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ANONYMISED

Int[[1]](#footnote-1): So it should have just popped up and said that it’s recording now.

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

Int: 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: Yes, that’s perfect.

Int: Okay. My questions over here on the left, you can probably see the screen reflecting in my glasses so if I’m looking over there and not at you, don’t worry about that, it’s just my reference point, I’ll still be listening to what you're saying, okay?

R: That’s okay.

Int: Right then. Do you think you could start by telling me a bit about your experience with chronic pain?

R: So I’ve had chronic pain, it started really in my knees at first, just because of a condition I’ve got where they dislocate, so I’ve done so much damage to them that now I’ve kind of got permanent pain, I’m told I’ll have pain for the rest of my life in them.

And then a year ago, that’s when the fibromyalgia started and I now have pain all over my body and as I said to you before, the pain in my knees and the fibro pain is very, very different. I think you can tell like from the research I’ve done, fibro pain is not supposed to be inflammatory pain whereas my knee pain is, so maybe that explains why the pain’s slightly different in like my body and my knee areas.

And then obviously IBS, I get a lot of stomach pain, so again, that’s like a different kind of pain and the constant headaches I get, I think are related to fibro but again... it’s like a different kind of pain and I’ve kind of got all these different, I kind of try to look on the internet and have done a lot of research and like especially on Instagram and heard other people’s stories, and I know that all these different kinds of pain do have names for them but yeah, that’s kind of [inaudible 00:02:11].

Int: You've just gone really muffled right at the end there... No, I can’t hear you!

R: Okay, I’m going to move slightly, this might make a difference.

Int: I can hear you now [audio echo at 00:02:30] ... and now I can hear myself!

How old were you when you first started getting pain?

R: I think about 15 and that would have been my knees, that’s kind of where it all started and then my IBS began about 17, so I was getting lots of tummy pains, tummy aches... and then obviously, I started getting really widespread last year at the age of 22, so really from 15 I’d say, like with my knees, was the first time really of experience just constant pain for a prolonged period of time.

Int: Okay, okay. When did you end up getting diagnosed with fibro?

R: That was last year, on 17th December and I first noted my symptoms around July time, but then if I look back, I’m pretty sure I’d noticed fatigue and pain a bit before that, but it was very on and off and then it got chronic in July and it just was so severe, I was just bedridden.

Int: Let’s talk about the different types of pain separately for a minute. With the knee pain, what was it like when it first started compared to how it is more recently?

R: When it first started, I could still dance because I was dancing four, five hours a day so I could still do it, but I was, I was still in pain but I could do it and then about three years later, when I was 18 and I had a really severe, bad dislocation, obviously that made the pain worse and it just got to the point where the pain got so bad that I physically couldn’t dance anymore. I can’t run. I can walk but my walking is largely affected at times, so I’ll go through periods where I can’t walk at all.

Now it’s like interfering with my life a lot more, as like the years go on and doctors have told me that especially with my knees, that’s going to be progressive, that’s going to get worse. Whereas with my fibro, it doesn’t usually like get progressive, it doesn’t damage anything in the body, the symptoms might flare up and down, it’s not something that’s going to damage anything and it shouldn’t get worse but…

Int: Okay. And has fibromyalgia... has what it’s like changed from when you first started experiencing symptoms until now?

R: Yeah, like I definitely notice more symptoms. Last year, I didn’t have so many headaches but now headaches are something that I have a lot. I think the pain as well, depending on whether as well, obviously we’re going into winter now, sometimes the pain feels a little different, like usually it’s this horrible dull ache but sometimes it gets really, really sharp and sometimes I get more sensitive where, even if I put a top on or my bottoms on, I will feel like pain just by touching my skin? And sometimes as well, the skin, when you touch it, it’s agonising so even if I go like that, sometimes I accidentally do it and it’s absolutely agonising but you're not proper pressing down, it’s only like this, it shouldn’t hurt but for me it really like hurts. And that’s been something that’s got worse, I think, I didn’t have that so much at the beginning but now I’ve got it all the time.

Int: Mm. You mentioned as well with your knees about not being able to dance at the moment, how does pain affect your physical abilities overall?

R: Yeah, massively, do you mean like in terms of exercise and-

Int: Yeah, actual physical day to day activities or sports, exercise?

R: I can’t do any sports, that’s completely just a no, I can’t go out on a jog, I can’t run. I do my physio exercises, which obviously are really important for strengthening the muscles but the issue is my knees will go through periods where the pain gets worse and they stiffen up as well, meaning that there’s no point doing the physio because it’s going to make the pain worse, so you have to rest.

It’s in those times where I won’t be doing any exercise at all - because physio is the only thing I can really do - with my physio, to warm up, I try and add like a little jog on the spot, but it lasts about two minutes and then that’s it, before my knees really feel like they’re going to pop out or they just get too painful.

Int: How about your school and uni and things, how does your pain affect that?

R: So, at the moment, I wanted to go back to do my Master’s, but I can’t now because I have to learn how to manage this first. I can’t sit down for long periods of time because when my knees, so you know when you sit down and your knees are bent, just the position? You can’t get out because it’s so uncomfortable, the pain actually gets very severe if I sit in that position for too long, so that’s a problem with work, it’s obviously a problem with studying.

When I was at university actually, sometimes the pain would get so bad that I’d get up and I’d have to just sit and have ice packs on before I left the building, just to kind of get the pain to a level where I can just feel okay again to walk back to the Tube station and go home. So yeah, it does affect a lot, even cooking and things like that, just standing up for a long period, I just can’t do it without it flaring, the pain flaring up really badly.

It’s just kind of now I’ve got to this point where you have to learn to balance all your activities, to try and manage and keep the pain at a manageable level, which I am getting better at but obviously, it has interfered a huge amount.

Int: Mm. What about your social life, how does your pain affect that?

R: Yeah, quite a lot actually because sometimes if the pain’s really bad then I have cancelled things before and I just rest and have ice packs on and stuff, and even with my friends, like obviously I’m 23 so a lot of my friends go on nights out, clubbing and I can’t do that, I can’t be on a dance floor for a long period of time.

I could do about five minutes but then I’m sitting down all night, so there’s just things like that really, like missing out on certain things and even if my friends want to do something like an activity in the day, usually I won’t be able to do it so sometimes I feel kinda bad because if they’ve planned something and then they want to include me, we have to change things, that kind of gets a bit, like I don't know, I just feel a bit bad sometimes. So yeah, it does interfere a lot, even with socialising I guess.

Int: How about your mood and your emotions, does your pain affect those?

R: Oh yeah, 100%. So yeah, obviously it does make you sad and I think at the start, when I was having constant pain and I was learning how to kind of manage it and live a life and dancing was all I was doing, so that was out the window, so I was obviously grieving for that. Yeah. A lot of nights I’d be in a lot of pain and would just sit here and cry because you kind of get through the day and think, “I’ve got to do this with my life” because you've kind of got to try and take one day at a time but it gets to the point sometimes where you just think of the whole bigger picture, of like I’ve got 60 plus more years of potentially this and you can’t think like that or else you will get really depressed, but yeah of course I think on my emotions and mental wellbeing, it has like really impacted.

I think a lot of doctors don’t realise that, especially with my knees, one doctor said to me, it was my third, fourth specialist I think I saw and he said that “you’ll be in pain for the rest of your life” and then I went out and that was it, no catch-ups, no checking up on me, just me to kind of work out on my own and I think for a 19 year old, that’s a massive thing to take on and to try and process in your head.

Int: Mm. And that was with the knees, was it?

R: Yeah, I think it’s just they’ve looked at it and I do have damage there and they won’t do surgery because of my hypermobility, just because it’s so bad, they don't think I would actually recover properly. He kind of explained it of being like an elastic band, like if you broke it and you try and fix it, it’s actually going to be worse when you fix it and I do understand that, obviously there’s painkillers but they said, “if you need them then have them but you're only 23, so it’s best to try and learn how to manage it, if you can, and then come back in years to come and try things like painkillers”.

So yeah, it’s just one of those things where there isn’t really anything they can do and you just have to learn to manage it.

Int: In terms of advice you’ve had from doctors and nurses, other healthcare professionals then; I know you mentioned physio before and a couple of things you just mentioned then as well...

Can you tell me a bit more about the advice that you've had from healthcare professionals about the pain?

R: I’ve been told about pain management therapy and that is an option and I’m supposed to be on a waiting list for that. That was when I got diagnosed with fibro but then they learned about my hypermobility and my pain in my knees, so they thought it would be really good to try that. Another thing was antidepressants, that was one of the first things they said to me, “look, we’ll put you on these” and they didn’t say very much about what it’s going to do for me. I know serotonin plays a part in the pain system but that’s about it, I don’t have a massive understanding and I’ve tried to do a bit of research on it, I have got a bit more understanding now how that might play a role, I don't know if it helps but I take them anyway.

They said to do swimming as well, like paced exercise. Swimming is okay and actually, that does help with my fibro pain but it’s not very good for my knees, so it’s just figuring out a way to use my body without using my knees when I swim, which is possible, you can swim with just your arms and that’s what I do, so that’s okay, like you can make adjustments for it and then obviously, my physiotherapy and I’ve got a private physio now as well. So I see him usually every three or so months and we just make the exercises a little bit harder, we might put the weights up, for example, and then add more exercises in and he’s really really helpful actually and he deals a lot with the mental effects of it as well because obviously, part of my knee was dislocation so that for me was terrifying, to have it back, to happen again, because the pain’s so excruciating when it does happen.

He does all this stuff with me to try and get my head around just the fact that, just because I think what I was doing is really concentrating on my movements too much, to try and not have a knee dislocation, so he’s kind of got me back to feeling, even to be able to touch my knee, things like that, so that really helped, he was really helpful.

Int: Okay. So, you had lots of input it sounds like. When you said about pain therapies, what sort of therapies did you mean?

R: She said a pain management course, and from that, I get the gist that maybe it would be like a group of us, I think they do it in groups. I just know there’s a huge waiting list so I might be waiting a bit for that.

Int: Okay. Have you spoken to anyone like a psychologist about the pain?

R: Yeah, I have actually. Do you know Time To Talk?

Int: Yes.

R: I don't know how big it is, but I’ve spoken to them and we just work with like the emotional effects of managing it. At the moment, I’m just talking to them, I’ve only really just started in the last few weeks but that’s something that could potentially be really helpful for me, I think, just to kind of… I mean obviously, I’ve started processing all this years ago but just to try and manage it and get back to normal life, so I can do my Master’s eventually, just set some goals really of things I want to do and then ways I can manage the pain when I do do them.

Int: Okay, okay. You say you're taking antidepressants now, anything else that the GP or the doctor recommended?

R: No, just antidepressants. Again, I don't know if they’re the right amount, I had to cut the dose because the side-effects are so awful, so I cut the dose. I don't know if they do a massive amount, but I’ve got them anyway, they’re a thing and maybe they help sometimes, maybe the help with the mood as well just because as I said, obviously it does affect your mood sometimes.

Int: And... Why did you decide to do private physiotherapy?

R: I was on the NHS for ages and they got to know me really well because I’d pop up there so often, it kind of got to the point where I just felt like I wasn’t getting the right individual treatment. They were giving me, the NHS are obviously amazing, but they were giving me these set exercises that I felt were really hard for me, and everyone kind of gets them, regardless of your problem and it just wasn’t very individualised enough for my problem. Then I thought, “I’m going to have to, I need this to be more long term and if I pay for a private physio, then I’ll have this forever”, it has to be something that I incorporate into my life for the rest of it.

So that’s where I came to the conclusion of getting the private one and I think my dad as well, he was seeing I was in absolute agony with it and I think he was just fed up, he said, “We’ll get you private”, more support as well and the mental support, you get 40 minutes with this private physio and he’s great, he listens to you and it’s just so much better, I think, for me.

Int: Okay. Have you had any advice from any other alternative therapists or specialists about the pain?

R: Not for my knee pain, when I’ve been to all three of them, I think it’s three or four I’ve seen now, they usually say it’s due to a combination, with my knee it’s the patella alta, the fact that I’ve had so many dislocations and complications from it and the damage, and then hypermobility obviously comes into it as well. So, I think they’ve all kind of said the same thing and they just can’t do anything.

Obviously, things like surgery, it’s just not- he said he knows young people who have had the pain worse afterwards, he said “If you go to a knee surgeon, that’s what they’re going to say, have surgery” but he just warned me that “if you do, then it might be a lot worse”, just out of his experience. So, they all kind of say the same thing and then just give you the conclusion that this is going to be how you are.

I think as I said before, with the NHS, it is so, they don’t have so much time for each individual patient and you sometimes feel like they just want to get rid of you, so I think you don’t get very long with each doctor, maybe 10 minutes if that and they listen to you and that’s it, they just say “sorry, can’t do anything, no further action” and that’s always what you get, really.

Int: Okay. In the past, when you've been trying to find out how to deal with pain, who or where would you say you’ve turned to in the very first instance?

R: Um, so... In my first instance... I did a lot of Googling, obviously, when I got all my diagnosis, that’s the first thing I did, I don't know if that’s the best idea really, it comes up with some, do you know what I mean, with fibro, for example, they say “if you’ve got this, you're more likely to have arthritis” and this and that when you're older, it just looks quite dark and negative and doesn’t make you feel very much better.

So I think after a while of doing that, I actually made like a little Instagram page and I follow people with fibromyalgia on there, haven’t quite found anybody with patella alta or anything similar which you know, not great but still, I put things on about me so if anybody else has it and they can see mine.

And then there’s a lot of people who on there who IBS and hypermobility syndrome, so I’ve learned a hell of a lot off them and what they do and what they find useful and... just knowing, you know, a lot of them say, even how many spoons you have for example, like we only have, for me I get really bad fatigue with the pain and there’s only so much you can do and eventually you're just going to run out of spoons completely and you have to try and avoid doing that and just kind of manage, learn how much you can do realistically in a day and make sure you get more rest.

Yeah, I just have learned a lot, especially about pain and the different kinds of pain as well and it’s really nice because I can relate with other people, so they’ll be like “I’ll have this and this” and then you sit there and think “oh my gosh yeah, that’s how I feel as well, that’s how my body’s feeling”, that’s really amazing, that’s probably been the best thing so far, this little Instagram community I’ve found is great, it’s so good.

Int: Okay, so you found out about spoon theory via the Instagram then?

R: Yes, I actually did and I don't know if in pain management, that will come up when I eventually have it but I learn a lot off other people and like I know a lot of people who I follow are in pain management, and they’ve got, they obviously see therapists and whatnot and so yeah, I guess that’s how they’ve learned and they’ve put all their stuff on and even people like health psychologists, there’s some health psychologists on there who I’ve looked at and they will put stuff and tips, you just find new things and learn new ways of potentially managing it. It just makes you feel so much less alone and it’s not all dark and gloomy like Google makes it out to be.

Int: Okay, so... I think there’s two things you've mentioned there that I’ll ask a bit more about.

In terms of finding information then via social media, it sounds like you do quite a lot of finding information on there. How do you go about that?

R: What do you mean?

Int: So, you say you set up your page and then… is that a page that’s specific for your pain? Do you have a separate page to that? How do you go through and start finding relevant things?

R: I made a page that’s specific for my journey with chronic illness or chronic conditions, I guess the knee is more condition, fibro is like an illness, for me it’s a bit different. I made that and then I write things like how I’m feeling, how I’m managing my knee pain or my fibro pain and my fatigue and then the relationship with my mood and my pain, just how I’m doing on there and stuff.

And on there, for example I found one girl who speaks a lot about her fibromyalgia and then she will put other people in her stories who talk about pain too, to help others. She just puts “oh look, this might help you guys, give her a follow” and then you go follow that person and then you can always look at who that person follows, and then you might find someone else who’s really relevant to you.

Recently, I found this girl who’s on a journey with IBS, she’s great, amazing, I haven’t seen anybody just put so many realistic posts about IBS, so that’s brilliant and then from even her, I found other people to follow and then you just build your knowledge more and more about all of your conditions and you kind of learn how so many of them are interlinked as well, especially fibro and IBS, like I’ve recently learned they’re so, so interlinked with one another and even how both of those are interlinked with how stressed you are, how much sleep you get, how active you are and like it’s, you just learn a lot and it just builds up, I guess, from person to person. Before you know it, you've got this whole knowledge form, I guess, in your mind of just different things. That definitely helps.

Int: And the other thing you said was more about feeling like there’s other people there going through the same thing as you.

Do you interact with people quite a lot via the Instagram?

R: I’ve actually made quite a lot of friends, I think we’re going to do a meet up eventually and we’ve all got the same thing and a lot of them do have, for example, one of the girls I speak to, she’s got fibro and IBS and hypermobility syndrome, so I’ve got all three of them as well and I messaged her and said, “I don’t know many people who have got all three together”, so I just said, “it might be really good to talk and see your experience”, so we always talk to each other, we always ask how each other is and yeah, we just relate really well to one another and learn off each other about what helps and what doesn’t.

Int: Okay – that’s good. You say about Googling, compared using Instagram and Googling, what is it you don’t like about when you just search on Google about these things?

R: It just gets very serious and they always put the worst case scenarios on Google, that’s all you're going to find, and I remember when I first started searching, especially about patella alta and it’s going on about how this is a relatively rare condition, it causes all these big complications and a lot of people have you know, extreme pain or they can’t do very much and it always comes up with just some dark horrible conclusion, and I think all that has done for me is just make me feel so much worse.

Also, as well I think, especially when I started [inaudible 00:27:44] so many of the symptoms I get with IBS come up in other conditions, so you find those conditions and you start really worrying and you think “what if the doctor’s missed something? What if they’ve diagnosed me completely wrong?” and that just gives you unnecessary health anxiety, it just makes you worry.

Obviously, you're just interacting with Google so there’s no-one actually interacting back with you whereas on Instagram, you feel like there’s a connection, you just feel like someone’s interacting with you and you're interacting with them. I can’t really explain it, I just think it’s just a lot more helpful to look in real life cases than on what Google’s made it all out to be.

Int: Okay. Do you remember any of these websites that you’ve been on, that you said you didn’t like, that you found on Google?

R: Even like Wikipedia and just random, the NHS website obviously, sometimes the NHS websites can be helpful... but again, they put worst case scenarios and that doesn’t help. I can’t remember all of the other links I’ve been on, I’ve been on a lot, like if you type in for example, patella alta, on the internet, you’ll get a whole section, a whole lot of different websites and I’ve just clicked on so many and yeah, it does scare you a little bit, it is a bit scary, it makes that your condition, not necessarily something that it’s not, it just gives you the worst case scenario that might not even happen if you have the right treatment and you manage it well and you learn how to deal with it, that might not happen. So yeah, I just don’t like the whole darkness of it, it just doesn’t sit right with me, I guess.

Int: Okay, and... you mentioned going on the NHS website and that coming up in the search. Can you tell me a bit more your experience of using the NHS website?

I know you mentioned it for the patella, but you know, for any other symptoms you tried Googling, for fibromyalgia more generally, have you used the NHS website for that and what’s the experience been like?

R: I think, when I first had my fibro symptoms, I typed them in online because I’d had them for so long and I just thought, “What could this be? Because this is making me feel so awful”, and then I found fibromyalgia on there. I was looking at it and I think my mum’s friends got it, so I’d heard vaguely about it but I didn’t really take it very seriously because I think when people say they’re in pain all the time, I just, I feel so bad saying this but I just didn’t take it seriously, I didn’t realise how much it interferes with your life, I had no idea really.

And then I found obviously the NHS page and just reading all the symptoms and it was just all adding up and “could it be something like this?” because it’s not like you can get a blood test for it and the doctors could just miss it. So I booked an appointment and I didn’t mention the fibromyalgia because I didn’t want to put something in the doctor’s head that might not be the case, but when I went to the doctor, I said about all my symptoms and the first thing he said was, “fibromyalgia”, he had just looked at all what I’d been to the doctor’s for previously and I think he just put it together.

Obviously, he was an incredible GP because a lot of GPs would not have caught that straightaway, but then it kind of, because obviously I had done some research on it which I didn’t tell him about, then I thought “Okay, that makes sense now”, and then as soon as I got to the rheumatologist, they just said “yeah, I think it’s this”.

You have like tender points, and I think, I don't know if it’s like 12 to 19 tender points or something like that and they just did a full physical examination and they just go through all the points on your body, and like I was just in excruciating pain in all of them. So I think it was quite obvious and I think the hypermobility as well, that was a confirmation, I think that was my fourth confirmation for hypermobility and they even looked at my knees and they were like, “they’re so unstable”, she couldn’t believe how wobbly they were and I obviously explained about the patella alta and then she explained that a lot of people who have hypermobility and IBS and other joint conditions, are a bit more vulnerable to other pain disorders, like fibromyalgia, so she explained everything.

I also had quite a traumatic event about a week before my fibromyalgia symptoms really started, so she was explaining that sometimes, when you have a very stressful event, they don’t know 100% why but it can actually cause fibromyalgia or it’s very related to fibro. They don’t really know much about it but she just tried to explain the best, why maybe I’ve got it now.

And she did say, at the end, she said “Look, you’ve got a good life ahead of you”, she said “a lot of doctors will say this never gets better” but she personally doesn’t believe that - she thinks that it could potentially, maybe not completely go but get very manageable and you can live like a good life with it. She was really really helpful, and I think the NHS website obviously did lead me to go to a doctor and really try and sort it out and tell him every single symptom that I had, so I think having that is really helpful.

Int: Mm. But then you're more drawn to other social things after that initial Google?

R: Yeah.

Int: Okay. Do you use any other social media for finding out about pain, such as Facebook or YouTube or others have said Reddit?

R: I went on YouTube when I first got diagnosed, I typed in “fibromyalgia” just to learn from professionals because a lot of doctors speak on there about the condition, and yeah, it’s weirdly fascinating, they don't know very much about it, how so many people have got this condition that has got no test for it.

It is fascinating, I could really relate to it. I think that did help and then even things like Pinterest as well, that was actually quite good because they’ve got lots of quotes, and sometimes they’re very relatable as well, just anything that would help me give a bit more understanding and help me relate a bit more, I think that’s why I used YouTube and Pinterest, really.

Int: Okay, okay. Did you look at anything else on YouTube, apart from doctors speaking about it, anything else?

R: I think I had looked at some stories of people who had it and what their experience was and how much it affected them, like I know Lady Gaga – she’s got the condition and so I was really interested, I read quite a lot about how hers started and how she manages it.

I was quite interested in the fact that your mental wellbeing and mental health is so linked to the development of fibro. So many people, and especially her said, she said she started therapy and had two years of it and it obviously didn’t cure her but it helped her so much, she realised her fibro pain was reducing so much and it’s almost like the body takes on so much emotional... distress I guess that you go through, I found that quite interesting, that a lot of people who had traumatic experience happened to them just before or not long before they develop the condition, so I think that gives you a bit of hope that maybe therapy could be a big part, which is why I’m just starting it just now to reduce the pain and fatigue and maybe see if it can make some kind of difference.

That’s where I first found her story, and she’s really open about it on there, and I think there was a story on This Morning as well, there’s like quite a lot of awareness now going about it and I think that’s what YouTube gave me, it taught me that there is a lot of people out there who are suffering from it.

And I think it was after that actually because that’s one of the first things I did, apart from Google, was YouTube, I think not long after that, that’s when I thought; I’ll just make an Instagram for this and see if I can find more people because it’s obviously not an unheard-of thing. It’s quite common, and I was really shocked to see how many people my age actually have it, and especially a lot of people say that before they got it, they were really perfectionists, they had a lot of stress in their life, they were very hard working, they didn’t listen to their body cues, they’re very stressy, very anxious, they had things like IBS already and that’s very similar to my story as well. So yeah, I think that’s why it’s just so helpful.

Int: Okay. So, my next question was how has your use of internet resources changed from when you first started getting pain to more recently.

It sounds like it has changed quite a bit. Do you use YouTube still now?

R: Yeah, I use Instagram more, I do still use YouTube to see other people who have got it and see what’s kinda out there. I think there’s one girl who puts on her experience of fibro and she does like updates and stuff, things like that are really helpful but yeah, I have moved on more to Instagram because a lot of people talk about their pain. They do videos and I think it’s the IGTV thing you can do now as well, so a lot of them will do that. And then there’s this other girl who travels with her chronic pain and I just love looking at things like that because it’s quite hopeful, and she’s got it really severely. She kind of says how to manage your pain and your condition whilst you're travelling because that’s something that’s really hard, believe it or not, when you're on holiday and you're trying to explore and it’s quite exhausting and time differences as well, so just things like that. That gives you a lot of hope that you can actually continue to do things despite the pain, and I don't think I would have got that so much off Google because obviously she’s posting pictures and she’s given a huge amount of information and she’s doing videos and that’s something that’s, you just wouldn’t really get that on just an internet search.

Int: Okay. Thinking not just about the internet as well, but you've mentioned quite a few different coping strategies and management strategies that you've seen.

What kinds of things do you do yourself to cope with any of the pains that you get?

R: Obviously, getting the right amount of rest, that’s so essential. For me, I use heating pads and ice packs, it’s really weird, I use ice packs on my knees, but the heat pads work better on the fibro pain. Again, I think it’s just because the pain is caused by two different things, obviously the knees is inflammation and for me the ice works a lot better on my knees.

That’s huge, that really really helps, especially when I go to sleep because the pain is a lot more… how do I explain it, like you really notice the pain more I guess, before you go to sleep, because everything’s quiet and you're just laying there and you're trying to go to sleep and then the pain hits you, and it’s really hard. That’s one way of managing it.

And I think as well, exercise, I mean I can’t do very much but my physio is really important because obviously, it’s the only activity I can really do, so I try to do it about five to six times a week and then I give myself a break. Sometimes I’ll go weeks without doing it because the pain’s too intense, I can’t do it and that’s fine, I just rest and you just have to be quite compassionate and not get too annoyed with yourself, there’s no point, you just have to rest.

But yeah, activity, a certain amount is definitely needed and getting that right balance of being up and then resting and doing nothing, and resting your joints, sometimes that doesn’t go so well but obviously when it does go well, that’s when I feel like yeah, this is manageable, and you’ll notice being able to walk a bit further and things like that, if you do manage it well.

So I think they’re the main things really, just getting a balance of activity and no activity and rest, for example, and then the heat pads and the cold ice packs as well, really amazing. And what else did I say?... I think obviously as well, the balance, not overdoing it because if I try and walk too much, that gives me a really bad pain flare and it’s like just listening to your body cues. I think that’s a thing that I never used to do and now I do it all the time, like if my body says it doesn’t want to do anything, then I just don’t do it. And it’s understanding that and learning that and just respecting your body’s needs. I think they’re the biggest things really, the biggest things in how I manage it.

Int: Okay, and do you do anything like relaxation or mindfulness exercises when you're just by yourself or on your own?

R: I’ve done the Calm app; I’ve been doing mindfulness for quite a while now. I just forget that, I just seem to do it quite naturally, so even when I’m like brushing my teeth, for example, I’ll try and even do minutes of it where I’m just focusing on my breath and just trying to take, because I think sometimes we try and focus too much on the pain and sometimes if you do that, it gets worse so it’s useful to just be doing an activity and focus on your breath and nothing else, obviously get thoughts come in but you're just focused on the breathing all the time and just appreciate the thoughts that come in.

If I’m in a lot of pain, I’m thinking, “I’m in so much pain that I can’t do it”, then I just keep breathing and like it’s okay to have those thoughts, obviously not everyday of managing this thing is going to be as easy as another day, so that does actually really help. But I tend to be mindful when I’m doing other things, I think that just helps me, like when I’m brushing my teeth or sitting on the train, or in the car, that really helps.

Int: And you said you use the Calm app to help you with that?

R: Yeah, I originally started using it quite a lot, more with my sleep, because I was finding it really difficult to get to sleep because all I was doing was sitting there and laying there, thinking about how much pain I was in and that was not helping me get to sleep. So that’s why I got this Calm app, I downloaded it and I just, I think it’s like 15 minute, 10-15 minutes, and you just sit there and like, I think it’s the guy going through like a load of stuff and you just listen to it.

I haven’t been on it for a while because I tend to do it myself now but that was really helpful, just taking your attention off the pain and listening to what he’s saying and… yeah, that was like amazing and I think after doing it so long on the app, you just kind of get used to the whole process of it and you start doing it yourself, so that’s what I kind of do and I’ve got in quite a good habit.

Int: How long would you say you were using the app to help you with that before you then started being able to do it yourself?

R: Probably like three to four months, this was like every day, I was using it every night more like, three to four months and then eventually you just get into like the habit, I guess. You know what to do and it just becomes second nature, so it’s just something like I’ve incorporated and it does really help alongside all the other things I use like the ice packs, the heating pads as well, all those things together does make a difference.

Int: Okay, that’s good. Have you used any other online resources or websites, apps to help you cope with the pain?

R: Um... I don’t think I have; I think it’s just that app and then obviously my little Instagram thing that I have as well. There’s another thing that I was looking into and I can’t remember what it’s called now, it’s so long ago I was looking at it, it’s quite expensive, it’s like a... I can’t remember what it is but it’s like a box or something that can actually help you with pain and I don't know how it works, whether you put these things on you and it like vibrates or something but I can’t remember what it’s called, but I’ve seen it on Instagram and I know some people with chronic people use it and have said it’s really helpful but I remember looking at it months ago and it was just so expensive, I was like I can’t, I could save up for it but I don't know if it’s going to work sort of thing. It’s really annoying me because I can’t remember the name of this thing that people use but that was another thing that I’d found.

Int: Not a TENS machine?

R: Yeah, it is, it’s a TENS machine! Yeah! That’s it. Again, I don't know 100% how it works but I had heard quite good stories about it and I was thinking of saving up for it to try it, and then like I said I was like if it doesn’t work for me, then I’ve just wasted so much money so I’m kind of, it’s still something I read about now and again if it comes up on my Instagram feed and it might be something I’ll look to try later on, but yeah, that was it [*laughs*]!

Int: Okay. How about offline? Have you had any other advice about your pain and managing it from your friends and family?

R: A lot of my friends, to be honest, haven’t really understood. Some people have said, like there was one girl who has her own little business or something, I don't know what it is, but she gives out all these nutritious products like capsules and stuff and she said, “this might really help you” and I said, “Look, I’m sorry, but I’m not really willing to try anything else, I eat really well, I’ve changed my whole diet”, which has helped with fatigue and stuff, not so much pain and I was like, “I don't think these little capsules are going to cure my pain”, I said it as nice as I could.

I don't think people really have a massive understanding of it and I’m not going to lie, before I got diagnosed with this and before I had chronic pain everywhere, I didn’t understand completely, I think you don’t understand it until either you’ve had a lot of education about it or you’ve got it yourself. A lot of my friends haven’t really been the best with my pain, they haven’t said too much, I don't think they know what to say because there’s not much there can say, I guess.

Int: You said before, of course, you have your other online friends who you’ve talked to on social media and things?

R: Yeah, those people, they’re giving me some advice, a lot of it, I think one of the girls was saying about the TENS machine, she was looking into it as well, so we were talking about that, that was like a few months back. With the IBS pain, people have given me tips, some people even try ice packs on their tummy and said that really helps. I don’t find that very helpful and even food as well, some people say, “it might not be the same for you, but this gives me a lot of pain”, like a lot of dairy products give people pain. I’ve not done too much with eliminating things out of a diet, not until a doctor says to do it, but I have reduced my dairy a little bit and that’s helped my IBS.

I’ve looked into even this FODMAP diet, a lot of people put information about it and again, I wouldn’t do it until I saw a doctor but I have looked into it and it does make, I have noticed that some foods that are supposed to be high in FODMAPs do cause my bloating and pain, so that is definitely something I’d speak to a doctor about in the future, to see maybe if I can try a low FODMAP diet and see if that can help my IBS pain. That I got off Instagram and people posting about it. One girl is on the low FODMAP diet, so she was talking about that to me as well, that was really helpful.

So yeah, they do say a few things, a lot of it is getting the right balance in your life and everyone I’ve spoken to has said that’s the best you can do, to try and get balance. A lot of them don’t have full time 40-hour a week jobs as they know that’s going to flare their pain up and their IBS and they just said, “I can’t do it, I have to find another way, and I do this and this”, one girl has her own business and said, “ For me, I’ve just made it work a different way”, I have had a few tips and I think getting the right balance is the most helpful thing at the moment.

Int: Okay, okay. Overall, which internet resources would you say are the most helpful?

R: Definitely the Instagram one, that little community is so amazing. I don't think you’ll get that anywhere else. Obviously there’s probably things on the internet, support groups, but I don't think there’d be anything like this where you’ve got pictures and constant updates and videos and just people talking to you all the time and lifting you up, that obviously is the most helpful thing, I think.

Int: Okay, that’s good. Which internet resources have you found... have you found any that were unhelpful, and why were they unhelpful?

R: Wikipedia is not the one. Not to say that it’s not valid information because I’m sure some of it is but again, it was just full of the worst-case scenario, sometimes the NHS does that a little bit on their sites, even though they are good and have helped me. Wiki wasn’t great, but there are a few others dotted around on there that just give out worst case scenarios and that’s not what you want because you're not in a worst-case scenario, you're at the beginning of it, you've just got a diagnosis; you haven’t deteriorated so badly that you're on death’s door sort of thing!

You want things that are going to be a bit uplifting, I guess, not unrealistic but just in the sense that you can live a normal life and you can manage it with this, this and this. You don’t really want something that’s going to make you feel worse.

Int: Yeah, that’s understandable, completely.

Thinking about any of the online resources, your websites, apps, all of it, is there anything else that you think would be helpful or perhaps would have been helpful in the past for managing any of your pain conditions?

R: I think earlier, I said the mindfulness, that’s just become second nature to me, that does help, especially with sleep and stuff. The ice packs, the heat pads, finding the right balance in your life, 100%, not overworking, really managing your stress, stress really flares me up because when my anxiety is really bad, it has been for the last few days, the pain will be so excruciating, like 100% that stress and pain and so linked with this fibro thing, so that is something I’m working on, just managing stress, managing my time, not overworking, so with my work shifts, I would not do more than 20 hours a week at the moment because physically I can’t and that is what it is.

Just accepting, not comparing yourself with either, with others who don’t have what you’ve got, that’s been a huge thing for me as well, just trying to accept your reality and I think acceptance is like the biggest thing.

Int: Okay. With any of that, is there anything online that you have been looking for that you wish was there, but isn’t there?

R: I think with my knees more so, I can’t find anybody else who has what I’ve got at my age which isn’t great because no-one can relate to me with this knee thing. Where suddenly I can be okay for a few weeks, I’m in a lot of pain but I can walk and I can do things and then suddenly, I can’t walk at all and I have to use a wheelchair. That, I wish there was something on Instagram or someone did something just to kind of make… because there must be more people with this knee condition out there, that would be really helpful, to have a bit more information on how to manage that.

I’ve got so much information on my fibro, my IBS, my hypermobility, there’s so much out there but on this knee thing, there’s like not very much at all. The private physio is the best thing for that, he knows quite a lot but other than that, there’s not enough information on it.

So that would be amazing, to have more, but for the others, I found this IBS Instagram page and this girl is so good, I can really relate to her and she makes me feel so much better, like I even got in a bikini over the summer, I felt a lot better in it even if I did have a flare up because I thought, “it doesn’t matter.” It’s not normal to have IBS pain, no pain is normal, but people get bloated, it’s fine, there are lots of people with IBS and I realise how common it actually is, a lot of girls were saying how bloated they get and her bloating’s huge, it made me feel a lot better.

I think the biggest thing is just my knees, having more information out there about it.

Int: Okay. That makes sense with everything you’ve said, yeah.

Is there anything else you'd like to add to anything you’ve said about your pain and pain management or about online resources, apps and websites?

R: Yeah, I think we just need a system where people get more support emotionally with the effects of their pain on their everyday life, because obviously I’m going to therapy now, but that’s a thing I didn’t get. I think it’s so bad how a doctor can just say, “you're going to be in pain for the rest of your life, you have this condition that’s going to progress”, and what? Like, in 30 years, I’m not going to walk sort of thing?

They don’t tell you that, obviously, but they don’t give you a very good picture of it all and then they send you out, you're young and you've got to process that all yourself and there’s no follow-up or anything. And I think that’s one of the things that would have helped massively with just managing it because it’s not just, “oh I’m in pain”, you don’t add pain to your life. It’s like you have this pain and it just affects everything in your life, I couldn’t dance etc., I would have liked some help, I think, psychologically with the adjustment, that’s the biggest thing that needs to change.

Int: Okay, yeah, that makes sense. Unless there’s anything else you want to add onto that, that brings me to the end of the questions.

R: No, I think that was it.

Int: Yeah? Okay. That’s the end of the interview, thanks very much, I’m going to turn off the recording now. If you’ve got any questions for me, you can ask me off the recording as well, that’s absolutely fine.

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