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ANONYMISED

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

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

Int: Great, thanks. Just a note as well, I’ve got my checklist questions over here on the screen, I might look over there to go through what I need to ask you but I’ll still be listening to what you're saying.

R: Yeah, no problem!

Int: Alright, so to start with, could you tell me a bit about your experience of headaches as I remember it?

R: Yeah, well actually I’m experiencing one now if that helps at all, however it’s at the moment, it’s not as um, as I guess affecting me, interfering with my life as it was this morning up until three hours ago, so I was actually not able to finish my day at work because I was not feeling well.

But yes, it started I would say about a year and a half ago, I had the first episodes of what I would consider chronic headache, as in not randomly but coming back over a week persistently. And then it faded for about maybe three months or so and then it came back in - at the beginning of this year and definitely of the last six months, again in a chronic way so there might have been weeks or a week or two weeks it was off but it’s yeah, recurrently been happening.

Int: How many days a week would you say you have headache or migraine?

R: Well I started, to take the example of the last two weeks, it’s been most days of the week so at least four days for the past two weeks and I think on average, this is the case normally, so I’d say four times.

Int: Okay, yeah. Do you think you could tell me about what it was like when it first started happening, maybe compared to more recent experience?

R: Yeah. I think initially I thought it was maybe uh, because it came about in the evenings mainly, I thought maybe it was spending time – and during exam periods – so I thought maybe it was spending time at the computer that was affecting this because I had things like flashing lights as well, which I still experience.

And then obviously it’s become a cause of concern because it’s not been going away although I’ve limited my screen time, anything, I don’t drink coffees or any of those things that could have been the case, I don’t drink alcohol so yeah, it’s kind of a stinging pain and then it fades, so there is moments like this morning where it’s really, really acute and it’s like it either really located on one side of the head or overall and it goes from being really acute, almost like cramps in your stomach that you feel but in my head, to moving to kind of like a milder pain but it’s like a humming consistently. It can make even keeping my eyes open difficult, like looking at lights and things like that.

Int: Are you able to distinguish between what you might call a headache and what you might call a migraine, or not really?

R: Yes, I mean I feel like where it is acute, it would be, I guess it’s to that extent that I would say it’s a migraine but I mean it’s all the same experience so I don't know if I would say it’s all migraine but it kind of gets less, or if it’s all like a very strong headache so I wouldn’t be sure of what to define it but I can definitely differentiate between the times where it’s really hard and the times where it’s still annoying but it’s um, but I can function, I mean I can carry out normal functions so it’s not debilitating.

Int: Is that kind of like how you're feeling now?

R: Yes, so now I’m feeling I can have a conversation with you but it’s still, especially if I stop, as long as I speak it kind of diminishes it, if I’m quiet, I probably feel it more but this morning it was debilitating.

Int: Yeah. You say you came away from work …?

R: Yeah, I was not able to finish my day at work at all because I just like, you know, it’s just really stingy headache, I’ve taken paracetamol.

Int: Does it affect your work life very much?

R: Yes, but luckily at the moment I just work two hours in person but some days like today, five, so two hours for most days of the week and today, and one day five hours so it’s usually manageable. Especially at first, it would start coming in the evening where I wasn’t working, lately I go to bed with it and I maybe wake up with it right away but yes, it definitely, especially if I’m doing online work so teaching online, I feel like sometimes I can’t even look at the person because it’s in my eyes or stinging.

Int: Can you remind me, did you go to university or were studying before this?

R: Yes, I went to university and I did a master’s and I’m also enrolled in an online course at the moment.

Int: Okay, and so, do the headaches affect your studying?

R: Definitely, it started when I was at university and I felt like I couldn’t complete my tasks at the time, it was intense and I thought it was maybe related to the work and exams but obviously, having continued throughout the holiday and everything, I realise it’s not.

But definitely there are times where now being online, I just have to turn the camera off and microphone off and I’m not paying attention because I’m just not able to.

Int: Yeah, okay. How would you say pain affects your mood and emotions?

R: Definitely because I feel very concerned when something happens so cyclically that there is kind of no way out, I’ve seen doctors, I’ve had suggestions, because it then affected various other parts of my health, sometimes it came with nausea, sometimes it came with ear pain or jaw pain and so of course, I get very frustrated and I guess I get very angry and upset and unpleasant because it’s concerning. I don’t mind so much if it was a one off, but I think the fact that it’s recurrent, that you're always waiting for the next episode is a bit distressing.

Int: Yeah, and you said when you're working, sometimes you just have to turn the screen off or you have to stop doing whatever you're doing …

R: I try and last as long as I can but there’s just that one very precise point where it’s like, “I can’t, I need to remove myself”.

Int: Would you say there are any other physical abilities that your headaches affect?

R: Definitely like just, I’d say things like reading, things like even moving to be honest, if I’m not lying down and kind of almost burying where it hurts in like a pillow or something, like I probably wouldn’t be able to do most - I definitely wouldn’t be able to exercise, I haven’t been exercising for a while now because I’m, it doesn’t allow me to exercise, reading, anything that requires concentration I would say, even watching TV because of the light and things.

Int: Okay - so exercise as well, the more typical screen headaches and stuff.

Would you say it does affect your social life and if it does, how so?

R: Yeah, definitely because I mean there’s times where I have all the best intentions to meet up but like I can’t get myself, I’m so exhausted or in pain that I can’t get myself to do it or I’m worried, I mean pre-lockdown, if I was going in a place that might have been busy or that there would be a cause for my headaches, I remember going to a concert and for the two days after that, I was like … completely debilitated, like it was really painful.

Int: Has that affected your friendship circles or not really?

R: Like I feel at this age we kind of have more of an understanding that we can’t see each other all the time and especially my friends who are aware that I’m not very, that at times I’m not very well, I’m still able to communicate, we still message and call and we still speak and maybe it’s just more so the in-face relationship that’s not as it used to be, maybe two years ago but then I’m not sure if this is just because of my headaches or also because obviously people are starting to work, you know?

Int: It’s that part of life when you're going from education to work that can be like that anyway.

R: Yeah.

Int: So you mentioned before that you take some paracetamol, do you think you could tell me about advice that doctors, nurses or any healthcare professional really has given you about your headaches?

R: Yeah, well I’ve had lots of visits with different doctors and the first thing I did was I removed my wisdom teeth because there was the idea that this could be related to my jaw structure changes... [interruption from ambulance noise 11:00] so there was the idea that this could have been linked because I had concurrent things like back pain as well, sometimes with the headache or ear pain, so I removed my wisdom teeth and they thought this could help, but it didn’t help.

I’ve been advised, I’ve been to lots of doctors who didn’t want to take kind of a stance or prescribe anything so mainly I’m just told to get paracetamol and I’ve recently, I was very against taking a lot of paracetamol because I think, you know, I don’t want to be relying on a medicine for a period of over a year so I’m now relying on homeopathic pills and oils, like lavender oil, I put that on my pillow before bed or arnica pills.

Int: Right. That was actually what I was going to ask you next about whether you’d had advice from alternative therapists or specialists?

R: Yes, definitely, I went through kind of a more natural homeopathic clinic who does chiropractic and these things, so they advised me to try with homeopathic herbs and I feel it helps a bit sometimes, I don't know if it’s kind of a placebo effect or if it’s actually the herbs but I guess it makes it more mild.

Int: Okay. How about psychologists or physical therapists, anyone like that, have you seen them about your headaches?

R: Yes, I’ve started seeing a therapist three weeks ago.

Int: Oh, right. And how’s that been for you?

R: I’ve been in therapy for a long time, I’ve been in therapy for 12 years when I was a child so it’s not been like a shock to my life but it’s, I don't know whether it’s obviously able to help the physical symptoms but I do think that the behavioural aspects, definitely.

Int: Yeah, yeah. I’m quite interested about these alternative treatments that you say about. Could you name some of the things that you've tried?

R: Yes, so one thing I said was arnica which was actually advised for things like osteoarthritis and these type of things, so I started it for like back pain but I’ve found it to be beneficial for my headache or again, I don't know if this was a placebo but I found it worked and it’s, it’s very healthy kind of overall, it can help your sleep so I take that.

I use oils on my pillow so lavender oil mainly. I sometimes massage with coconut oil, which is just more, one of my friends who’s into herbal remedies recommended, I don't know if it’s at all an official thing but I guess it’s just the act of massaging probably that helps.

Another thing that I use, I know the name in Italian, it’s “valeriana” and it’s kind of a sleep aid, like if I have it at night and I feel like I would not be able to sleep, I take these herbal things to help sleep.

Int: It sounds like it’s affecting your sleep a lot …

R: Yeah, because especially at the beginning, it was starting at night so the acute would be at night and obviously everyone says, “try and sleep it off” but it’s very difficult to fall asleep when you have like a banging in your head.

Int: Okay, okay. And... In the past when you've been trying to initially find out how to deal with these headaches, where is it you turned to first or who did you turn to first?

R: First, to my GP at the university, because it was the most immediate person and after that, because I found they weren’t very helpful and I think what they suggested was just paracetamol and that it could be stress-related, I went to see my doctor in Italy and they started [inaudible 15:54] so I removed teeth and then I went back to the GP here in London, then I went to a different homeopathic clinic here in London.

Int: Have you had any advice about it from friends and family?

R: Yeah, definitely, I had advice from the, a while ago when it kind of first started, because I work as a special needs teaching assistant and the mother of the boy I work for, she passed away recently due to cancer but she suffered from migraines, from back pain and this sort of thing and she was actually the one who recommended arnica to me. And then as I mentioned, my other friend recommended coconut oil, so I’ve tried that.

Int: Okay. A lot of this is stuff that you do yourself at home but is there anything else that you do yourself to cope with the headaches and the pain? Like relaxation or mindfulness? Or exercises?

R: Yeah, I try, my boyfriend recommended meditation so I try and do mediation or PMR – progressive muscle relaxation but it’s, I have not found it to be particularly useful but the one thing that strangely, I don't know why because it’s just a type of meditation but I find it helps is this like child meditation that I listen to, so that’s the only – and it kind of helps children fall asleep – like imagine you’re a [inaudible 17:42] or this sort of thing and that strangely helps fall asleep.

Int: So again, more for helping you sleep?

R: Yeah, and I don't know why that helps compared to other types or even PMR but yeah, because I guess it helps take away the thought of, from your pain.

Int: Yeah, yeah. Do you use any online resources to help you with those strategies? Are you listening to any stuff online or using apps, anything like that?

R: I use Google, at the beginning I wasn’t really interested in researching much because I did think it could be stress, caused by stress so I was just taking paracetamol and then I started Googling it some more, and then I thought it was the teeth so again I tried not to Google because I often see like things that are really scary, so you think it’s like something terrible. But I do sometimes Google homeopathic or non-medicinal remedies and I’ve found that, actually my friend recommended hypnosis, that that might help with the pain, so I considered trying that but I’m not sure I will.

Int: Why not?

R: I’m a bit reluctant to the practice, I think I’m one of those people who are a bit kind of worried of not being in control of myself, I’m a bit reluctant to that but I might be giving it a try.

Int: You say you're going on Google and having a look for some strategies to help or some medications or techniques to help, what is it that you're hoping to find? Is there anything that you're specifically looking for?

R: I think that it goes away, like I think what I’m hoping to find is people who said, “I’ve heard this, it lasts one or two years but then it went like by itself or I did something that helped it go away”.

I guess it is migraine, I guess at this point that it is actually episodes of migraine from what I’ve been reading online. I know that there are things you can do like Botox helps relax the muscles, that’s one thing I read online, that there is like a 60 or 70% improvement in migraine patients trying Botox but again, I’m afraid of needles and injections so I’m not sure about trying that but I guess if it does keep going, that’s the only thing I can try, I will try everything.

Int: Yeah. It’s interesting what you said that you’re searching on Google for these techniques to help you, but perhaps what you're actually looking for is people who have come through the other side of the experience...

R: Yeah!

Int: ... so do you look at any blogs or anything like that?

R: I’ve looked on Twitter, I found a tweet of someone and everyone was commenting like how long did it last and I kind of have been following that. I look at blogs sometimes on Quora or things like this but I guess most of that is I don’t think I’ve ever seen someone say it does go away, so it’s always maybe you realised the cause of it so for some, I get it was actually the teeth or things like that but I guess I’ve not found the cause for me personally.

Int: It’s interesting you found something on Twitter. What did you do when you saw something that you thought, “this might be helpful on Twitter”, did you go and follow it?

R: Yeah, well I’m not really active so I commented on the post and then I always go back through the comments, I’m not very active so it was easy to go back to.

Int: How about other social media like Facebook or Instagram?

R: I don’t have either, so no.

Int: Okay. Or YouTube?

R: No, actually, I’ve not used YouTube, just mainly written, I find it easier to follow written information.

Int: Okay, that makes sense.

When you've been looking for stuff online, have you gone to the NHS website at all?

R: Yeah, probably initially as well because obviously my GP being part of the NHS, I saw their standard recommendations but it’s always like very superficial, obviously they don’t go into like a diagnosis or what it can be or what the problem is, there’s a list of things I’ve read what they said about migraines but again, it wasn’t in my case particularly helpful to find a cure.

Int: Hm, okay. What about those similar health advice websites like Healthline and that kind of thing? Have you been on any of those?

R: No, no.

Int: No – okay.

Do you think that your use of any of these internet resources, do you think it’s changed from when you first started getting headaches compared to more recently?

R: Yes, because at first, I mean I wasn’t going much on it because I just thought I saw my doctor, they said, “it might be this”, I tried this, it didn’t work but I was still thinking it was a short term thing so just really relying on the doctors. And then I started really getting into it and then I kind of read everything there was to read so I’d say now, I’m not really going frequently because I guess I’ve seen all the resources I could.

Int: Okay. So you don’t read blogs or anything as much?

R: No, I’m not under the impression, even when I was looking at it, it’s like maybe things that were written like two years ago or a year ago, it’s not like it’s a very burning topic and every month there is a new blog article on it, I guess what I wanted to know was a broader, you know, if it goes away, what could it be due to and after having read all of that, I don't think there’s much else.

Int: You said before about trying a few different strategies at home as well, have you had any problems with anything that you’ve tried or looked up on the internet and tried, and if so, how have you dealt with those problems?

R: No, again I don't think there was any kind of almost side-effect or counter-effect or thing that was more damaging, like it might either have not worked out at all or kind of helped a little bit, maybe even just through placebo effect but I never had a negative experience of something I tried. As I said, meditation wasn’t particularly helpful but I wouldn’t say it was damaging.

Int: Okay. Are there any internet resources that you think were particularly helpful for you?

R: No, because I guess what would, I maybe had very high expectations of what is helpful which is like an answer and I didn’t find that, so it was interesting to see what other, what it was for other people but again, knowing that that wasn’t the case for me made it less helpful.

Int: Were there any internet resources you found were unhelpful?

R: I guess these like Yahoo answers where it gets really, everything is turned into being like the end of the world, which was just making me anxious.

Int: Okay, yeah.

So, thinking about online resources, is there anything else that you think would be helpful or would have been helpful when you were looking before for helping manage the pain with your headaches?

R: I think I was just a bit disappointed with the doctor’s reluctance to kind of explore it a bit more than “take paracetamol and it will go away”, I feel there was a bit of reluctance to diagnose it as something that is actually chronic or whether it is or not migraines, I don't know why but I felt there was a bit of reluctance to label what I was feeling and I think if I had a, I mean I understand that obviously it’s difficult to diagnose if you don't know what it is due to or if you haven’t explored all the causes that it might be. I’m not disappointed with the fact that there’s nobody online who has the same exact experience as me or who can give me a cure but I guess I would have expected a bit more follow-up from GP rather than “I’ll see you in six months’ time and see if you still have this.”

Int: Yeah. You said before about the NHS website being a bit, how did you word it, vague?

R: Yeah, superficial, like again would I understand because I mean with everything, if you're looking at nutrition, you can only give like a basis and then obviously every individual is going to need adjusting and react differently, so again it’s not a fault, it’s just from someone who’s not feeling well, it’s obviously a bit of a disappointment if you expect more but you also rationally understand that not always more can be done.

Int: Okay, okay. Is there anything else that you'd like to add to what you’ve said about your experience with headaches or about online resources, social media, in general?

R: No, because not using social media, I can’t say if it would be helpful but I guess I’d find it difficult to think that on Facebook or Instagram, people would give advice because I think that’s places where you kind of post the highlight reel of your life so I’d be very surprised if there was more advice there, than there is on like anonymous blogs.

Int: Okay, yeah, that makes sense.

That’s great. So, that’s the end of my questions. I’ll turn off the recording and if you have any questions or issues you want to discuss with me, we can talk about that. Thank you very much.

R: No problem.

[CLOSE]

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