

**Prepared For: Anna Hurley-Wallace**

**University of Southampton**

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ANONYMISED

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

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

Int: Great thanks.

And a note as well. My screen is over here so I’ll be looking over there as my question reference point but if I’m looking over there, I’ll still be listening to what you're saying, okay?

R: Yeah, that’s fine.

Int: Alright. Some of the questions are a bit similar to things I asked in the screening but that’s fine, we’ll just start from the beginning as a warm-up and go from there.

R: Okay.

Int: Okay. Could you start by telling me a bit about your experience of the persistent pain?

R: Basically, I’ve always had some amount of pain since I was a child but it wasn’t kind of that bad, it was just focused on my legs and occasionally my fingers when I kind of wrote too much, and then it was when I was about 13, 15, started puberty, started growing, where I kind of had a major spike in pain and sometimes it was like I’d curl up in a ball and ignore the world for a while.

Then started to settle back to like a high amount of pain I had as a kid, but still not really that bad because I think I was still doing loads of swimming at that point, so it was fine. And then it was around sixth form, so I was 16, 17, dropped out of football and swimming and then the pain started getting worse, especially doing lots of walking, lots of typing because of coursework – wasn’t such a fun time for me - and then when I was into going to university with a lot more walking to different lecture theatres, it got more intense and then having to stop walking, well walking to the town centre or doing shopping, having rest breaks more often because of the pain and then it kind of settled at that point most of the time. But now, it’s more every joint rather than just my lower legs and fingers.

Int: Okay. So, getting pain in other joints now, across the body?

R: Yeah.

Int: Could you tell me a bit more about the pain type you have?

R: Basically, most of the time it’s kinda dull with a sharp kind of feeling, aftertaste to it? And when it’s a build-up, it feels like there’s something in the middle of my joints just swelling up and then just popping, once it gets a bit too bad kind of.

Int: Okay, okay. You mentioned quite a bit about sixth form and university, do you think you could tell me a bit more about how pain’s affected your education life?

R: Well, it didn’t, well I always had dyslexia, which wasn’t diagnosed until last year, but I have difficulty writing because of my wrists and my finger pain. The main problems I had was doing exams, obviously you had a question and they wanted you to write two or three pages and I could only physically write one page in that time, because I have to have rest breaks to get feeling … because exam essay questions are at the end so you have to do all the other questions and my hands are already dead by then, so I couldn’t keep up the speed writing as long as I should have been writing for, to get actually good marks.

And then with course work, a lot of typing, because we had three-hour lessons at sixth form and you had lunch or breakfast break but physically writing for three hours, my finger joints stuck too much and at the end of the day I was physically in pain, just exhausted from the pain and I couldn’t do my homework because I had to have some recovery time, sometimes I just forgot to hand in homework assignments because of it.

Also carrying stuff around, was, because we had to carry all our books around with us and I used to just drop the folder off somewhere because I couldn’t carry it anymore, and then I’d walk away from my folder, but my wrist hurting still so I honestly thought I was still holding it and then I’d get to class, and I’d have no idea where my folder is in the entire school.

Int: Right, okay. What about university? You mentioned the walking and going out, how has your pain affected you in that way?

R: In my first, first year, because I changed subjects and I had to redo my first year, they had me in one building on the second floor and then within ten minutes, I had to walk to another building on the opposite side of campus on the third floor so I kept turning up late because I can’t walk that fast up and down stairs and then walking across campus within. I mean it was ten minutes but most of the time it was three minutes because the first one refused to let us out on time, so it was mainly actually getting to lectures on time has been a bit of an issue for me, happy they don’t take attendance like school does.

And then some problems with doing multiple coursework’s, if I just have one coursework on the go, it’s fine because I’m just focused on that and skip over writing my notes up and do my notes over Christmas to make sure I’m not too bad shape, but it’s when I have two pieces of course work due at the same time, then I’m having to type for longer, which obviously causes my hands to hurt more, which causes me to type less, which still causes an issue of actually finishing coursework sometimes.

Int: Okay, okay. Does pain affect your physical abilities in any other ways apart from what you've already described?

R: Kind of like lifting and carrying stuff is one because in my shoulders is kind of a weird joint pain because my left one’s too stiff and my right one has an interesting effect where it feels very loose from my body, I usually joke about it being partially dislocated all the time because [1] most of the time I swear my right one’s lower down on my body than my left one, but sometimes I forget I have an arm attached to it, I just can’t feel that area properly and it feels too loose so I have to carry stuff on my left arm which isn’t my dominant arm, so it doesn’t go too well and carrying heavy stuff with one arm doesn’t always end well.

Int: Mm, yeah. I can imagine that it doesn’t. Yeah. All of this that you've said about with the pain, how does that affect your social life?

R: I know... Obviously, it’s a bit better now because I have my flatmate who I’m forced to spend time with her but I don’t mind it because I get to see someone, but especially kind of like in secondary school and sixth form, because with my school, we’ve had students from my town and also from the neighbouring city and my friend was from that city, and I kind of refused, train travel was a bit awkward because of my back pain so I would make up excuses not to go to their house. Mainly because like them wanting to go on shopping trips and it’s like I don’t like walking, they wanted me to walk about five hours around shops I wasn’t going to buy anything, and I don’t like carrying stuff around for that long, so I would make up excuses to kind of ditch them the week before.

I have some trouble regularly attending sporting things too, but I did sign up for a few sports societies in my previous years, but then I couldn’t guarantee I could actually attend them because it was at night, by then I’d had a full day of walking and coursework and, nine times out of ten, my body just wouldn’t let me move out of the apartment, I couldn’t make the walk to the sporting things, let alone actually going to them. I had some problems with the anime society because that was on the third or fourth floor of the Guild and it’s like I was not making that climb up those stairs every Friday between 7 and 11, it wasn’t happening, so I just watched the anime from my laptop to stay on track with it.

Int: Okay, okay. And how would you say pain affects your mood and emotions?

R: Obviously, on the more pain free days I’m very happy. The problem with me is when I reach a certain point of happiness, I become very bouncy, I mean like physically bouncy, which obviously doesn’t always do well with landing on the side of my foot instead of my actual foot, so that doesn’t make me feel happy, well it lowers my mood down pretty quickly after that.

Obviously, on days I can ignore the pain or it goes, if I’m kind of not in pain as I’m walking along, my legs kinda just feel weak so when it’s at that point, I’m still fine, I might be a bit tired more than anything but then on bad days, I’m like “just don’t talk to me”, I’ll just be in the room, on my bed or on the couch trying to do work and it’s like I can’t focus on other things. I’m not that approachable shall we say, on those days.

Int: Okay, okay. Could you tell me about any advice that you've had from doctors, nurses or other healthcare professionals about your pain?

R: Well, the most unhelpful advice I got was to “get over it” because I was because she kind of thought it wasn’t as bad as I was saying and she was like, “everybody experiences this, you just need to get used to it”, so I was like “thanks for that”. But the most advice I get is to take paracetamol and ibuprofen every day, all the time, which I refuse to do because I don’t want to be on that much medication all the time, paracetamol and ibuprofen, both of them aren’t exactly that cheap to do for months on end so I should probably listen to that more but I kind of just ignore it at the same time.

Most of it was trying to do my physio, kind of every chance I get to loosen up when it starts getting bad. I have sleep splints I wear on my wrists, so that, to actually use them overnight and basically, obviously try not to overextend myself because I let my body do what it wants to do but then letting it bend too much whilst holding something isn’t the best idea possible for me. So, it’s just basically trying to pretend my body kind of has this normal flexibility levels and just trying to stick to that more, and a bit of exercise, I should probably do.

Int: What’s your experience of the physio been like?

R: A bit annoying because in the first session we covered obviously that, well because my legs are the worst, but I was doing online picking at a supermarket as a job and that involves lifting heavy crates, so my wrist was getting worse because of it so we kind of covered wrist and shoulder ones, and then the next session I asked, because this was during COVID so it was phone call conversations and I asked for some on my legs specifically because obviously that’s my worst area and I used my legs a bit more than I used my arms.

And then she told me, “it’s not that bad” – not exactly that but kind of the general feel of it and she told me just to do some basic exercises like squats and stuff, which my knees have a problem with because it clicks every time I go up and down, it isn’t exactly that comfortable and I feel like, considering she was going to give me exercises on my knees and legs on the first session, I don’t see why I lost that, those exercises just because I focused on my wrist because of the job I was doing. So that was slightly annoying.

But physio isn’t... Physio exercises have been helpful but I’m a very forgetful person, it’s why I didn’t want to take the medication either because I would have to put timers on my phone, it looks a bit weird, let’s be honest. But most of the- at least like 80% of the time, I forget to do my exercises, especially since I’m supposed to be doing them three times a day and when I was doing my job, I was coming into work 1am, 2am, that sort of times and obviously once you're doing seven hour shifts, you don’t want to then do a round of physio, so kind of forgot about them until about October, well end of September, so I forgot about them for a few months but I’m kind of getting back into the habit of actually doing the physio.

Int: Okay, okay. That all sounds like a mixed experience for you.

R: Yes, that’s why I don’t necessarily go with the doctors.

Int: The first doctor you were talking about that you said was dismissive, was that your GP?

R: That was the rheumatologist.

**Int:** **Ah, okay.**

R: Yeah. Because the GP that I had first, no, the first few ones were... gave me the wrong diagnosis, a few times, but then the GP who referred me to the rheumatologist, he was very helpful for actually diagnosing me with the right thing, hopefully.

Int: Okay. Have you had any advice from anyone like a psychologist about the pain?

R: No, but that might be coming up, because I had a recent doctor’s appointment with the eye clinic because I have a pain behind the back of my eye, which has been here for a while and I thought it was because there’s something wrong with my eyes, but they think, my eyes are healthy thankfully and they think it’s because of the nerve going between my eye and my neck, so because I have neck pain, I get eye pain.

They referred me to the GP, but the GP is currently only dealing with emergencies because half their staff got COVID, so it’s kind of whenever I get back to them, I might be seeing someone about it but then obviously it depends on if there’s something else that’s causing the eye pain.

Int: What about any other alternative therapists or specialists, have you seen anyone like that about it?

R: I was tempted to go to a chiropractor or something like that, but obviously COVID hit and it’s trying to get somewhere that’s open and are doing something because there’s this one, a massage one, which I was thinking of also doing just to relax the muscles a bit, they’re currently only offering a few minutes on a massage chair and it’s like... I might wait until things start reopening, especially since I live in Liverpool at the moment and obviously, we’re having more restrictions come every day because of how bad everything is so yeah, not the best time to be seeing people about pain when everybody’s got COVID here.

Int: Yes, yeah, that’s totally understandable. In the past, when you’ve been trying to find out how to deal with pain, who or where have you gone to first, in the very first instance?

R: Obviously, my first kind of call was going to a doctor to see if there was, then obviously when I was just a child, my mum took me but then the one I went to when I was having the growing up joint pain, plus hypermobility, I went to the doctor first who was useless. I’ve had useless doctors before in my hometown, so it wasn’t that unexpected, to be honest. And then obviously, I wasn’t really active on social media that much, so I was kind of you know, my nan, she has that pain because she slipped a disk as a child so obviously, I was going to her because I thought it was bone problems and obviously, that’s a bone problem because she broke her spine when she was a kid, so I was going to people who I knew had similar problems.

But then when it moved onto, I got diagnosed with hypermobility, I kind of joined up with a lot of hypermobility, fibromyalgia Facebook groups because now I had an actual diagnosis, I also knew it wasn’t something to do with my bones and nobody I knew personally had it because one of my friends - she has hypermobility - but obviously I didn’t want to go up and ask her kind of what’s, “what do you do?” because she has it a lot worse because she has dislocating bones and joints, and I don’t so I didn’t want to get advice that is for kind of a more severe version of what I have.

So joined a lot of Facebook groups, trawled all their posts for the first few days and then I started either commenting on similar posts to what I have, or actually posting posts on that, to get more specific ones that I couldn’t find on the Facebook posts.

Int: Okay. I’ll come back to the Facebook groups in a minute - but you mentioned your friend who has something similar but a bit more severe, have you spoken to them now about it? Have they given you any advice?

R: I think we kind of joke around about it to be honest, it’s actually quite funny, we’re part of the Disability Society and it was only since knowing these people that I kind of started getting diagnosed with different disabilities, so we joke around a bit. And obviously we have the general chats on what to do when she’s feeling really bad pain, and little stuff, but it’s kind of stuff in general conversation, like I haven’t just randomly messaged her asking, “I’m dealing with this at the moment, do you have anything you can help me with it?”, it’s just kind of passing conversations that we have when we’re in the group.

Int: Okay. Was that through your university disability society?

R: Yes.

Int: So, these Facebook groups, tell me a bit more about your experience of using the Facebook groups and how that’s been for you?

R: I mean the hypermobility ones, they’re really good. You do get the occasional post about someone whose child has hypermobility but most of them are people with personal experiences. On one hand, it’s more what we do to make our lives feel better, but there’s the random post where it’s like a picture of a body part or some pain and saying, “is this normal to have or not?”, because obviously, at least in my experience, doctors haven’t said “this is what hypermobility is, these are the affects you have” and for a lot of people, they haven’t had that chat either, so it’s trying to understand what’s normal with hypermobility and what’s a problem that you need to go to the GP for?

For me, my leg can just die after I’m sitting down and obviously it gets a bit concerning when it happens for a while, and then ten minutes later my leg still doesn’t have feeling in it. So, I went to the GP, he was basically just “yeah, that’s hypermobility, you're just going to have to live with it”, but obviously, if I hadn’t asked on the Facebook group, I wouldn’t have had to make that slightly embarrassing trip with me sitting there awkwardly trying to say what’s wrong and him just not looking at me at all, so should have been that first.

It’s good because, even like some things where obviously I think it’s normal to have this pain or it’s normal to do this, because I did like W sitting as a child, which sounds bad now but to me, I mean I still do it, it’s how I like sitting and I didn’t actually realise [1] that was a bad thing to do and [2] it’s part of hypermobility because it’s one of the signs of having it. It’s like I do this thing where I twist my tongue to my nose which I thought was not exactly normal because only me and my grandad could do it in my family, but I didn’t think there was anything specific to it but then it turns out most people who have Ehlers-Danlos, which is part of hypermobility, most people can do that, have that.

So, I might have that I might not have but you know, I’m not planning on trying to get a specific hypermobility diagnosis when it won’t do anything for me, but it’s kind of nice finding out stuff that I thought was perfectly normal to have, like having pain or having sleeping problems or that sort of stuff, and finding out it’s not that normal but obviously it’s not anything to be going to the doctors about.

Int: Okay, so kind of using it now as something to maybe do pre going to the GP?

R: Yeah.

Int: So, you kind of ‘vet’ going to the GP before, on Facebook?

R: Yeah.

Int: Do you use any other social media resources in a similar way like Instagram or do you watch videos on YouTube?

R: I’ve watched the more technical videos on YouTube when I first got diagnosed but to be honest, I don’t really like blogs or vlogs as they call them, I don’t do that but I am on Tumblr and I’m on the hypermobility for that, chronic pain thread because, well yeah because both Tumblr and Facebook only comes up with stuff, kind of how to help you get a bit better and some places, it makes me laugh sometimes, all the random stuff it pops on, especially the ones, “I’ve shown my boyfriend I can do this kind of thing” and like their complete over-reaction to doing it, it’s quite funny to hear about.

Int: Yeah, sure. So, Tumblr as well then?

R: Yeah.

Int: Okay. Do you think you could tell me a bit more about any other internet resources you’ve used to find out information about the pain condition, when you're just doing your initial internet search?

R: Obviously, I had the NHS website, and I can’t remember but I think there’s like a specific website about, I think it’s Hypermobility.org, which is a site dedicated to hypermobility syndromes but that kind of got a bit… it became a bit of a problem. When I read a checklist of stuff, I kind of take it along with me and it was like more going to look at the different syndromes, I kind of got lost in there, I fell down the rabbit hole a bit and then I spent… not like the entire day but not far off it really, just going through that website and I got a bit too interested, I would say.

Int: Mm. On the hypermobility website, you really went through it…?

R: Yeah.

Int: Okay. You mentioned the NHS website as well, what’s your experience of that like to find out about the pain?

R: It’s useful because it did help with the whole, I never knew like heat or ice my joints because I didn’t have that much experience in using either and it did help me with how to heat stuff and it does give some help advice, but then obviously it’s a bit more basic. Obviously, I know people use it, doctors use it to help diagnose and give basic treatments so it’s not exactly that in-depth, but for me to kind of appreciate it as much as I probably could because like I said, I like knowing a lot of it because I’ve done that with my other diagnoses too, was just to research everything and then try to fit every behaviour that I had into those sections, which obviously isn’t that helpful when it’s kind of basic definitions, some symptoms and how do you treat it, basically.

Int: Okay, and so then you used a hypermobility website to help find out more information. Did you use any other health advice websites like Healthline or WebMD for that too?

R: I would have, but I kind of promised myself not to go… because I used to have headaches, I have eye pain and how many times I searched it up and came up with brain tumours, so I promised myself not to go down those websites and just go to a GP if I feel something’s wrong with it. I did that like the week before my A-Levels so that I was legitimately freaking out doing some of my A-Levels because I had a brain tumour, so I avoid those websites now.

Int: Okay, that’s fair enough. When you're searching the internet, what do you think you're hoping to find?

R: I know I don’t want to go to the GP to get a specific diagnosis but I kind of wouldn’t mind actually knowing, from my point of view, my specific diagnosis and if I feel I need to get a more in-depth one, I can go to the GP with, “I think I have this, here’s a checklist for it”, because my GP back at home, I don’t really think knows about hypermobility, at least they didn’t when I was a teenager and I don’t really touch my doctors back at home, so if I want to get a more specific diagnosis, I would need to do the research myself.

But just like helpful advice, helping with the pains and stuff like that because I didn’t think about getting an ergonomic chair before kind of finding what to, how to help with hypermobility with students because you know, it’s a bit of a hit and miss sometimes with chairs and me. But yeah, kind of like tricks in daily life to help get a bit better and then just kind of like [inaudible 00:33:44] those stuff really.

Int: Okay, okay. Moving away from internet resources for a minute...

What kind of things do you do you do yourself when you're by yourself or at home, to help you cope with the pain? I know you mentioned heat pads and things like that.

R: I have three different normal water bottles and then I have a long one with a unicorn on it, my nan bought it for me for Christmas, I use the long one when I’m sitting around and use as a neck one and then I use them for my lower back and knees occasionally, I sometimes have it by the side of me when I’m doing work so I can quickly heat up my hands a bit.

When it gets bad, I use one of my less fluffy pillows and put it on my lower back when I’m sitting somewhere or I’m trying to go to sleep, so it’s supporting the natural curve of my spine, so I don’t just kind of just flop and end up in an awkward place. I have a lot of hoodies, I walk with my wrists in the hoodie pouch, I don’t really swing my arms when I walk anyway, but I like having it more supported in the pouch.

Obviously, I’ve got my insoles now for my shoes and it’s also not wearing trainers and wearing my lace-up ankle shoes, just so I’m less going over on my ankles.

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

R: No, I’m in an awkward situation where my mind kind of feels blank normally, I have the liberty of hearing my own thoughts, but I try to shut off and do like actual mindfulness, I become really jittery and I have to get up and start walking around because really, the most I do is just put headphones in, listen to random soundtrack. Lately it’s been different musicals and just lie in bed for a while and just close my eyes, and I sometimes, I have a gel eye sleep covering thing, I can’t think what they’re called, and I kind of just put that on for a while because I can’t see with it on but you know, it came with my pyjamas so I use it and then heat it up a bit, put it over and just sit there and relax, listen to music.

Int: Is that to help you sleep or just generally relax?

R: Just generally relax, because it’s maybe when kind of the pain is a bit worse and I know that I can’t concentrate on work, but I do need to do work at some point today so… but I don’t generally fall asleep during that time anyway, I just sit there for like an hour or so and just listen to music, close my eyes and stay relaxed for a while.

Int: Okay, have you tried any of the meditation or mindfulness apps or websites?

R: Yeah, I haven’t done any subscribed ones because I’m not going to put money onto it... to do that, but I always start kicking my leg out because my leg can get quite twitchy sometimes and then like, my whole knee starts going so it’s not worth it, especially because… and also. I tried doing it in the living room and there’s a lot of things my leg can hit. One time I hit my TV cabinet which my ankle did not appreciate for obvious reasons. For my safety, that’s when I try to force it from happening, so I have one leg, well I don’t try to do it, but I feel like if I kick my leg out and a bit of energy for that, I forget where I am and always hit something. It’s a talent of mine, I can’t do mindfulness.

Int: Okay. So, you gave it a go and it’s something that you didn’t stick with.

R: Yeah.

Int: Yeah, okay. Have you had any problems with other coping strategies or techniques that you’ve used?

R: Because, obviously, I kind of picked up when I stopped doing so many sports because in primary school, I used to have a sport every, after school club and then I did about four hours outside of school as well and then when I stopped, started doing swimming and football, it kind of went and started getting worse and then I went somewhere, with joint pain, start doing lots of walks and those kind of things to loosen up the joints or strengthen it and then, well it’s really, well I’ve found it’s very awkward to kind of not walk on a road? But there’s a little wooded area, it’s not that big so I used to do walking around that, only obviously my ankle bones, well my feet go either way, and kind of… didn’t end well walking through a wooded place where my, I kept going over my ankles and step.

You're trying to find the balance between exercising more but then trying to ensure that I don’t actually do damage to myself because I did kind of the park runs for a while, I would either gag or try to throw up... I threw up the one time, afterwards, because I think it was because of the pain and obviously trying to run whilst you're in pain is not the best idea, it wasn’t an enjoyable experience for me and my mum kept making me do it afterwards because I didn’t have anything wrong with me back then apparently, so you know!

Int: So, it sounds like you've tried to adjust your level of activity to try and overcome the issue? Yeah?

R: Yeah, because I have read somewhere that actually running is worse for hypermobility because it’s more like impactful on your legs, like swimming is better for it... but then obviously, it’s a lot easier to go for a run that it is swimming so I was forced to do more running, instead of more swimming and I didn’t like going, well for my knees, for school.

Int: Okay. Alright then.

Are you doing anything differently now to help you overcome the problems you had before?

R: At least... I started before COVID doing early morning swims and then I’m gonna, once I’ve settled into uni life because we still haven’t started uni because my school wants to start two weeks late for whatever reason they want to start for two weeks late for! But once I’ve settled in, I’m going to start doing some more early morning swims. I’ve also got a job up here and I’m hoping to stay as an online picker which gives me about five or six hours of constant walking, which isn’t the best straight afterwards but it has been obviously helping me actually go out for longer walks, going down hills, well more up hills, actually both down and up hills, I don't like either of them, going across hills, I’ve been able to do more of it than I have before and it’s just, you know, little stuff of swimming, sticking with the job and then not going on long runs, basically.

Int: I’m going to move back towards the online resources, it sounds like you do lots of things yourself, we talked about a few different things that are online and not online.

You're still using the Facebook group?

R: Yeah.

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

R: I mean I would say yes but then I don't know if that’s a bit of me becoming more aware of online sources because obviously, I mean my school hours was half past eight to four o clock, then until quarter to six, if we had after school activities, so I didn’t have that much time to go on the internet unless I was at school and they specifically monitored your computers and they could take over if they wanted to. So, I don’t quite feel comfortable about you know, doing those sort of internet searches.

But I definitely feel like joining Facebook groups has become more popular over time, I remember because originally it was only like fan clubs or more academic school pages and stuff for that but I feel like people have split off and made their own personal life Facebook things than other things, because I remember a time where people didn’t go on Facebook to complain about their lives and they just did someone’s birthday, somebody’s wedding, oh, I’ll play this game on Facebook. I feel like especially Facebook has become more personal to people’s lives, it’s not a thing to only show your better side on, a lot of people use it to complain about their lives and because of how it’s gone more personal, like more those medical issues, like Facebook groups has popped up to let people complain about what’s happening and be as a community with each other because obviously, it was a bit weird to get a voice from online strangers when Facebook first started and I was specifically warned against becoming friends with people because I got Facebook when I was about 10, because I was going away from primary school so Mum wanted me to have my primary school friends. But obviously she wasn’t about to tell me to go meet a random person on Facebook and say, “I have these problems” and yeah.

It did get a bit like, back in those days, not when I was like 10, but it got a bit pervy when I was in... we had this weird person in my secondary school and somehow he heard about the fact that I had ankle pains and stuff like that, and he just claimed he was studying to be a sports physiotherapist, despite the fact that we were still, this was before we did our GCSEs so we didn’t do sports physiotherapy as a GCSE and then he offered to massage my feet for me which was obviously, really creepy and a big no but like obviously, kind of like you know, I’m not scared of internet strangers anymore and I don't know if that’s obviously I suppose because of me actually becoming an adult, or if that’s also because obviously Facebook is a bit more, you know, everybody’s aware of the dangers so it’s not as easy to get, to put yourself in that situation so they’ve kind of like moved onto other platforms and other stuff like that.

Int: So, it sounds like maybe as you've developed as an adult, as you say, and then as the technology has changed as well, you’ve oriented naturally more towards Facebook more recently?

R: Yeah.

Int: Okay. I was going to ask which internet resources have you found the most helpful and why, but I guess we know the answer?

R: Yeah, it’s definitely Facebook because obviously, well I don’t like Snapchat, Instagram I kind of forget exists, I would forget Snapchat exists but I have my academic advisor group on Snapchat so I can’t forget it exists until next year. And obviously, with Tumblr, I just go on it more to have a laugh and to read fan fictions to be honest but to make me feel better, where obviously I use Facebook to actually get more actual real life help rather than anything else.

Int: Okay. You mentioned Snapchat there as well, but any internet resources you've found were unhelpful and why?

R: Definitely Snapchat, because I mean, I did have Whisper for a while, I would get asked for help on Whisper, it was like sending Snapchats and it was like, then it’d be like, normally it was at least a five-minute conversation, other times it was less and then it was just like “ah, send nudes!” ... and I was like “seriously?” [*laughs*] so kind of both Whisper and Snapchat are just unhelpful in general because I feel like both of them’ s kind of been taken over by a lot perverts lately, or just guys having nothing better to do than to do it because obviously, it’s a lot harder on, I think it’s a lot harder on, I guess they’re a lot less trustful to send nudes over Facebook but obviously Snapchat’s kind of became the thing to send nudes on so… kind of both of them are unhelpful and both of them I try to avoid now.

Int: Okay, so you have tried to go there to ask for help and info but found that’s not…?

R: Yeah.

Int: Okay. Thinking about online resources, anything, websites, apps, social media, is there anything else you think would be helpful or would have been helpful for managing your pain?

R: I don't know if there’s kind of like a specific one, like kind of a symptom checker so you can use like a pain diary, so you can pinpoint what times of day you feel more pain, obviously not, I have a lot around the revision time and because I’m at a desk all the time just putting my head at a weird angle and obviously, I am aware of that, what are my peak times in the day so I know kind of to take a break around those and like ones where you can obviously put... what were you doing? Because like some things I do, I then realise it’s going to cause me pain a minute or two later and it kind of took a lot of trial and error to find out what sort of things, because like I normally sleep, well I used to sleep with two pillows because that’s how I liked but it turned out that causes me to have more neck pain and I hadn’t realised it was the two pillows that was pushing my head up at a weird angle whilst I was sleeping. So kind of something kind of like that just to keep track of your symptoms so you can find out what specifically I’m doing, that’s causing me this pain, later on.

Int: Okay, okay, yeah. That makes sense.

Is there anything else that you would like to add to anything that you've said about your experience of pain or about online resources?

R: Well, I mean I don't know if this is a kind of general pain thing but doctors taking stuff I say seriously because like I mean, I was going to the doctors, having multiple visits when I was 2 and it literally took me 18 years later to actually get diagnosed with something because obviously, I don't know if they thought I was just exaggerating the pain a bit? I was literally told that it’s because I was like flat footed that was causing pain in my entire body, which I understand like kind of pain radiates up but I don’t know that it goes up and then goes down to my fingers most of the time and then it was kind of my Vitamin D levels were normal range, but kind of lower average, which then got me put onto Vitamin D tablets, which then made me sick because I was getting too much Vitamin D, but then he put me back on Vitamin D tablets because he didn’t believe me because I took, I had them over the Christmas holiday, and it was making me sick so I stopped taking them, so I had to be put back on them, to then go to him whilst I was sick to actually get, you know, him to stop making me take Vitamin D tablets.

So, it’s just like doctors taking questions about pain seriously. Because I know a lot of people, mainly obviously, well women and other groups, mainly like racial groups, who get told either, we kind of have something seriously wrong with us when we don’t... but I know this one person, it was because she was wearing a sports bra that was causing her to have so much pain because she was an athlete so she was wearing a sports bra all of the time, and then they started having her tests to have, because they thought she had breast cancer, and then obviously like other people, if you are actually in serious pain, they just brush you off.

So them taking us a bit more seriously to actually when we say we’re in pain, kind of trusting us that we know we’re in pain. Especially since it’s not like we’re asking for drugs. I can understand, if you went to a hospital and you're asking for drugs because you're in so much pain but we’re just asking “how come we’re in pain?”, we’re not asking to give us morphine or codeine or anything like that, we’re just wanting to know why we’re in pain and they don’t listen to us that often, to be fair.

Int: Yeah. And I think lots of people do have that experience as well, you're not alone there. Okay.

R: Yeah.

Int: Okay, well thank you for all of that, that brings me to the end of my questions unless you have anything else that you want to add on?

R: No, nothing I can think of no.

Int: So, I’ll turn off the recording now, and we will have a quick chance for you to kind of ask me any questions that you have.

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