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ANONYMISED

Int[[1]](#footnote-1): It should say on the banner that it’s recording and just to say as well that some of the questions might be quite similar to the questions that we did in the screening, so don’t worry about repeating anything, I just use those for a warm-up, okay?

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

Int: My screen is over there so if I’m looking there and not looking at this way, it’s just because I’m looking at my questions, okay?

R: Okay.

Int: So - you're still happy to take part and to be audio recorded?

R: Yes.

Int: Great, okay.

If you could start by telling me, from wherever you want to start, a bit about your experience of persistent pain?

R: I think it started when I was around 13 to 12, I think that’s when I became more aware of it. It was things like lactose intolerance or things like PMS or a back pain, shoulder pain. I think that’s around the age when I started becoming more aware of it.

Int: Okay. So a few different types of pain, can you describe those a bit more for me? The different types.

R: So, with lactose intolerance, it was like pains and nausea after consuming say dairy products like milk and with PMS, that came with my normal cycle, but it was things like - I didn’t know that the pains were related to that. Also with the shoulder and back pain, those were things that just started when I started secondary school and I had to take a back pack with me or heavy items with me, and school textbooks. So yeah.

Int: Okay, thanks. Do you think you could tell me about what it was like when it first started compared to what it’s like now for you?

R: When it first started, I didn’t know how to manage it but afterwards, I kind of just used the internet to search out what kind of things I could do to help with that and then it’s not as bad as it was before.

Int: So a lower level of severity of pain, maybe?

R: Yes.

Int: Is that the same for the back and shoulder pain, as the PMS?

R: Yes, because I learned that on the internet, sitting for a long time or there are other alternatives to back bags, or like taking rests or just being more active, that could help with back and shoulder pain.

And I learnt about lactose intolerance through the internet because I heard of it but I didn’t really know what it was or that I as an Asian was more susceptible to it. So I found out about that through the internet and just excluded lactose from my diet as a result and it’s kind of become... that pain, I know why it’s there now and I can manage it better now.

Int: I’ll come back to more specific resources that you’ve had a look at in a minute.

Have you had any advice about it from doctors, nurses or even people like psychologists or physios about any of the pain you have?

R: Because of my lactose intolerance, I was often in quite a bit of pain and that meant I sometimes would come to school late or just be delayed by a few minutes. They’re not health-related, but I was told that it might be related to stress, but it wasn’t a doctor, it was just a teacher. Also, with regards to PMS, I was told to sort of use painkillers or birth control, by the GP.

Int: Did you find that was useful advice?

R: Yes, the painkillers were because I didn’t take painkillers before but then I started taking painkillers and that eased the pain a bit, but not entirely. Also, with regards to lactose intolerance, when I was little, I went to the GP to get it checked-out but it was kind of vague, the symptoms they gave me was kind of vague, “stomach pain every morning” but they didn’t really see it as being related to diet, so they didn’t really investigate that.

Int: Okay, I see. What about for the back and shoulder pain? Have you seen either a GP or physiotherapist or anyone like that about it?

R: No.

Int: Okay, okay.

You mentioned there about where you're talking about the person at school who gave you advice, that it was affecting your school life at the time.

How does it affect your school life and your whole educational life? How has it affected that over the years?

R: I’d say lactose intolerance in combination with PMS has affected my life because, of course, that means double the pain and it meant that I sometimes couldn’t go into school because of digestive problems.

Because of PMS, it’s quite painful so I couldn’t go into school because I didn’t know how to manage it, I should manage it using painkillers and with lactose intolerance - that persisted every morning so that meant I was often delayed by a few, I wasn’t extremely late, but I was late by one or two minutes sometimes in the morning. But that wasn’t stress-related, it was more related to my diet, but I didn’t really know at the time.

Int: Okay. How would you say your pain affects your physical abilities? I know you mentioned about the backpack before, but is there any other way it affects your physical abilities, day-to-day?

R: It might mean that I just need to walk slower, I can’t be as active, I can’t run for the bus, normally when I would in the morning, or I can’t go upstairs. I might not be as physically active as I used to be. I might not take part in physical sport as much because of how intensive it is.

Int: What about your social life? Do you think your pain affects that, and if so, how?

R: I might be more withdrawn, not because of any mood-related problems but because it takes a lot of effort to be social and talkative, physically, I think for me. Just to walk around with people because it is quite physical related to walk around with people or to hang out outside, or to go upstairs because my school is - usually I meet my friends in school and it’s a two-floor school so normally they’re upstairs in a cafeteria and I might not go upstairs because I don’t feel as good as I normally would. Yeah. But usually I speak to my friends online using WhatsApp so it doesn’t affect it that much.

Int: And you said as well when you were speaking at the beginning of that bit you just said, about “it isn’t mood-related”, so do you think that pain affects your mood and emotions?

R: I think I might be slightly more irritable, and I might, just because it’s not comfortable, it’s not a comfortable feeling. I don’t think it affects anything else though.

Int: We spoke a bit about doctors that you’ve seen, have you seen any alternative therapists or anyone like that and had advice from them?

R: No.

Int: Okay.

Let’s talk a bit then about the internet use for finding out about pain.

Can you tell me a bit more about the resources you’ve used to find information about the persistent pain?

R: Mainly Google and I might go on the NHS website first. The other websites as well that kind of list out all of the possible conditions and like the symptoms, and I might sort of just try and ‘cancel out’ using that. I might Google one or two symptoms and I might try to be more specific to see which one might be related to what I’m feeling.

Int: Okay. Can you give me an example of when you're more specific?

R: Recently, I’ve been having a sort of heartburn, I Googled “sharp pain in chest” which is obviously quite broad and then they listed out different diseases, different conditions, and I... think I went onto the NHS website and I might have looked at one condition called pericarditis and then I read up what that was, then I looked at the symptoms for that and it was like “sharp pain when you lie down”, which is what I was experiencing.

So that’s how I kind of just zero out, ‘cancel out’, what my symptoms are and which ones relate to which condition. I think after that, I might look at advice for how to deal with something, because I might not be experiencing that exact condition, but the symptoms are similar, so how do I manage those symptoms?

Int: Okay. With the NHS website, what’s your experience been like using that? What do you think of it?

R: I think I trust the NHS website over other websites because it is registered with the NHS and also, I like that there’s, it’s kind of laid out like symptoms, when it’s more severe and when you should be more concerned and then what you can do to help with that, when you should contact the doctor, all of that So I like, I liked using the NHS website and I think I rely on that more.

Int: You mentioned a couple of other similar health advice websites, can you remember what ones they are?

R: I think one of them was called Health Advisor, I can’t remember any others though.

Int: Okay. What’s your experience like when you’ve used those?

R: They’re kind of all over the place, it’s just like a really long list of conditions and what kind of things could be causing them and the symptoms of them, so yeah, it’s just a really long list that I can scroll by.

Int: Okay. You said before that you trust the NHS website more, is that right?

R: Yeah.

Int: Yeah.

Okay. What are you hoping to find when you initially go to search the internet and you're starting to search for either information or ways to manage? What are you hoping to find?

R: I think what I’m hoping to find is a condition that’s similar to what I’m experiencing and ways on how to manage what I’m experiencing.

Int: Okay, that makes sense.

What about social media then? Do you have any experiences of looking for information or management advice on social media?

R: No.

Int: No, not really?

R: No.

Int: What about YouTube, have you ever looked on there?

R: Not really, not specific conditions related to myself, but I use it as an educational resource.

Int: Okay. Have you found anything helpful on there for you, for the pain?

R: Well, I never really used YouTube to search up how to manage my conditions, I normally use Google. But with YouTube, I use it to learn about different conditions and diseases, especially because I study biology so that’s why it’s helpful.

Int: Okay – that’s interesting.

I’ll skim through some other resources to check you haven’t used them for that. There’s also Facebook, Instagram, Twitter, Reddit as well some people have mentioned - any of those you’ve used for that sort of thing or not?

R: No.

Int: I’m going to ask you a few questions back because I skipped forward to the internet use questions.

What kinds of things do you do yourself to cope with pain when you're at home or self-managing?

R: I might use painkillers, or I might try to not be as active, I might try and eat less but that’s as a result of nausea. I might lie down, I might use a cold compress, things like that.

Int: Okay. Do you find doing those sorts of self-management things okay to do? Or struggled with them at all?

R: I think they’re okay to do. I don’t really struggle with them.

Int: What about things like relaxation and mindfulness, do you do anything like that to help with the pain?

R: If I’m feeling any physical pain that might be related to things like school stress, then I might do mindfulness or meditation or I might listen to ASMR as a form of mindfulness. That kind of helps because it steadies... I don't know, I don’t feel as uncomfortable after mindfulness, sometimes, if it’s stress-related.

Int: Do you still use mindfulness now?

R: No, because my exams are over, so I don’t really need it anymore.

Int: When you've been using mindfulness or ASMR you said as well, I think?

R: Yeah.

Int: Have you used online resources to help facilitate that?

R: Yeah, I use YouTube - YouTube videos that might be an hour long or 10-hours long and they just like… different sounds and maybe different types of music or different moods and all of that.

Int: What about apps, do you use any of those?

R: No, I tried Headspace, but I didn’t like it as much.

Int: Okay, why do you think you didn’t like it?

R: I think it was okay at first, but I think - I didn’t find it as effective, as just listening to, as immersive as listening to ASMR maybe.

Int: Okay. That’s fair enough, everyone has preference.

Have you had any advice about pain from your friends and family, about how to manage it?

R: Um.... Not really. Once I heard that having sugar and water would be helpful for period pain.

Int: Okay - so not too much, alright.

And you mentioned at the start that the internet is where you go, is that where you've turned to first would you say when you're trying to find out about managing pain?

R: Yep. [noise interruption – music/ ringtone 00:18:10]

Int: That’s alright.

R: Sorry!

Int: No problem, it’s fine.

How would you say your use of internet resources has changed from when you first started getting pain compared to more recently?

R: Could you please repeat that?

Int: Yeah. So – how has your use of internet resources, any websites, social media, anything, changed from when you first started getting pain to now?

R: So, things related to lactose intolerance or PMS, I don't think I search about them as much because now I know how to manage them. So, I think - I still use Google as my main source of information, but I don’t search about the things I’ve already searched about and learned how to manage.

Int: So maybe searching for more management advice rather than information about a condition?

R: Yeah.

Int: Okay. I think I may know the answer to this, but which internet resources have you found the most helpful and why?

R: NHS.

Int: Yeah. And you said because you trust it, and it tells you when to go to the doctor, I think you said before?

R: Yeah.

Int: Have you come across any internet resources that you’ve found were unhelpful and if so, why do you think they were unhelpful?

R: I haven’t really seen anything medically unhelpful; I’ve just seen maybe adverts on social media that are like, “this tablet will help you with this, this, that”, just that’s the only thing I can think of as being unhelpful.

Int: Okay. Why is that?

R: Because it could be things like this tablet will help you with everything blah blah blah, I just think that’s false advertisement.

Int: Okay yeah. Thinking about online resources, is there anything else that you think would be helpful or would have been helpful when you tried to manage your pain in the past?

R: I think the only thing I accessed - when I first started using Google, I found the same things that I would find now, things like the NHS website or all of the other websites that I mentioned before like Health Advisor and all of that.

Int: Okay. So, nothing that you wish had been there or wish would be there in future?

R: No.

Int: Okay, that’s fine.

Is there anything you would like to add to anything that you’ve said – either about your experience with pain or about internet resources generally?

R: I think the first thing I go to before I go to a doctor is the internet – just to see -because the internet is readily available to me, it’s quick to access so that’s why it’s the first thing that I’d look at before I go to the doctors.

Int: Okay, that makes sense.

That brings me to the end of the questions. Thank you – I will now turn off the recording and if you have questions for me you cam ask them off the record, okay.

[CLOSE]

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