things. Yeah.

Int: Okay. I’m going to skip back a little bit. We talked quite a lot about seeing the doctor and looking for information, but what kinds of things do you do yourself to cope with pain when you're by yourself or at home, self-management type things?

R: I guess... I use the classic things that people recommend like hot water bottles, heat bags, resting and trying to, distractions, obviously just paracetamol and stuff, that sometimes helps, it sometimes doesn’t.

Int: What about things like mindfulness, do you do any of that to help with the pain?

R: No, I don’t really, I used to do quite a lot of meditation stuff, but I haven’t done it that much lately and it’s never, I’ve never done it specifically for my pain.

Int: Okay, okay. Do you use any online resources to help you cope with pain when you're by yourself?

R: Yeah, I guess online communities can be, it’s quite nice, like that sort of community. I keep a symptom checker just so I know what’s up, that I use.

Int: Is that like an app type thing, the symptom checker?

R: No, I made a spreadsheet [*laughs*]. Quite organised.

Int: Okay, okay. What about the online communities, what ones are they? Where do you go to?

R: I use the Instagram one quite a lot, yeah. Because it’s nice to be able to see other people, people my age or you know, below 30, and there’s lots of nice resources and people like link nice stuff. I also use Reddit - I find that quite helpful. I use the Instagram one more to see other people like me and follow their stories and stuff and I use the Reddit one for more of an advice, conversation thing with other people.

Int: Do you take advice that you see online?

R: Obviously, if it was something like do something that’s potentially harmful or ridiculous I wouldn’t, but things like … what have I used it for? I just follow, some people share tips and tricks that help and obviously there’s lots of discussion about medication and stuff, I’ve asked questions, like “has anyone else experienced this side-effect?” and if people do, you're like “okay, this makes sense, it’s this medication” and kind of take, there’s lots of people that share little tips, especially stuff like with PoTS, “Here are some really tasty electrolyte drinks” rather than Gator Aid and that kind of thing, and products that might help.

Int: What about other resources like Facebook or YouTube, have you ever looked for information or support on either of those?

R: Yeah, I’ve used You Tube, I used it to find other people who were doing, I actually used it when I was applying for the disabled students allowance and I found someone else who talked about applying for pretty much exactly the same conditions and stuff, so that was quite useful and then I have been following her, watching her videos talking about uni life and stuff and I also watch a couple of other people like … what’s her name, Jessica Kiljer Proson, I think her name is, she’s quite popular, she does disability videos and she’s also LGBT which is cool. So, they’re nice, again with the Instagram thing of seeing other people who are also in the same situation.

Int: Okay, that makes sense. Do you think your use of internet resources or social media has changed from when you first started getting pain, to how you’ve used it more recently?

R: Oh yeah, definitely, mainly because at the start I didn’t know anything, now that I know what it’s caused by and I have an acceptance of it being like a condition rather than some random pain that I would experience, being like “this is a thing”. I definitely use … so I feel more valid by the fact that it’s a condition, beforehand you wouldn’t go on Instagram and just search like “pain” but if you follow people who have got like EDS and people talk about that stuff, yeah.

Int: Which internet resources have you found the most helpful and why?

R: Probably Reddit because it’s a, just the way the format is, you can ask questions because there’s lots of internet forums, like patient internet forums, and proper medical ones, but they’re always full of really old people and Reddit is a nice middle ground where most of the people on there do tend to be not like old people but they’re not people my age, so a lot of people have more experience of dealing with things. Especially when you mention that you're quite young, it feels like you’ve got lots of [*laughs*] mothers offering you advice.

Int: Any internet resources that you’ve found were unhelpful and if so, why?

R: I think patient forums or medical forums online unhelpful, because it’s like older people and sometimes they’ll talk about feeling, having … like you know, it makes me feel worse because I’m like “this is an old person” and they’re talking about feeling restricted because they can’t do these things, but I can do even less than them sometimes and I’m like “wow”.

To some extent, Instagram can be both helpful and harmful, you just need to take into perspective sometimes because it gets very, some people get very competitively ill, if that makes sense, they go really hard on how, it’s like the most ill people get the most attention so you feel like, “I’m not really in pain compared to this person who is literally in hospital at this moment”, but if you take it into perspective and kind of... chill out, it’s alright.

Int: Alright, so a bit more selective maybe about the pages and people that you follow with Instagram?

R: Yeah, there’s the temptation to just follow anyone who shows up but then some people are just like… they won’t share anything helpful; they just share their misery and obviously good for them venting and stuff but at the same time, it’s not going to make you have, especially I’m like quite high empathy so it can be quite difficult if you're just sharing the world’s problems.

Int: Indeed, it can, yes.

Another question I have from a little bit earlier back. With the coping strategies you use, not online stuff but everything together, your medication, your physio, all of that, do you have any problems with the coping strategies that you use at all?

R: What do you mean by problems?

Int: Any issues with medication management or with physio things, even if you’ve tried stuff you’ve seen online and had any problems with that?

R: Mm. I guess I’m quite sort of disorganised so often, when you need to be really organised, like do your exercises each day and take these medications, I’m quite bad at doing that but you know, you just work around it. I’ve got like a pill box and stuff that’s right next to my bed so as soon as I wake up, I know to do it and like notifications on my phone constantly, that kind of stuff, reminders.

Pretty much the main problems I have are remembering to use coping strategies because often, I’ll be in pain or have a migraine or... I have lots of things that can help in these situations and I just completely forget, I would just like won’t take painkillers or take paracetamol, I won’t lie down and close my eyes because I just keep on rolling with whatever I’m doing and I just don't think, and then I just need someone to prompt me to be like “look this is your... if this will help” and it always does and I’m always surprised and I don't know why! [*laughs*]

Int: So, in terms of overcoming that problem with maybe the organisational element, I know you said you had a spreadsheet but is the spreadsheet and trying to organise, is that your main way of overcoming the problem? Or do you do other things to try and help?

R: Yeah, so setting up phone alerts, through DSA, I’m supposed to be getting this app thing where it can, it’s called Brain In Hand and you can put in all the things that you need to do and stuff and it’ll have like, it has like problems and then you click on the problem and it brings your solutions that you have put in, like for that problem in, of what you should do in this situation when it occurs.

So yeah, making use of reminder things and often, sometimes just mentioning to a friend or family, “I’m experiencing this” and then they’ll be like “this is what you always do, you need to do this”. Yep.

Int: Okay, and you mentioned the DSA app, what is that? Can you explain to me a bit more about that?

R: So it’s like this app called Brain In Hand, it was developed for people with autism and then now they use it for quite a range of people, especially if you have trouble with organisation, feeling like making decisions, feeling kind of overwhelmed in situations and I’m still waiting for it... because it’s quite, you have a mentor that helps you set it up so I’m still waiting for that to be sorted out but you can put in your calendar, you can put in like a bunch of, like your daily tasks so especially it depends on how good your own things are because for some people, it’s like “get out of bed” and you tick that off and then it’s “make yourself some breakfast” and tick that off and kind of go all the way through, and they will come up with reminders if you need them to, and then it’s also got like a problems thing where it’ll be like “here’s your problem”, like you have a headache and then you flick through and it says, “here are your solutions you’ve come up with” and so you go through and like try these solutions.

It has also has an access line to a mentor to help. So, if you're feeling overwhelmed and you don’t really know what to do and you're in a panic, then you can say that on the app and then someone will ring you and talk it through with you.

Int: That sounds really good, where is it that you get that through, which organisation, where does it come from? Where is the mentorship coming from?

R: The mentorship and stuff is all through the Brain in Hand, I think they’re a brand, like the Brain in Hand is an app and all the mentors and stuff are through that, but I think it’s... I’m pretty sure it’s expensive because you have access to a mentor and stuff so you need to get the funding through, I know a bunch of mental health trusts use it, have funded it, but my funding will be through Student Finance, through the Disabled Students Allowance. I think some unis might fund it as well, privately.

Int: That’s interesting, I didn’t know about that. Alright then, so waiting for that one.

R: Yeah.

Int: Hopefully that will be useful to you when you do get it.

Thinking about online resources all together, is there anything else that you think would be helpful or would have been helpful for managing your chronic pain?

R: I guess more like the, I’ve got a bunch of resources through the physio, PDFs that they would normally have given us leaflets of... some of them are quite helpful but to some extent, they were all aimed at like older people, like not even proper elderly people but it mentions sitting down and when you're seeing your grandchildren, I’m like “I know I’m sitting down, when I’m seeing my friends in a pub”, but also they would be more helpful because they would mention stuff like “do an activity planner” and stuff but then it wouldn’t come with it. I think having printable resources from that - those kinds of things would really help because I quite like doing stuff on paper, having pretty resource sheets and stuff, if that makes sense. Obviously, you can just draw a table and write it in, but pictures would be nice.

Int: Something a bit more aesthetically pleasing perhaps?

R: Yeah, like the same as how there’s lots of nice study planners, that kind of thing.

Int: So, a bit of an update as well of the resources coming from the NHS?

R: Yeah, like obviously I get they’re just trying to do the basic stuff, but I haven’t really been able to find any when I’ve been looking online either. There’s lots of nice mental health resources but there’s not so many ones for chronic illness.

Int: Okay, okay, that makes sense.

Alright then. Is there anything else you'd like to add on to anything that you've talked about? Either about the pain condition or about internet resources?

R: Yeah, I guess just in terms of the pain having a name if you like has both been really helpful and really unhelpful, because finding out that it is something that’s not going to go away is really difficult, and is really hard, but at the same time, now knowing what kind of ball park I’m in, now when I’m using the internet, I can know to put in stuff to do with hypermobility, stuff to do with PoTS and because a lot of... If you're just Googling, you get stuff that’s relevant to… people without certain conditions, like with my stomach stuff that’s been going on, you just get lots of stuff being “it’s probably don’t eat spicy food” or whatever but when you look at the hypermobility websites, you can see that, no, it might be something to do with this instead, and conditions that are quite uncommon with other people more, maybe potentially more likely. That kind of stuff has been quite helpful to navigate which places you're looking.

Int: So - you think having a label or not having a label is better?

R: I think having a label is definitely better, especially when trying to find information and use online stuff, it’s way better because you can actually find stuff but it’s just difficult, I guess, in terms of... finding out that you have that, but like I would rather know I have this than have it and not know, I’d rather be diagnosed. Even if they’re saying this is a very temporary condition that will go away in six months but the fact that I now know I have it is very useful.

Int: Okay. I think I understand where you're coming from. Right so, unless you have any more to add, that brings me to the end of the questions. And then what I’ll do is turn the recording off and give you an opportunity to ask me any questions that you have, off the recording, okay?

R: Yeah.

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