

**Prepared For: Anna Hurley-Wallace**

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**Recording Details: banana**

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**Transcriber: L Eyre**

**Recording Length: 32 minutes**

ANONYMISED

Int[[1]](#footnote-1): Okay, so it should say it’s started recording. So, 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 for this?

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

Int: Great. And as a note, I’ll be looking over here at my questions, it doesn’t mean I’m not listening to you, so if I’m looking over there, I will still be listening to what you’re saying, okay?

R: Yeah.

Int: Alright, so we would have gone through some of these similar questions in the screening but I’m going to start through them again as a warm up.

R: Yeah.

Int: So, could you start by telling me a bit about your experience of chronic pain?

R: So, I have wrist and ankle pain, so my wrist pain stops me from being able to write for extended periods of time, type for extended periods of time. It affects my ability to play my instruments and do my work. And my ankle pain flares up when I’m walking long distances or particularly hilly areas.

Int: And what instrument do you play?

R: I play flute, clarinet and saxophone.

Int: Okay, so it affects all of those, yeah. Okay, and how old were you when you first started getting those pains?

R: Ankle pains have probably been there for about five, six years, and the wrist pain for the last four, five months.

Int: And you say the ankle pain affects your walking, your ability to walk long distances?

R: Yeah.

Int: Does that affect any other areas of your life?

R: It affects playing sports, yeah, that sort of thing. Sorry, I said my wrist pain four to five months. I’ve completely lost track of the time because of the six months we’ve been in lockdown. It’s more like a year [*laughs*]. Four to five months before lockdown.

Int: Okay, yeah, that’s fine.

R: Sorry about that [*laughing*].

Int: No, [*laughs*] that’s absolutely fine. And what about your school and working or university life, whereabouts are you at the moment, can you remind me?

R: I’m at university.

Int: Yeah, so does it affect any of your educational stuff?

R: Yeah, I have to have extra time in exams, I have to have a laptop in exams so I can type instead of write. I have the ability to have my lecture materials before so that I’m not having to type everything up in the thing, access to lecture capture because I can’t type continuously throughout a lecture.

Int: And how about your issues with your ankles, anything at uni or college that’s been affected?

R: No.

Int: And do you think you could tell me, if we start with the ankle pain, do you think you could tell me what it was like when it first started compared to more recently?

R: It’s definitely got slightly better since I’ve, when it first started, I was riding competitively, horse riding competitively, and dancing. Since then I’ve stopped riding and stopped dancing, competitively anyway, so it’s got better since I’ve stopped doing that but it’ll never be 100% better, it’s just there. But it’s definitely improved since I’ve stopped doing the activities that were clearly hurting it.

Int: And do you do replacement activities then instead?

R: Yeah, I run now instead of dance, get some pieces like that.

Int: Okay, and similarly, how about the hand and wrist issues, what is that like compared to when it first started?

R: It’s been better since I’ve been playing my instruments less because obviously I’ve not been in school, but obviously I’m going to start playing them again more because doing a music degree, but it’ll probably get worse again so that’s not really changed since it started.

Int: Okay, and do you think pain affects your mood and your emotions?

R: I think that the pain affecting my ability to do the things that I enjoy doing definitely does.

Int: Yeah. And what kind of feelings do you have about that?

R: It makes it stressful because you want to be able to do the things that you enjoy doing, I want to be able to play my instruments without being in pain and want to be able to dance and things like that, but I can’t do that without being in pain, that’s just a fact of life at this point. So, it makes it stressful and it makes it less enjoyable than it was.

Int: Okay, and so with your, especially playing your music, do you do that on your own or with other people in a band or orchestra or …?

R: Bit of both, I was in a marching band before I moved to [location] and obviously at the moment bands aren’t able to play, but once they’re back playing, I’m sure I’ll be joining something in [location] to play with people, and also do practice and play on my own.

Int: So, in terms of your social life then, do you think through what you’ve said there, do you think your social life has been affected by the pains or not really?

R: I think yeah, a little bit with the stopping riding because I’ve lost a lot of my friends from that and the dance. But with the music, because I’d still go and I’d just, if it was hurting me, I’d just stop for a bit and then carry on, so it’s not really affected that part of it. But definitely my ankles with the riding and the dancing.

Int: Okay, okay.

And could you tell me about any advice you’ve had from any doctors, nurses, physiotherapists or any healthcare professional about the pain?

R: Yeah, I need to - I’ve got a set of exercises that I have to do for my wrist pain which is like wrist strengthening exercises. But mostly the advice has just been to stop playing or stop doing something, which I’m obviously not going to do because it’s like my degree and my livelihood and everything.

Int: Hmm. So, who gave you the exercises, was it a GP or a physio or …?

R: A physio.

Int: Okay. And have you seen anyone else like a psychologist or a nurse specialist about it?

R: I’ve seen a music therapist but not about my pain, that was for something unrelated.

Int: What was it, if you don’t mind me …?

R: It was for surgery prep before I had my heart surgery.

Int: Oh, okay. When was that?

R: That was last year.

Int: Okay, it all went okay or …?

R: Yeah, fine, no problems.

Int: That’s good then.

Have you had any advice at all from other alternative therapists or any other specialists about the pain issues?

R: No, not particularly. I’ve been to physio and to doctors but nothing outside of that.

Int: So, what is your experience like of talking to the GP, I presume you mean about going to the doctors? And also getting advice from the physio. Did you find it a good experience or what’s your thoughts?

R: Yeah, reasonably fine. I’ve sort of dealt with doctors all through my life because of my heart condition, so it’s not like an ‘out there’ experience for me, it’s just something normal. So, yeah, no different from any other sort of doctor’s trip.

Int: Okay. And previously when you’ve been trying to find out how to deal with the pain, who or where have you gone to first? Is it the doctors or is it a person or something else?

R: So, with my ankles we went through the NHS GP to the NHS orthotics, that side of things. With my wrists we went through private healthcare straight to a, we referred to - it’s like an online GP system and they just refer you straight to a specialist, so straight to a paediatric, oh gosh, I’ve forgotten the name, someone that deals with joints and arthritis.

Int: Oh, a rheumatologist?

R: That’s the one.

Int: Okay, so for the hands you had that?

R: Yeah, for the wrists.

Int: Okay, and have your friends and family given you any advice about it?

R: No, not particularly. Just sort of things like, ‘You should do what the doctor tells you to do’.

Int: Yeah, yeah, okay. I’m interested about the private route that you went through because you said about the online GP. What’s that like, can you describe it to me?

R: Yes, so it’s through an app and you just do a video call GP thing and you’re like, ‘You have these symptoms, please can I be referred to a specialist’, and they give you a referral letter and you find your own specialist.

Int: So, does it have a symptom checklist type thing?

R: No, it’s like a video call.

Int: Oh, literally just a video call, okay.

R: Yeah.

Int: Okay, and why did you decide to go that route instead of through the regular GP?

R: Well, it started to flare up the September that I was in year 13, so, well, I would have had exams coming up if obviously this hadn’t have all happened, so we wanted to get it, if it was something that could be sorted, we wanted to get my exam arrangements, get it sorted before the March. And obviously NHS has quite long waiting times normally and we had the private healthcare through mum’s work, so we just figured it was worth using it instead of waiting.

Int: Okay, yeah, that seems logical.

And in terms of things you might do yourself when you’re at home and you’re managing your wrist pain, your ankle pain by yourself, what sort of things would you do?

R: I’ve got my wrist supports that I wear, so I wear them at night while I sleep, and if my ankles are sore I will strap them so that they can have a bit of a break. I also will stretch, so my ankle problems, we’ve half worked out that they might be partially due to having quite tight muscular calves, so stretching, stretching my legs, stretching my arms, stretching my wrists, to sort of loosen everything. Strengthening, doing my strengthening exercises for my wrists. Just bits and pieces that I’ve found over the years tends to alleviate it or just make it more bearable.

Int: Yeah. So, you do quite a lot of physical stuff, it sounds like?

R: Yeah.

Int: Okay, what about medication, do you take any of that for it?

R: I try not to take medication. I’m already on aspirin daily for my heart condition so I just try not to take too much else. I can’t take any anti-inflammatories anyway because they interfere with the aspirin and paracetamol just doesn’t, it’s not the right sort of medication to help with the joint pain anyway, so I just try and deal with it myself.

Int: And what about things such as relaxation or mindfulness, have you tried any of that yourself or not really?

R: I’ve tried a little bit of it but I don’t really find that it helps.

Int: Why do you say that? You just didn’t get on with it?

R: No, a lot of the mindfulness stuff that I used that worked best for me going into hospital and stuff was to do with playing my instruments and singing and stuff like that, and that’s a lot of the stuff that aggravates my wrist more, so it kind of doesn’t go between. And a lot of the other mindfulness stuff that I’ve tried doesn’t help.

Int: Okay, and have you used any online resources to help you cope with pain by yourself? Have you tried any apps or websites or anything to help you manage at home?

R: Well, I guess I kind of do, I use stretching apps to help with my stretching and stuff, so that sort of thing, but nothing really other than that.

Int: What is it called, the stretching app you use?

R: Oh, gosh, it’s just a really generic legs stretching for 30-days sort of cycle app that I just use.

Int: Okay, was it a recommended one or did you just search for it yourself?

R: It’s one of the ones we used to use when I used to dance. So, I’d just gone back to that because I knew it and I knew the stretches sort of thing.

Int: And when you’re doing your pain management things at home, when you’re making a support for your ankles or your wrists or you’re doing your exercises, have you had any problems with those strategies at all?

R: Sometimes things are too painful. So, if my wrists are really hurting and my ankles are really hurting, sometimes I have to get someone else to do the wrapping because my wrists are just so sore, I’m not able to do that myself. But other than that, I’ve generally been able to do that.

Int: So, you get help from someone else to do it if you can’t?

R: Yeah.

Int: Okay. Do you think you could tell me about any internet resources you’ve used to find out information about the pain you’ve been having?

R: Definitely when I wasn’t sure what it was, like reading up on the, mainly the NHS website about the different conditions that could cause wrist pain so that I had some sort of idea of what I might need to, what sort of specialist I might, because I had to find my own specialist so finding what sort of specialist I needed to go to.

 When my ankle pain started I was too young, I was only 11, so I didn’t really have access to the internet at that point. And so, as the years have gone on, I’ve just learnt through my own ways to deal with that, so not really ever accessed the internet to help me with that. Definitely like videos of ways to manage and stuff, but not particularly, no.

Int: Okay, so when you’ve looked for or when you’ve watched videos about maybe exercises or how to manage it, are they something you’ve found in the NHS website via that way, or do you go on YouTube or somewhere else?

R: A bit of both really, so sometimes the NHS stuff, sometimes other charity websites that deal with this sort of conditions that cause skeletal pain. And yeah, YouTube as well.

Int: You said initially you went on the NHS website to try and find out a bit more. What was your experience of using the NHS website like, how did you find using the website?

R: For the wrist pain I found it quite easy to use, the link between, so you start off where your brain goes to, the arthritis kind of route, because I know there’s quite a bit of it in my family medical history, and then generally there’ll be links for like, ‘This can also cause wrist pain’, and it just takes you through and it will show you lots of different things. So, I found that quite accessible, quite easy to use, yeah.

Int: And have you gone on any other similar health advice websites, for example, Healthline or anywhere like that to find out about pain or …?

R: I think so but I can’t remember specifically which ones.

Int: Yeah, so it sounds to me like NHS was kind of your go to?

R: Yeah, I think because it’s always been the, like, if I need to find out whether I can have something because of the aspirin, the NHS website is quite useful for that. And the heart condition, so because I’m so familiar with it from my own medical history, it’s just where my brain goes to if I need to find information.

Int: Yeah, okay. I’m going to ask about the videos again but specifically more about YouTube, but it’s okay if you can’t remember.

R: Yeah.

Int: What’s your experience of looking for pain management information on YouTube, what’s that been like?

R: You tend to get a lot of things that aren’t useful. It tends to take a lot of trying before you find one that is useful. So, generally when I’ve found one that is useful, I’ve saved it and I’ll keep going back to that one when I need it, because it takes quite a long time to find one that suits you because obviously there’s so many videos and some of them aren’t official or by professionals, and you’ve just got to be careful with what you’re following.

Int: Hmm. And how can you tell if a video is professional, in your view?

R: I think that often I will, so if it’s a particular person that’s got a particular set of credentials, I’ll search them and see if they’re on one of the named databases and check that they are actually qualified as what they’re claiming to be. And other times if they’re YouTube videos that have got charity websites linked in the descriptions and stuff, often they’re normally checked and okay to use, sort of thing.

Int: Okay, that’s really interesting and good that you do that as well.

Do you go on Facebook or Instagram or any other social media stuff looking for pain-related information?

R: No, not really. I am on them but not for that sort of purpose.

Int: Do you think, when you’re typing into a search, I know you said it is mainly for you to look at information, but do you think about any other things when you’re looking for information online or have you got a background motivation?

R: Sorry, I don’t really understand what you’re asking me.

Int: No no, I’ll rephrase. I guess, what are you hoping to find when you’re searching?

R: I think at first you’re hoping to find something that fits your symptoms and is going to tell you what it is, but obviously at this point I’ve kind of like not got any hope of figuring out what that is anymore, sort of thing. So, now just finding something that at least sounds similar and might give you something to Google to find strategies to help it.

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

R: I think definitely when I first started getting pain I was definitely trying to like look for an answer, look for a cure, sort of thing, and now I’m more looking for a way to minimise it or a way to help it be less and a way to help, different things to help me do day-to-day things instead of something to cure the problem.

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

R: Probably the NHS website was very helpful starting point because it just helps you see where, it gives you a starting point, or it just helps you see... or it gave me a starting point of other things to search and things to find out. Because when I first started getting pain, I was like, oh, maybe I just need to rest it for a bit. But searching it, it was like, no, you probably should go tell someone about that because it might be something more serious or it might be something that can be sorted. So, it definitely helped getting a starting point of things to look at and whether it needed to be just rested or whether it needed to go to the doctors with it, sort of thing.

Int: Okay, so, as a starting point it’s good to use the NHS website?

R: Yeah.

Int: And which internet resources have you found perhaps unhelpful and why was that?

R: I think just like forums of people, because it can make you think the worst or whatever, or people can be unhelpful and not give good advice. But also, at the same time, the NHS website because it can make you think the worst. Like when you’re Googling your symptoms and you’re getting horrific things back, you’ve got to reign yourself in and be like, it’s probably not that, sort of thing. So, you’ve just got to have, I don’t know, I’m quite good at sort of saying, ‘Well, it’s not going to be that’. If it is, you’ll go into the doctors and you’re going to find out whether it is that or not, but you’ve just to wait until you know. And if you can’t find anything then you then can start to just Google symptoms and try and find out for yourself’.

Int: Yeah, so it’s [NHS website] kind of the most helpful in some senses and the least helpful in others.

R: Yeah, I think it depends on your frame of mind and how you’re looking at things. Because I know that I’m quite good at saying, ‘Well, it’s not going to be that, it’s not that serious’. But some people obviously will obviously just like panic.

Int: And you mentioned then about forums, which you haven’t mentioned before, that you think they’re... you’re a bit wary of forums maybe?

R: Yeah, I think so. When I was trying to find out from other people’s experience what exam arrangements I would possibly be able to get, because I knew I was struggling, you’d just get people being like, well, so if someone had put their experience in, you’d be like, ‘Oh, that’s quite similar to mine’, and read their replies and people would be quite nasty towards them, and you’re thinking, ‘That’s not helpful, that’s not what I came here looking for’, sort of thing. But, at the same time, they can be really useful in some aspects, just I didn’t find them to be useful.

Int: Because of the kind of responses from other people to posts?

R: Yeah, it was like nice to know that you weren’t the only person, but also at the same time it wasn’t helpful because no one had given a helpful answer.

Int: Right, okay. Yeah, that makes sense.

And so, thinking about online resources, is there anything else that you think would be helpful, or perhaps would have been helpful in the past, for helping manage your pain?

R: I think that it would be really helpful for - so when I was first starting off with the, and having to give up riding and having to give up dancing with the ankle pain it was sort of like, I’m the only one, I didn’t really have access to the internet and stuff and they didn’t know what it was. And so, it would have been helpful to have a community of, like a safely accessible, because I was only so young, safe accessible sort of forums and sort of support group discussion type things for younger people experiencing it.

Int: Yeah, okay, that makes sense, so maybe a forum or a group or something that is more monitored and it …

R: Yeah, because obviously you’ve got things like ChildLine and stuff for mental health and other disabilities, but there’s just not a lot of resource on there to do with pain management and that sort of thing. A lot of it is geared towards behavioural and mental health issues, and I think obviously that’s great and very helpful for a lot of people but also there’s the other side where people don’t particularly, or like have mental health issues stemming from pain management and that sort of thing, and it would be nice to see some support for the base of the problem instead of what comes from it.

Int: Okay, alright.

And so, is there anything else that you’d like to add on to anything that you’ve said?

R: Not that I can think of.

Int: No? That’s the end of my questions for today, unless there’s anything else that you think, ‘Oh, burning, I must say about that’?

R: No.

Int: Okay, and yeah, other than that, thank you. I will turn the recording off now and if you have other questions for me, then of course we can chat off the recording as well.

[CLOSE]

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