

**Prepared For: Anna Hurley-Wallace**

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**Recording Details: lime**

**Date of Transcription: 21 October 2020**

**Transcriber: J. Mason**

**Recording Length: 35 minutes**

ANONYMISED

Int[[1]](#footnote-1): Hello?

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

Int: Okay, so it’s recording now, so just to state again that you’re still happy to go ahead with the interview and still happy to be audio and video recorded for this?

R: Yeah, that’s fine.

Int: Great, okay, and like I said before, my questions are over on the screen, so I will, every now and then, I’ll be looking over there but I’ll still be listening to what you’re saying, okay?

R: Fab.

Int: Perfect. So, do you want to start then by telling me a bit about your experience of chronic pain in the form that you have?

R: So, I have lower back pain and I get chronic migraines. My migraines, I have them probably every two-days or so, every other day, to the point where I just have to go to bed and go to sleep and try to sleep it off in a dark room. Often they can make me throw up when they’re really, really bad, I have to wear blue light blocking glasses to try and prevent it because for my job I’m on the computer a lot of the time. I have to take Co-codamol for it but we did try Imigran but it just didn’t do anything. And, I’ve suffered from them pretty much for as long as I can remember, to the point where like I’d have to either not go in to uni or college or school if I’d had one the night before, because they’d put me in a daze the day after. Or, if I was in school or college or uni, I’d just have to leave and go home if I felt it going on because it gets that bad where I just can’t focus on anything and it gets too overwhelming, the pain.

Int: So, you have a reasonable amount of time off from education and your work because of it?

R: Yeah.

Int: Yeah, okay. That does sound really challenging if you’re still feeling really out of it the next day as well.

R: I think as well with the tablets, because like, because they don’t really do the job of like completely getting rid of it, every four hours I’m constantly taking the Co-codamol, so that puts me in a bit of a daze as well.

Int: Okay, and have you always been taking Co-codamol or was it different when you first started getting them?

R: So, I started on Co-codamol and then because they were so like frequent and stuff, I went on to Imigran. So, basically when I was in high school we trialled it and my mum would bring in Imigran for me to have, because it’s like funny in school with taking tablets and that and so she’d come in but it just didn’t do anything so Co-codamol was kind of like not getting rid of it but making it a bit more bearable so we just stayed on that whereas Imigran just did absolutely nothing.

Int: Okay, and... rough idea of how old you were when it first started? I know you said it’s a really long time.

R: I mean my earliest memory is about six-ish.

**Int: Yeah?**

R: But my mum says I got them earlier than that because my first memory is like I was getting overwhelmed, and it’d come on and I had to go to bed and I woke up you know with them Cool Head strips on?

**Int: Yeah.**

R: My mum had put it on in the night to try and help while I was asleep, so that’s my earliest memory of it but yeah, just kind of since then it just got progressively worse.

Int: Yeah, and what about the back pain?

R: So, I’ve had that as well most of my life, but there’s no, like, I haven’t been given a specific diagnosis other than lower back pain because it’s so difficult to kind of get to the root of it. Like I’ve had MRIs and everything and like I’ve not had anything from it, just that I have this lower back pain and it is really bad. It gets to the point where like in college in particular I had a period where I was off for two-weeks and I just had to stay on the bed downstairs because I couldn’t even get out of it, I couldn’t go to the toilet or anything. Yeah, and it often gets to the point where it’s to the point where I can’t get out of bed because it’s so painful.

Int: Right. The lower back pain, has it stayed the same since it first started, or has it been more different recently?

R: So, it’s got more intense recently, to the point where it’s making it difficult for me to sleep and things, so I’m increasingly tired and that in turn has an effect on my headaches, I get them, like my migraines are worse when I’m tired so it kind of, it’s a knock-on. But, usually like in university and in school and in college, I had things in place, so like DSA would fund for me to have like, so stools, I did science so the stools would have a back on and stuff, I could leave my books in class so I wouldn’t have to be carrying around heavy bags everywhere. In uni I got funded to get like a special chair and things like that and like parking so I didn’t have to walk as far but now that I’m working and I’m kind of from home, in my new job, like I haven’t been in yet, it’s kind of hard for me to get the kind of you know ergonomic support and stuff, so that’s still pending, so I think that’s why it’s gotten a bit worse at the minute, yeah.

Int: So, you think it’s worse at the minute because of the working from home, pandemic situation?

R: Yeah, definitely.

Int: Hmm okay. And, I mean you talked quite a bit then about it affecting your ability to get up and go and you know go to places, or you have to lay in bed and wait for it to pass.

How about any other kind of physical abilities, does it affect your physical abilities day-to-day, even on days, maybe the ones after you’ve had the headache and the knock-on effects? Does it affect you in a physical way... or maybe your mood and emotions?

R: Yeah, so definitely physically, like little tasks like even putting my jeans on, so like bending over to kind of like pull them up past my feet, that can be really painful, tying my shoes and putting my shoes on. So, I often need to get help with that. Anything where I have to like basically bend over is really painful or if I have to kind of stand for a long duration, it tends to get increasingly sore then, so it feels like it goes in to spasm. Yeah, and then mood and emotionally wise, like in school and things, I couldn’t really go as many places because of my back and like my headaches and stuff. So, when I was in pain I just couldn’t face going out, like especially with my migraine as well because it gets like sensitive, so even going out in the daylight can be really like painful and triggering for it. So, I used to get down about that because especially like, people stop kind of asking you to go places after a while. They see it as an excuse where it wasn’t, it was just I did want to go I just couldn’t, so that used to get me upset.

Int: Okay, so it does affect your social life then?

R: Yeah.

Int: So, is that only not going places? Have your friendship groups and things changed because of it, do you think?

R: Yeah, I think I definitely lost quite a few friends over the years because of it. Because as I say, people just like, they don’t really understand so they get in to that mind set of like it’s an excuse so why bother asking, you’re only going to say no. But, currently my immediate social circle is like my boyfriend and my family who have a greater understanding of it so that it’s not as bad then. But, I get anxious and worried in the sense like it’s going to happen. So, I don’t want my boyfriend’s family to think I’m just being dramatic or like I’m not doing something as an excuse, I just don’t want to do it as opposed to like I can’t [*laughs*], I physically can’t because I’m in pain.

Int: Okay, okay. Well hopefully they can find an understanding with you.

R: [*laughs*]

Int: So, you did say a bit as well there about kind of treatments that you’ve tried in terms of medication.

What about any other advice that you’ve had from a doctor or a nurse or physios, or even psychologists, about the headaches and the back pain?

R: So, I’ve had physio for like my back pain and stuff and I just don’t think it’s durable, like it’s never seemed to really last if that makes sense? Sometimes it just gets more painful because a lot of it is like stretching your back out so like touching your toes and stuff. So, sometimes it is hard for me to do it because when it hurts while I’m doing it, it makes me feel like I don’t want to do it, if that makes sense? Like I don’t want to do something that’s going to cause me more pain when I’m already in pain, so it’s that kind of like toss up with it. But, for my back pain it has just mainly been like physio and medication. I’ve been told like yoga and stuff like that, to do like Pilates and stuff, but again it doesn’t really do much.

Int: Who told you to do those? Who recommended that, the doctor?

R: Yeah.

Int: Hmm - okay, but you didn’t get on with those?

R: No, I think for me, I think I struggle with an active approach, I’m better at a passive approach where if I just take the tablet, it’s easier for me. Where if I feel like it’s hard for me to face the fact that while I’m doing this, I am going to be in pain so it’s not as like immediate. Like if I take a tablet it’s not going to go away but over time it’s going to at least ease a bit while the painkillers are in effect. Whereas, with the physio, because I’ve never had any like positive results from it before, it’s harder for me to kind of engage with it and see it as like a useful tool.

Int: Okay, and what about someone like a psychologist or anyone like that, have you seen them about your pain at all?

R: So, with my headaches - I’ve been under like therapists quite a lot for mental health issues - and obviously like stress and things go hand in hand a lot of the time with headache and migraines. So, there’s nothing specifically I’ve been given to tackle the migraine and headache side of it, more ways of kind of calming myself down so like it doesn’t trigger that. But, again it’s not really, like I’ve had some really stupid things mentioned to me, so like for example like panic attacks that come along with my headaches as well. Like one person told me to spin around on the spot to kind of get used to what the feeling is which I just thought no, that’s not going to do anything! [*laughs*] So, I kind of like lost my kind of faith in that as well, if that makes sense, like I just feel when I’m being told stupid things it’s like you don’t really understand.

Int: Yeah, so you’re thinking, yeah, they’re kind of giving you advice about the panic attack maybe but when it comes to the headache, spinning around is not going to be helpful.

R: Yeah. No one really gets to the kind of root of it, like I understand trying to like pick apart the kind of like psychological aspect of the migraines and the headaches and stuff like that but it doesn’t do anything for it for me personally.

Int: Okay, so you say they suggested a few things, have they suggested anything to help you cope with the pain yourself at home, apart from what you just said? You know that you don’t like that they mention doing that for the panic attacks, but anything like relaxation or mindfulness that you’ve tried at home to try and manage?

R: Yeah, but I don’t know if it’s just mindfulness and relaxation, I think me as a person I struggle with it. I think because a lot of the relaxation techniques I’ve been told to do is like imagine it starts in your fingers and like relax your fingers and then your arms and you know like doing it joint by joint, muscle by muscle but then it gets to my back and nothing happens [*laughs*], so it’s like I’m still in pain so it’s hard because that muscle is still so tense and in pain, I don’t feel relaxed and then if anything it’s like I become more mindful of that pain and how that muscle, it’s just like really in attack mode.

Int: Hmm. Like you’re focusing on the pain?

R: Yeah.

Int: That’s alright, everyone has different experiences. Have you seen or had any advice from anyone like an alternative therapist or specialist?

R: No, but I know things like acupuncture and stuff, my only issue is like I’m scared of needles, so like I couldn’t really do that. But, I do know of other like alternative avenues, I just haven’t reached out to them because of that kind of fear. I don’t like needles or anything being related, so it’s just straight away a “no!”

Int: And, what about friends or family, are they giving you any advice about it, practically?

R: Yeah, so my mum actually has chronic back pain as well, so she was medically retired. So, around the house we already have like little things in place that can help. So, like our couches are raised to help my mum, so that helps me as well, it’s not as painful getting up and down. But when it comes to like my bedroom and stuff, I haven’t got that kind of equipment. But, around the house and stuff, with the equipment my mum has, because it’s obviously a communal type thing, I can benefit from that. My mum’s very like in favour of yoga and Pilates and stuff, but she doesn’t practice it either, she’s just been told so she’s telling me that will help but she doesn’t practice it. So, I don’t know if that kind of affects it because she’s not doing it and I know how much pain, like more pain than me she’s in, it’s kind of like, “Well is it really that beneficial?” and then my mum again with my migraines and my sister, because my sister has chronic migraines, so it’s like sitting in a dark room, we try and avoid like sensory, so like lights, smells because we’re all really bad with smells. We get like cold compresses for our heads and put a fan on to try and reduce it. We always have blindfolds on deck to like block the light and stuff, but universally we say like go to bed, put the cold compress on, block the light, take your tablet and then get on with it type thing, see how you are when you get up.

Int: So, it sounds like you talk with, especially the women in your family a lot just because they’re having a similar experience to you with various pains.

 Would you say that’s who you turn to first in terms of dealing with pain or is there anywhere else that you think, “Actually I would go here first when I’m trying to find out…”?

R: I’d probably say my mum. My mum is like the main one because she was a nurse before she retired as well, so I very much trust like what she says being a nurse and experiencing it herself for so long. Yeah, that’s who I’d probably turn to first and foremost but if I feel a bit embarrassed or anything or I struggle because like sometimes there’s a specific answer I want so if I don’t get that then I’ll search on the internet and see what they say or like if, so like my mum with like Pilates and stuff, she doesn’t do it so then it’s not very motivational for me, I’ll go on the internet and stuff.

Int: Okay, yeah, that makes sense.

And do you think you can tell me a bit more about internet resources that you have used to find information about either your headaches or your back pain?

R: Yeah, so I’ll just search on like Google originally and then usually a lot of the sites that I kind of come across are obviously like the NHS website, that’s kind of like fundamental, like WebMD and then if I see something specific I’ll go down like you know a wikiHow route where they show you the pictures and stuff like that? And then there’s some like support groups on Facebook and stuff and I kind of see what they say but they don’t tend to be as informational in terms of what can help as opposed to like it’s more people just being like, “What can I do for this? Does anyone else experience this?” and it’s kind of more like an outlet as opposed to a source of treatment information or like resolving an issue.

Int: Yeah, and is that something that you personally like or you don’t like?

R: It depends what I’m after, like it depends on the day. Some days it can get a bit annoying because I just want to know what other people are doing for it because I don’t know what’s right and what’s wrong because obviously like the things that are right in terms of like a medical perspective haven’t really agreed with me, so like physio - I don’t gel with that. So, when I’m trying to find like alternative routes that other people have found useful if they haven’t like agreed with something and then I’m not receiving that kind of information that can get frustrating. But on days where it’s kind of like, I don’t know like you feel like you’re the only one going through it, it’s good to kind of have other people there to say like, “I’m going through this as well, like this is what’s happening with me, I’m going to bed at… and missing out on…”.

Int: Okay, so different things depending what you’re looking for and how you’re feeling.

R: Yeah.

Int: You mentioned the NHS website as the first point of call, when you’re going on Google, so can you tell me about experiences that you’ve had of using the NHS website, how that’s been for you navigating and finding out things?

R: So, it’s quite handy in terms of like gauging, because sometimes you can kind of doubt if you’re being too dramatic in terms of your pain and stuff like that, so when you go on and you read what’s actually a symptom and stuff, it’s good in terms of like solidifying like, “Right okay, I’m not going mad, I’m not being overdramatic or anything”. But, in terms of like treatment and stuff, I don’t think it’s updated very recently and it’s a very one road type approach to treatment, so it just like your typical pharmaceutical approach, your physio. I mean there are alternative approaches as well, like sometimes people mention things like cupping and stuff like that but other than that, it’s just fairly kind of standard. But, I think sometimes when I’m looking for an answer and I’m not getting it from, for example the Facebook support groups, it’s good to kind of have it there and just be told like, “Drugs can work” because that is what I go to more than anything.

Int: You mentioned as well about using WebMD, how’s that been? What do you do when you go on there?

R: I just tend to like click the first link that appears! [*laughs*] but it tends to be quite repetitive sometimes of the NHS, it doesn’t really, it gives a bit extra but not much.

Int: Okay - do you like it?

R: I wouldn’t say I like it as much as the NHS but again, like when I’m searching for specific answers and like I’m trying to like, I suppose, support my own judgment and what my experiences are, it can be quite useful.

Int: Yeah, and you mentioned as well about Facebook groups, could you tell me about your experiences you’ve had of maybe looking for information about managing your headaches or your back pain on Facebook groups?

R: So, in terms of like finding them, sometimes it is very repetitive as well and sometimes it’s just like people kicking off in the comments and you can find it’s kind of like people trying to outdo each other.

**Int:** **Okay.**

R: But sometimes you do come across like something that may help, so people like recommend certain like rock salts and Epsom salts for baths and stuff like that and like ways they’ve kind of dealt with the pain. I think it’s more useful as well in terms of like experiential, so even though people are trying to outdo each other, you can still get something from it, so people will say like, “My friends stopped talking to me” and someone else will say it but they might say like, “Well my friends stopped talking to me when I was 14” or something. So, even though they are trying to kind of outdo each other, there is still something behind it that I can take and it makes me feel not as alone because sometimes it’s hard to say like you’ve lost friends because of it and like people don’t perceive you in the same way because I am still young at the end of the day and it can be difficult, but to know other people in these groups kind of have the same experiences is good.

Int: Okay, and what about other social media platforms or blogs, YouTube, Instagram, any of those that you go to for similar means?

R: I mean for Instagram I don’t use it so much for pain directly but more like the mood associated side of it. So, people post obviously the quotes and things like that, so I find it quite useful for stuff like that because I find quotes quite nice to kind of ground me and get back to a better place and understand that like I might feel down over it for like this period of time but it won’t kind of last forever, I’ll be okay in a little bit. So, I use it for more that. But, in terms of any other outlets, not really to be honest. YouTube I just, I don’t use for that because I tend to speak to obviously my mum or my sister and my mum tends to do the kind of YouTube side of it, so I just ask her [*laughs*].

Int: Does your mum go on YouTube and look at stuff?

R: Yeah.

Int: That’s interesting... and you’re getting relayed that information over.

R: Yeah, pretty much, because for me sometimes it’s hard to kind of think, on YouTube specifically to kind of perceive what they’re saying and because I suppose I have walls up to certain things, when my mum watches it and tells me it’s kind of easier to digest.

Int: Okay. And do you think that your use of internet resources or social media outlets has changed from when you first, maybe not when you first started getting pain, maybe when you first started using them up until now?

R: I think so, yeah, because I think when I was younger, I don’t want to say I wasn’t looking for it but it wasn’t as like published, it wasn’t as out there, whereas now it’s very kind of like in the media that you can use social media for support and stuff. With like therapy and stuff, you’re told there are certain media outlets that you can use. I think it’s just the visibility in terms of social media accounts has increased, so it’s allowed me to be more knowledgeable and know what’s out there. Whereas, when I was younger I just, I didn’t know, I was very oblivious to it all.

Int: Yeah. Do you mind if I ask as well about kind of managing your mental health? And you said maybe Instagram is nice for quotes but do you use the NHS website or health advice websites for that type of thing or not really?

R: To look for like quotes and stuff?

Int: Well, to look for information or how to manage your mental health?

R: I have done in the past, yeah, because I’ve been in therapy so much, I think I’ve been like seven or eight times now. I think I don’t use it as often as I used to, but I do have things like apps and stuff so like I tend to like pick at my skin and stuff to kind of like regulate and distract myself, so I’ll have an app on my phone which, I think it’s called CareHarm, Selfcare, something like that, so it basically gives you different things to distract, so that can be quite useful. I wouldn’t say I explicitly go on the NHS website to look but I don’t know as well because my background is psychology in terms of like that was my undergrad, I think when you kind of, you have all the modules where you’re looking at it all the time, it can get a bit repetitive, so it’s not as, it’s not something I’d actively seek.

Int: Okay, but you use a couple of apps and things to help you manage in other ways.

R: Yeah.

Int: In terms of... we’ve mentioned a lot of things kind of about various stuff that you do to help yourself cope, when you’re at home and like talking to your family, as well as like going on the internet searching stuff and on media researching stuff... but have you had any problems with any of that? And, if so, how have you got through those issues?

R: I wouldn’t say with the internet in particular directly, I suppose my struggle would be trusting what people are saying will actually work because like I said, the physio and stuff, it’s hard to know it’s going to work when you’re in pain doing it. So, as I said, touching my toes hurts my back so then having exercises that is actively touching your toes, so you’re in pain while doing it, it’s hard to trust like why you’d actually do that, why you’d put yourself in more pain than you already are, just to get on the other side of it. So, I’d say trusting what people say is a very big struggle in particular of mine, trusting that the treatment is actually beneficial.

Int: And, I suppose one of the ways you’re coping with that is getting the information through your family. Is there anything else that you do to try and like overcome that worry about trust?

R: I mean other than trusting in what my family say, because even that can be a struggle because I’m very like, I can be opinionated sometimes so if I think something doesn’t work, it doesn’t work. So, my mum could tell me like umpteen times, “Do it this way, do it that way”, obviously she’s better at breaking that barrier because she knows me better than anyone! But, other than that, I think it would just be like if a doctor said it to me, when a doctor says like, “Do physio, do mindfulness” because I hate mindfulness and I know physio is hard for me, I’m just kind of like, “Oh, I’m not going to do that”.

Int: Okay, okay.

So, in terms of internet resources then again, which have you found the most helpful, overall?

R: I think for the mental health side of it, Instagram, like beyond everything because there’s such a wide variety of like different types of quotes you can look at and I think the design of it, so people make them look really aesthetically pleasing, so like you can put it as your background on your phone just to keep reminding you. So, I think in terms of like that, Instagram is really good for pictures and something you can keep referring back to without actively going on the Internet. And, I suppose Facebook is good but as I say, there’s a lot of people just trying to outdo each other, so it can be good but there is that kind of downside to it. And then, I do find YouTube sometimes useful but only through my mum, so I wouldn’t say that’s like an active effect on me, it’s more passive. I’d say Instagram is the only thing that is practically working more tackling the mental health side.

Int: Yeah, and the Facebook group is more for the pain and headaches side, is that right?

R: Yeah.

Int: Okay. And, any that you’ve found particularly unhelpful and if so, why?

R: I keep saying but like the Facebook groups, they can be really beneficial, but as I say, when people are just trying to outdo each other it’s just like... you can find the good in it, so like I said, in terms of like people saying that they’ve got experience of using like friends and stuff like that, but it can be quite draining just seeing people all the time being like, “Well I’ve got this” or, “I’ve got that” or downplaying people’s pain so being like, “No, you haven’t got that, yours isn’t as bad as mine”, that can be quite, I don’t want to say “toxic” but it’s not very good.

Int: Yeah, not helpful.

R: Yeah.

Int: Okay. And, thinking about online resources, is there anything else that you think would be helpful or perhaps would have been helpful in the past for managing your headaches and the back pain?

R: I think a resource that could have been implemented in to schools because I think people, like young people aren’t as educated on it. You tend to think like pain and stuff is something that older people get, you don’t kind of, unless you’re living it, you don’t realise that people in your age group obviously get it and you don’t realise how early it can start. So, I think if there was like an online resource that could have been targeted at schools to widen people’s understanding would have been very beneficial.

Int: Hmm – okay, okay.

Well, do you have anything else to add on to anything that we’ve talked about?

R: No, not that I can think of, no.

Int: I think we’ve talked about a lot of things, so thank you for that. Unless you’ve got anything else to add then that’s the end of my questions, and the end of the interview.

So I’ll turn off the recording, and a chance for you to ask any questions you have as well, and that’s it!

R: Okay, great.

[CLOSE]

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