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ANONYMISED

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

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

Int: Great, thanks. So, my interview prompts are over here, so if I’m looking over there, I’m still going to be listening to what you’re saying. It’s just my reference point, that’s all.

R: Fab.

Int: So could you start by telling me a bit about your experience with the fibromyalgia?

R: So I was diagnosed in December of 2019, so the December just gone, and I think what prompted like the diagnosis was I was getting these pains in my chest. It was like a stabbing pain. It was really, really horrible.

And then they said that, like after loads of scans and stuff they were like, ‘nothing’s coming up’, and the thing is, I’d been, like it was sort of a joke between me and like people that knew me, that there was like always something wrong with me, but like it just kind of went under the radar for a really, really long time, and it was not until the chest pains that people started to take note, and even then it took quite a while, because nothing was coming up on scans and stuff.

Int: And how long before that was it that you started experiencing body pains and such?

R: I want to say as long as I can remember. Obviously it’s not, but like I’ve always had these really intense muscle knots and a real tenderness when, like with, what is it? - like tactile pressure, like I just, yeah, sore quite a lot and very tender all the time, and I thought that was normal for years.

Int: Yeah, yeah, okay.

And from back when you can first remember when the pain first started or the tenderness first started, could you maybe tell me what that was like compared to how you’re feeling more recently?

R: I think I just thought it was normal, like I think I just thought it was normal, and now I know like it’s not... to just be in pain constantly all the time and always have something wrong with you, I think it’s a bit of a relief, but since I was a teenager I think it was just something that I thought was just normal, and like I was tired all the time and falling asleep in school, and how did people not realise that something was wrong? Like, yeah, but just kind of relieved I think is the main one.

Int: Yeah. And so it’s like you’re feeling more relieved but you’re having some more symptoms, if you like with the chest pain and that now?

R: Yeah. Yeah definitely, like the chest pain isn't there all the time, like that comes and goes every few months, but even stuff to do with my bladder and my stomach, the pain kind of rotates and so when I was in school, I was just like oh, it’s just like, yeah, I can’t really, it’s hard to describe like just thinking that it was all normal and that maybe I was just tired and run down. But yeah, if that answers the question.

Int: Yeah, it does. And you talked a bit as well about school and falling asleep in school.

Do you think you could tell me a bit more about how your pain and things resulting from pain have affected your school and your university life as well?

R: Yeah, so I remember I was always quite studious, like my parents pushed me quite hard, and I think the real shift happened when I was 17, 16/17 and I was going into sixth form, and I’d always been really, really focused on my work, and by the time I got to 16/ 17, after GCSEs, I found it just so difficult to remain in concentration, to remain focused, and I physically just couldn't do something for more than half an hour, which was so unlike me from before.

And I put it down to me being lazy or me not getting enough sleep. Now I know it’s not, and I want to give 17 year old me a hug, because I was just like, I was being really harsh on myself, but I just thought it was normal and I just thought I was disillusioned with school or something [*laughs*].

I couldn't stay properly awake most days I was in school. I started, like my attendance was really low. I didn’t go into school for lessons that I, like if I didn’t have any lessons and the teachers like, luckily my head of sixth form was really onside and she put it down to having anxiety or something, but like it was, because I just couldn’t get in [*laughs*].

And then when I got to uni, similar things were happening and I thought maybe when I was in school it was just because I hated school so much and so uni would be different, and then it wasn’t and I was like, oh maybe I am just lazy! But yeah, that’s when I can really remember being like tender all the time, which was just horrible, and attendance wasn’t great.

Int: Hmm, yeah. It’s interesting about university. Did you get any sort of help from the university?

R: Not really because I didn’t think I needed it, because I thought it was just me. I thought, again, I thought I was just being lazy or lacking concentration, and I thought everyone was in the same boat, and then when I realised it wasn’t, like since I’ve got my diagnosis they’ve been really onside and I think if it wasn’t for this one welfare tutor who’s so nice, he’s really lovely and he helped me through the whole thing, I probably would have dropped out by now.

Like all throughout the first year I was like, ‘I want to drop out, I want to drop out’, because I just didn’t think it was for me, not that I was struggling because of my condition. I just thought it was not for me [*laughs*].

Int: Yeah that’s understandable as well. I’m glad you’ve found a good tutor.

R: Yeah, me too.

Int: And you talked a little bit, kind of in and out about your mood and emotions in what you said, but do you think you could tell me a bit more about how the pain especially affects your mood and emotions?

R: Yeah for sure. I think it’s kind of like the mood affects my pain and the pain affects my mood, I think it works both ways, and throughout sixth form, like apart from school, I was going through quite a lot, and I was living quite a, I don’t want to put it all to that, but it was quite a stressful household for various reasons.

But yeah, I think like recently I’ve been, over lockdown, I was seeing a physiotherapist who’s really shifted my perspective on how my mood affects my pain, and I’ve been a lot more proactive recently.

But I think, yeah, I’ve had anxiety for quite a long time and I don’t think that helps, because my body gets quite stressed when I get stressed, and I can feel it, like I can feel it in my muscles, like all over. Yeah, I think that’s my answer.

Int: Okay and you said you started seeing a physio now. Is that you having them by video?

R: Yeah, so I’ve done my course now. It was pretty much the whole of lockdown, which is kind of a long time, but yeah, it was all over Zoom and he was really helpful.

Int: Okay. How do you think the pain affects your physical abilities overall?

I mean I know you said you’ve had some time off and things like that, but more specifically how does it affect your physical abilities and maybe has it improved since you’ve had the physio?

R: I’d say when it comes, like sometimes I will just have to lie down because it’s just so overwhelming, especially when I get the chest pains as well. I know now that it’s not going to kill me, but I just think there’s something about it being in your chest that is still quite scary, and so when it’s like that, I will just have to lie down.

And then I’ve got like pain in my hips and my shoulders that sometimes the shoulder one, it prevents me from carrying heavy things and stuff, which is really embarrassing, but my hips... a lot of the time I will just have to lie down.

I try to push through it a lot, because I know it’s not going to kill me and I think my physio has helped me, not realise that, but like motivated me almost, but a lot of the time I will have to take the escalator instead of the stairs, just stuff like that.

Int: Okay and we’ll definitely talk a bit more about the physio that you’ve had in a minute, but before I do I’d like to know, how does pain affect your social life?

R: Quite a bit actually, like there’s plenty of nights out where I’ll have to go home just because I’m feeling so bad, and I don’t think alcohol helps at all. I think that increases the tenderness quite a bit, and so I’ve had to either not go at all or go home early on various occasions, and even stuff in the day, like if I’m too tired I won't be able to do stuff with my friends. It has happened a lot.

Luckily, I’ve got really good friends around me and they’re just great and I’m really grateful for them, and we... if I’m not feeling so good they will do stuff in the house with me, which is really nice.

But it does have an effect, and say if my bladder’s playing up a bit, like it’s just not convenient to go out, stuff like that, just like little things, little inconvenient things that just prevent it, which is really annoying and really sad.

Int: Okay. And what about any advice you’ve had from your doctors, nurses, anyone like a psychologist as well about the pain? What advice have you had?

R: So when I got the diagnosis from my GP, she referred me to a rheumatologist, and because of coronavirus, luckily my grandma paid for us to go private, but if I hadn't have done that I still wouldn't have seen a rheumatologist by now, which is like really scary, and I was put on firstly amitriptyline to help my sleep.

It was a really low dose, and then I was on that for quite a while, and then I think it was August I said to my GP “I don’t think it’s working that well”, and so she put me on a bit of a higher dose, which like it hasn’t eradicated everything obviously, but I am feeling a difference, or I was at the start.

But other than that, apart from my rheumatologist saying that I need steroid injections, like not a lot from doctors. They just say ibuprofen or paracetamol and then when I said in August I was taking that every day; that was the only thing that they said. They were like, “yeah, you’re taking it too much”. But yeah, other than that, not a lot.

Int: Okay. So from what I’ve understood there, the medication that they gave you was to try and help with the sleep aspect of things.

R: Yeah.

Int: So how is it going now?

R: Yeah, like it is, I am sleeping a lot more, like I used to just never sleep and I just put it down to like, I don’t even know, like me like being, like my body just being annoying, like not actually something that is quite serious.

But yeah, I find like the amitriptyline is working a bit. I got pretty immune, if that’s the word, to the lower dosage in a matter of months, which was not great, but I think yeah, it’s working. It’s not eradicating stuff, but I am noticing a difference.

Int: Okay and let’s talk about this physio a bit more then. So, was it a GP who kind of referred you to the physio?

R: No - it was my rheumatologist.

Int: Rheumatologist – okay. What was your experience of having the physiotherapy like?

R: I was really, really grateful. Firstly he was really nice and it was all, because it was lockdown, like this was probably not even relevant, but like he was doing it in his house and like his cat and dog would jump on the screen sometimes, which was really nice.

But yeah, he was really good and he definitely like shifted my perspective on like how to view it, I think. By March-time I was getting a bit fed up about it and I was quite upset, because it is quite upsetting, but he definitely shifted it and made me realise... or like motivated me to be more proactive in it, and to notice little things and keep track of things, which is good. Yeah, I was really grateful.

Int: Okay that’s good. What about someone like a psychologist or a therapist, anyone like that have you seen about the pain or the fibro?

R: Not about the pain specifically. When I was in sixth form, because a lot of the doctors just put a lot of things down to me being anxious or me being depressed, and so I saw a counsellor, who was lovely, but it was never really about the pain, because I just thought, like I thought it was normal, so I didn’t really bring it up, and I thought maybe I was probably just tired or something like that.

Since my diagnosis or actually since I got to uni... hmmm yeah, second year I went to see my doctor and said “I did see a counsellor when I was in sixth form and I think I need some help”. So they put me on a waiting list, and then when I got my diagnosis she was like, “yeah, you definitely need a waiting list, like you definitely need to see someone”, and I’m still on the waiting list and I don’t want to ask my grandma to pay again, because it is a lot of money.

Int: Okay so potentially something that you will have more input on then, and especially now they know about the diagnosis, you might be able to talk about that a bit more then.

R: Yeah, absolutely.

Int: Okay, any advice from any other alternative therapists or specialists?

R: So before I knew anything about fibromyalgia, I did see a massage therapist quite a bit, and every time I went she was like, “yeah you are re-, like you have a lot of tension”. I was like, yeah, yeah, and I really enjoyed that, like some days I was more tender than others and we’d talk about it and stuff, and I found that helped, and then when I told her that I was diagnosed with fibromyalgia she was like, “yeah, you’re very young to have that but I’m not really surprised.”[*laughs*]

Int: Okay, so do you still go at all?

R: I haven't been in a while just because of like lockdown. I think the last time I went was February I think, but yeah, I really want to go again.

Int: Okay. And...

Now this might be a tricky question as you said you can’t pinpoint when it first was starting, but when you’ve been trying to find out how to deal with the pain, who or where have you gone to in your very first instance as your very first instinct?

R: I think my mum, just because I was always at home. I was always at home and she always knew that I felt a lot of pain in my shoulders and my neck, but she was just like “oh, you and me are the same, like we get a little bit of stress there”, but I don’t think she realised, well, she definitely didn’t realise the gravity of the situation.

And I went to the GP a couple of times for various things, like my eyes would always, I got a lot of pain in my eyes and they would just be like, “yeah, sometimes that happens but we can’t do anything”, and it was getting to the point where I would keep, I think I went to the GP about four times to say “I can’t live like this, like I’m in a lot of pain”. But yeah, I think my mum and my GP.

Int: Okay. And any other advice that either your mum or your other friends and family have tried to give you over the years about dealing with it?

R: I think like they would always stress the impor-, like my mum would always stress the importance of sleep, but then I was having a lot of sleep problems and again I just put that down to... maybe not having the best sleep schedule? But I think I was being very harsh, like very harsh on myself.

And I think I always got really painful periods, even though I was on the pill, and she would just be like, “oh yeah, I think it’s just the curse of being a woman”. I think that was a lot of it as well, like women feel a lot of pain and they think still like women are expected to be in pain all the time, which is just not sustainable and it’s not right.

Int: Yeah, yeah. Okay. And aside from advice from everyone else then, what kind of things do you do yourself at home to help manage the pain?

R: Well I use a lot of Deep Heat or Biofreeze for the muscles. Sometimes I’ll have to have ibuprofen or paracetamol, even though I don’t want to, just because there’s no alternative or I haven't been given an alternative.

When I told them that that never worked, they prescribed naproxen, but they’re always like “don’t use it because it’s really strong, like that’s only for emergencies”, so I try to stay off that, but sometimes I just have to.

Oh, I have an electric blanket that’s been kind of my lifesaver, and I’ll just like lie down on that, but yeah, it’s difficult. It’s difficult... when there are so few options.

Int: Yeah. So you’ve got your electric blanket and you’ve got your heat and cool, did you say it was gel, sorry?

R: Yeah.

Int: Okay. What about things like relaxation and mindfulness, do you try any of that to help with it?

R: Yeah, so like the massage lady that I went to, she runs like meditation things which I really like doing, especially over lockdown. I drink a lot of tea, like a lot of tea. I used to do a bit of yoga but I found my body just wouldn't do it, and whenever you tell someone who doesn’t really know what they’re talking about, like whenever they ask about it they’re always like “have you tried yoga”, and I’m like “yeah”. But yeah, other than that, yeah...

Int: Okay.

R: ... those, yeah.

Int: And what about those meditation things that the massage lady does, how do you go about them? How does she deliver that? Do you listen to it on audio?

R: Yeah, so over lockdown she put them all online, and she’s still doing it now, which is really nice, and she would do a different one each day, like she’s really committed, and so yeah, it would just like be on, like I would just put it on my phone or my laptop or something.

Int: Okay, okay. And it’s good that you can still access that as well.

Is there any other online resources that you have used to help you cope with the pain?

R: I don’t think so. Oh wait, there are aerobics videos on the NHS website for people with chronic pain that someone suggested, and I did do quite a bit of those. I did try yoga for a while, even though it hurt, and I just couldn't do it. I did quite that a bit and that was all on YouTube as well. But yeah, other than that I don’t think so.

Int: Okay and let’s talk about, seeing as you mentioned the NHS website, let’s talk a bit about that.

So you say you went on there and you found, or someone suggested to you, exercises you said?

R: Yeah. Do you know what, it’s been so long since I did them, like I can’t even remember what they were, but I just remember doing them.

Int: Okay - can you tell me about your experience of using the NHS website for pain management?

R: Yeah. Because like I’ve had, like with fibromyalgia comes a lot of other things wrong. I don’t know how to say it, like I’ve got bursitis in both of my hips and my shoulders, and like the stuff with my eyes and the stuff with my bladder, and like different, like there’s just so many things, so I’m pretty much always consulting the website.

I think with the fibromyalgia, like it doesn’t give the full picture, and so I remember when I was first diagnosed my friends were looking it up on there, and I was like, yeah, like they’re just missing a lot out. It’s not... yeah.

Int: So do you wish there was more information or more management advice on there?

R: Maybe not on there, because I do get that like it’s such a complicated thing, and you could, I mean you could spend hours writing about that, but if there was more information given to me by my GP, maybe on like management, I’d appreciate that.

Int: Okay, okay. That’s interesting you say, when you told your friends that was the first place they went to, the NHS website, to find out about fibromyalgia.

R: Yeah. As well as the Lady Gaga documentary.

Int: Oh really?

R: Yeah. They all watched that, which was really sweet.

Int: Okay that’s interesting. And you mentioned as well before about using YouTube to look up yoga videos, but you didn’t really get on with the yoga?

R: The thing is I think it’s a really good idea and I liked it, but I just couldn’t do it.

Int: Okay, because of the pain or...?

R: Yeah and just because my, yeah, because my body just doesn’t want to do that [*laughs*].

Int: Okay and what about other social media resources, have you had any experiences of either looking for information or looking for pain management strategies on things like Facebook or Instagram?

R: Yeah. I find the Fibromyalgia Action UK Facebook quite helpful sometimes, and they have really interesting articles about new ways of dealing with it. I think my favourite one recently was the idea of a therapy dog, which sounds amazing. But yeah, I do find them quite interesting. But there’s not a lot out there really.

Int: Okay, and you say it’s interesting, but is there anything else you like particularly about that group?

R: Well I remember when I was first diagnosed they said like “try support groups and stuff”, and there are a few on Facebook, and I just had to leave them because I found it very, very depressing, and I think for a lot of people, like obviously it offers comfort and I’m not slating it, but I just didn’t like how it seemed almost like a competition about who’s got it the worst, and a lot of it was like, ‘I’ve got this, this, this, this and this’ and ‘I can’t move!’, and it was just like that all the time, and I just had to leave because it was just too, it was too much.

Int: Okay and you found that the Fibromyalgia Action UK was not the same as those?

R: No, because it was like, I mean it was giving information, like you can look on the comments and it’s like a lot of people doing that, but I think these targeted groups for sufferers, like just for their output, it’s just not for me.

Int: Okay and how about Instagram, do you use that at all?

R: Yeah I do, for my sins. I wish I didn’t but [*laughs*].

Int: And what things do you follow to do with your fibro and your pain on there, and what do you like?

R: I mean I follow Lady Gaga. I think she’s quite inspirational and I love her anyway, but it’s nice to see someone who has fibromyalgia doing so well despite it, and I follow the Fibromyalgia Action UK on Instagram as well, but other than that, nothing else.

I just don’t like, yeah, I just can’t follow people who, not revel in it, but like bombard the internet with all their problems, like I just can’t, I’m not there to see that, do you know what I mean? Which sounds really harsh and really mean, but if that’s someone’s way of coping with it, great, but yeah.

Int: Okay yeah, that makes sense, what you’re saying, yeah, okay.

R: Good.

Int: And, if you’re just looking on Google, trying to find out information, what are you hoping to find if you go onto Google and start searching the internet?

What are you hoping to find?

R: At the start when I was getting the chest pains and I had no idea why, I found I wanted to find other symptoms of certain things, and when I saw fibromyalgia I was like, well yeah, I’ve had that for years obviously, and so that was nice [*laughs*].

But I think at this point now, I’m nearly a year in or like nine months in, 10 months really... a cure, but that’s not going to happen! Or just like ways to help it or like medicines you can take that better it, I think.

Int: Okay that’s fair enough. I think a lot of people do, are hopeful for that as well.

R: [*laughing*]

Int: Okay what about if you’re looking on the internet, searching for information about the pain or the fibro, have you looked at any other similar health advice websites outside of the NHS? I’m thinking like Healthline or WebMD.

R: Yeah, I mean I’ve scoured both of them. Sometimes if I’m just curious I’ll just go back on them and just confirm that yeah, I do have all of that, and I think they’re a lot, I think it was WebMD that I found most helpful when I was getting diagnosed, because I think it gave the most pertinent information for me. Yeah, yeah.

Int: Okay, okay. And do you think this use of internet resources and the social media you mentioned, do you think it’s changed from when you first started getting pain, or even when you were first diagnosed back in December to more recently?

R: I think my, I mean my own search history has changed since I was diagnosed, because I just never knew anything, like I hadn't even heard of it, like I’d probably heard of it because, like I said, because of Lady Gaga, but I didn’t register.

I think all of my friends just like knew she had something really wrong with her that was to do with pain - because she had to cancel her world tour - but I don’t think, the internet probably hasn’t changed. I think it’s just where I’m looking that’s changed since I was diagnosed.

Int: Okay, so moving from what sort of resources to, I mean I guess you’re looking more on the Facebook now?

R: Yeah.

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

R: Probably, I think it was either Healthline or WebMD, I think, that when I was first getting diagnosed I was like, oh my god, like yes, obviously that’s me, because they’ve mentioned the costochondritis as well and I can’t remem-, it might have been both, but it was either one of them or both of them which I found really helpful.

In terms of like post-diagnosis, I think Fibromyalgia Action, like they’re, I think there’s still a long way to go with them, but I have found it helpful. Yeah, I think those two. Oh, and Lady Gaga [*laughs*].

Int: Okay and have you come across any internet resources that you’ve found were unhelpful, and why was that?

R: Well I’ve already said this one, but definitely the support groups. It wasn’t just that I was like I didn’t want to see that. I did find it unhelpful. This probably sounds too harsh, but a lot of it seemed people wallowing and competing to an extent, and I didn’t just dislike that; I did find it actively unhelpful, and yeah, if that makes sense.

Int: Yeah, yeah, I understand that.

And I suppose then thinking about online resources, is there anything else you think would have been helpful in the past for managing the pain?

R: Hmmm.

Int: Or would be helpful to you now?

R: Hmmm... I think what I would want doesn’t exist yet, like the more research into it, like different, yeah, I guess like a cure, but that isn't going to happen. Yeah, if that answers your question.

Int: Okay, so, kind of like a website with more information?

R: Yeah, I think so, just like more informative rather than people’s own opinions, if that makes sense? I think the Fibromyalgia Action website is very outdated. It would be nice if that was updated.

Int: What do you mean by outdated?

R: You just can’t, well the layout is really bad, firstly, but also you can’t, yeah, it just seems very, like I mean fibromyalgia isn't taken seriously at the best of times. I would just like to see more, just like more information and better presentation, I think.

Int: Okay, yeah, something maybe a bit more streamlined?

R: Yeah exactly, yeah. Yeah that’s exactly the word.

Int: Okay. Is there anything else you want to add to what you’ve already said, either about fibromyalgia and the pain you experience, or about internet resources?

R: I don’t think so. I think I’ve covered it, I think [*laughs*].

Int: Okay, well yeah, so that brings me to the end of the questions in the schedule. So, unless you’ve got anything else that you suddenly think, ‘I want to add that’, then it’s thank you and I will close the recording, and if you have other questions for me, then we can talk about that as well.

R: Yeah I think I’m good. I think we’ve covered everything!

Int: Okay.

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