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ANONYMISED

Int[[1]](#footnote-1): Just to double-check then that you’re still happy to go ahead, you’re still happy to be audio-recorded for this?

R[[2]](#footnote-2): Yeah, I’ still happy.

**Int: Good, great, thank you. And just a note as well – because my screen’s over there, which has got my prompt notes, I might be looking over there but I’ll still be listening to what you’re saying, okay.**

R:That’s fine.

**Int: To start off with then, do you think you could tell me a bit about your experience of chronic pain?**

R: Well, I did get diagnosed officially on Monday with EDS, but I have had issues sort of surrounding chronic pain like in my joints since I was, probably since I was quite young but it only really started to become a problem when I was sort of around 12. So, it’s been like four-years now since it really kind of became worse, as it were.

Int: Yeah. Oh! That’s good that you got the diagnosis on Monday. I mean it’s good and bad, right? But I’m glad to hear that now you know what it is you’re dealing with.

R: Yeah, of course, that’s the main thing.

Int: And so, did you say it was about 12, when it first all started getting worse?

R: Yeah.

Int: Okay. Could you tell me a bit about what it was like when it first started compared to more recently?

R: To be honest, it was quite isolating really because I mean I didn’t know anyone else who had problems like this. At that age I didn’t really know that it was abnormal, even, I mean I didn’t really have any way of knowing whether it was normal or not because it was normal to me, so it was quite, once it got like worse-worse it was kind of like, “Oh, maybe this is not right” and it was kind of like scary not knowing.

Int: Yeah, and has how you’re feeling about it changed now or not really?

R: I’m not really as kind of worried about it now because I know the cause, I know that there is support, so I’m kind of better with that now but it still is kind of like, there’s always that worry that people won’t understand and stuff.

Int: Okay, and you talked about two different things there really, one thing about how you feel about it, like your mood and your emotions surrounding it, and the other thing being more the social side of things. Could you expand on either of those a bit more for me?

R: Well, socially I’ve never really had any... my family haven’t been the most supportive at times. I haven’t really had friends who have understood at all, I mean I can’t really blame them, I mean it’s quite hard to understand, really, but it did make me feel quite lonely not having like people around me who understood.

Int: Yeah, and in terms of your social life, has it impacted how your friendship groups are? Have your friends changed?

R: I definitely think it has impacted that. I mean in secondary school I really did struggle to maintain friendships because there was like, I was having like, problems with chronic pain and I was kind of like that one weird kid, you know? I just kind of felt like isolated from everyone else, like I was different maybe. So, it was kind of hard, like my friends were always like not understanding either so it was quite difficult in that respect.

Int: Okay, and how about other aspects of your schoolwork, did the pain affect those in any way?

R: To be honest, the pain really does affect it a lot. Especially at the moment, it really is kind of, like that and my other symptoms that come with my condition, they really do kind of negatively impact it. I mean my attainment at the end of primary school, before I began to get worse, I was literally like the highest kid in the class from SATs, but now I’m literally sat on grade Es in my A-Levels at the moment, it really is a struggle.

Int: Yeah, that’s difficult. Yeah...

R: Yeah - it’s the frustration of knowing that I’m able, like mentally, but then the pain kind of limiting me.

Int: Yeah, I get that. And, is that more to do with your physical ability to be able to do things or is that a concentration thing, or tiredness, what do you think that is that’s making it…?

R: I think it’s a combination of all of that really. I mean the pain makes it more difficult to focus of course, I mean there are techniques like trying to ignore it and stuff but sometimes if it is severe, it’s just impossible to ignore it and kind of like do everyday things to like schoolwork and stuff.

Int: Yeah, and you mentioned as well about the other symptoms that you get with what you now know is EDS, what are some of those? Can you describe them to me?

R: I get quite, I get subluxations in my joints, so they do partially dislocate. I do kind of find myself walking down the like corridor at school with like my bags and the weight of my bags pulls my shoulders out of the sockets, so it is like, kind of like frustrating because there’s nothing anyone can do about that as well. And then I do get quite bad brain fog which affects my concentration as well. I get headaches a lot, which obviously affect concentration as well, a lot of neck pain. I get a lot of muscle cramps, especially in my hands if I write. Yeah, it’s hard to list things on the spot, you know?

Int: No, that’s fine, it’s a lot of things to try and remember as well, it’s got so many things associated with it.

I mean it sounds like you’re still going into school and things, what about your day-to-day physical abilities? Just day-to-day things that you do, general activity, how’s that and how does the pain affect that?

R: I would say it does affect it quite a bit because I kind of worry for when I’m an adult, you know? I mean I get free travel as a child but when I’m an adult I’m thinking I can’t walk very far, so it’s, things are going to cost me so much more and that’s a worry because obviously I’m not as able to do as much or participate with things as much.

I mean I’ve tried pushing myself like I tried to go to a taekwondo class with a friend as like a social thing and it was a really bad idea. It kind of makes me feel really isolated with that, yeah. I mean I struggle to, I’ll be honest, I struggle to shower myself sometimes. Sometimes I do skip a few days between showering because it’s just exhausting, and I feel like that’s kind of gross, but I can’t really help it.

Int: Yeah, and you’re not alone in that, a lot of people say similar things with EDS and pain conditions. So, it’s affected you a lot then and you mentioned a few times about it being very isolating.

R: Yeah.

Let’s talk a bit about medical advice that you’ve had, okay? So, could you tell me about advice that you’ve had, either recently or a few years back, from any doctors [or nurses...?]

R: [To be honest], the advice I’ve had is awful. I’ve been sent to physio, that’s about it but the physiotherapist I’ve been sent to literally has no knowledge of EDS so they’re just kind of like, even the doctor last week said, “Basically no one knows what to do with you” and I got told that I need to see orthotics and that I need better pain management but then no one will refer me anywhere and the only places they could suggest were private, which obviously I can’t afford to pay like £600 for one appointment, you know? Like most people can’t, so, the kind of support has been kind of poor, to be honest.

Int: Okay, so that comment about “not sure where to send you”, was that a GP or a consultant doctor?

R: A consultant basically said that no one actually knows what to do with me or people with like EDS and similar things because there’s not really a, there’s not really treatment as it were. I mean it’s more like looking at symptoms and then trying to reduce them, as opposed to actually treating it. There’s not really been a lot of support for that either.

I mean I’ve never been trialled on any kind of pain medication, nothing, and I don’t think it would be beneficial for me but at the same time, it would have been nice for someone to sort of offer some kind of like support in that kind of respect.

Int: Yeah. Have you attended any physio with the hospital or through NHS?

R: Yeah, yeah, I’ve been going for over a year now. Obviously, I haven’t been able to go for the last kind of like 8-months like in-person, but I’ve had like video calls with them.

Int: How have you found that?

R: To be honest, it’s just the same thing every time. It’s not really, I don’t really find it helpful because I’m literally doing these same exercises that are not making a difference for me. I’m persevering with it and I’m just going with it in the hope that it will eventually kind of help. But, it just kind of feels like everything I’m told just doesn’t help.

Int: Okay, even though you’re attending regularly, and you’re doing the exercises at home as well?

R: Yeah.

Int: Okay. And, what about anyone else, someone more like a psychologist? Have you seen anyone like that and spoken to them about the pain and managing it?

R: Recently I’ve been seeing a counsellor, through my school, about it and that’s quite helpful. It’s just kind of an opportunity for me to talk about it and explain how I feel which does kind of help because then I feel heard and stuff.

Int: Yeah, and do you talk about the pain and things that go with the pain, specifically?

R: Yeah.

Int: Okay - that’s good. Was it the school who recommended that?

R: Kind of, I mean I was kind of having a difficult time with everything and it was just quite overwhelming so I, someone, one of my friends recommended to me that I should because like the lady who runs it is really lovely, so I signed myself up for some sessions. I just thought it would be a good idea to kind of... help myself, you know?

Int: Yeah, I mean it sounds like you’re having an overall positive experience with that?

R: Yeah.

Int: Okay, good. What about anyone else such as an alternative therapist or a different sort of specialist? Have you seen anyone like that about it?

R: No, I literally don’t know any that are not private, so it’s not really an option at the moment.

Int: Yeah, you do find that with alternative therapies in a lot of areas.

R: Yeah, because I mean I’d love to see like a chiropractor or an osteopath or something because so many people say about how helpful it can be but like none of it’s really offered on the NHS so…

Int: Mm. Could you tell me [Name], did, with the EDS diagnosis, do you know whether you’re still under paediatric or child healthcare or whether you’re under adult?

R: I think I’m still under paediatric, because I was referred to a paediatrician just before I turned 16 and I think if you’re, most services if you’re referred before 16 you stay until you’re 18, so I should still be on there until I’m 18.

Int: Okay, yeah, I’m just trying to get a clear picture of what might have been suggested.

R: Yeah, I mean I’ve only ever seen paediatrics once so…

Int: Okay. And, in the past, when you’ve been trying to find out how to deal with the pains that you’ve been getting, who or where would you say you’ve turned to first?

R: I know there’s a big community of people with similar issues on Instagram and I’ve got quite a few online friends on there, of similar age, from around the UK and we all kind of just help each other out really.

Int: Okay. And, is that for support or information or advice?

R: I think a bit of everything really, we all kind of look after each other. If someone wants some advice or to ask a question, we’ll all kind of do our best to help each other out. I mean it’s a lovely community really, it’s been such a big help to me to actually have like people online because I mean not many people I know in real life, like in person, actually get it. But, obviously like connecting online with people who do makes it easier.

Int: Yeah, it’s interesting about Instagram, do you use Facebook or anything like that as well, or not really?

R: I’m on some groups on Facebook but I don’t really post on them or talk to anyone on them, they’re just not really... yeah, I find it hard to keep up with them and stuff because there’s so many people, and it’s mainly all adults on there, like older adults. So, it’s kind of hard to relate to any of them.

Int: Mm. And, why do you think it is that you’re drawn mostly to Instagram for the chronic pain type things?

R: I mean I just feel like Instagram is a place where people share a lot of things and like a lot of people I know, like I don’t know how to explain it really, we’re all just kind of on Instagram and we’re all kind of in a similar situation really. We’re all just kind of looking for support and maybe advice, so I just kind of, I mean Instagram it’s easy because there’s like DMs, you can post on your story and ask people questions and stuff as well.

Int: Okay, so it’s not just looking then, you’re also interacting with other people?

R: Yeah.

Int: Okay. Any other social media that you use to either find out information or seek support with the chronic pain?

R: I go on like the EDS website and stuff sometimes. I am on one of their Facebook groups, sometimes I’ll have a flick through but there’s not, they don’t really post much on there at all on the kids’ group so there’s not really much there. There’s like one post a month and no one on there seems to really interact with it either.

Int: Okay, and what do you make of the EDS website?

R: I like it, I mean it’s, all the information is kind of there, and I’m pretty sure on their website they’ve got like resources that you can send to schools or like dentists and stuff for like advice on like just everyday general things with EDS and stuff. Because not everyone is going to know about it or understand, so it’s good that there’s kind of like resources to kind of like educate people on it.

Int: So, not just information for you, for other people around you as well?

R: Yeah, like family members, teachers, whatever.

Int: Have your friends and family tried to give you any advice about managing it?

R: Not really. I mean some of my friends online have, I mean they recommend stuff like icepacks or just general kind of techniques to kind of like make things easier and stuff as well.

Int: Yeah, if you wouldn’t mind, I’m interested in what sorts of things people have recommended online, which things you’ve tried that you’ve seen online or spoken to someone about online?

R: Well, the first thing that comes to mind is like in my shower I’ve got handles that are like suction-cupped to the wall. I mean they really help because I’m not like unstable, but I do get dizzy sometimes, so it is kind of scary standing in the shower thinking, “God, what if I like fall?” cause it’s just embarrassing so that’s actually a big help even though it’s like a small thing that someone mentioned to me. Mainly, a lot of the stuff that I’ve been recommended is like support in school, so like a lot of my friends online have been like, “Oh you should ask for permission to use a keyboard” and stuff and that’s made things a lot easier especially... It’s hard to think of things right now.

Int: It’s okay if you can’t remember.

R: Yeah, just general things like even down to like pen grips and stuff, small things.

Int: So, practical things?

R: Yeah, small things that you wouldn’t think would make much of a difference, but they kind of do.

Int: Yeah, that makes sense, okay.

Do you think you could tell me a bit more about any other resources you’ve used to find out information about the pain or about EDS from the initial Google search?

R: Definitely a lot on like Google searching. When I went to the doctor’s last week, they told me to go on to the GeneReviews website. It’s like a bunch of random letters with dots in it that’s the website, and I have no idea what it’s called but I’ve had a long kind of flick through there. Sometimes, if like, because obviously EDS is a connective tissue disorder, so a lot of different things can be affected. So, whilst it’s probably terrible to Google when you notice more things, the first thing I think of is, “Google this and see if it’s like related” or if it could be a big problem, because, I mean I don’t like bothering the GP, so I actually prefer sometimes just to Google things just to make sure it’s like, just to kind of like reassure myself really. Because I know people say when you Google headaches it comes up with brain tumours and stuff, I mean it’s not really like that in my opinion.

Int: Yeah, it’s moved on a bit from that.

R: Yeah.

Int: Okay, and what do you think you’re hoping to find when you’re searching on the internet like that?

R: I think part of it is like the need to know that I’m not the only one and that I’m not like really weird. Because like sometimes I notice weird things and I’m just like, “Oh my god, this is so weird” but then I Google it, and Google’s like, there’s like a bunch of people who have put on like websites about it and it’s like linked to EDS or something like that and I just think, “Oh, so it’s not that weird” you know it’s just kind of like reassuring.

Int: Yeah. Have you used the NHS website at all to look-up things about pain or about EDS?

R: Yeah, I mean I’ve had a look on there about like, obviously on the EDS page, I’ve been on, I’m pretty sure they’ve got like a couple of pages on like alternative kind of therapies. I mean I’ve had a kind of flick through those just because I kind of want to try them out and they seem interesting to me, they might help. I mean generally, the majority of the stuff I Google is just me trying to find ways to help myself. Because I almost feel like with the lack of treatment and support, I feel like if no one else is going to help me then I’ve got to try and work things out myself.

Int: Yeah, so looking for that more self-management advice, yeah.

R: Yeah.

Int: Okay, what do you like about the NHS website, or what do you dislike about it?

R: I like it because sometimes like I find that reading large blocks of text is quite difficult to concentrate on sometimes because of the brain fog. So, like the fact that it’s all kind of broken down into smaller bits and it’s not too much information is good. But then again, it’s annoying when some of the information that I would think is kind of important, it’s not on there.

Int: What kind of things?

R: Like there’s a lot of co-occurring things that can happen with EDS, but I don’t think any of them are actually listed on the NHS website at the moment.

Int: Okay, what about other similar health advice websites like Healthline or WebMD, have you been on any of those?

R: I don’t think I have.

Int: Okay. And the other thing I wanted to ask you was whether you look on YouTube for either advice or support with the chronic pain?

R: Yeah, I do watch, I can think of like one YouTuber who I do watch sometimes. I mean some of her videos are quite informative, but they’re not like serious or anything, so it’s more like relaxed as it were.

Int: Mm. And you follow that regularly?

R: Not regularly, I wouldn’t say regularly, I mean I don’t really watch YouTube that much, but I’d say like maybe once a month I’ll have a look just through YouTube and it usually comes up and I’ll have a look.

Int: Okay. And is that a channel by someone who has pain themselves?

R: Yeah.

Int: Okay.

I’m going to skip back a bit just to a question that I skipped over, to ask you a bit more about self-management. What kind of things do you do yourself to cope with the pain, when you’re just by yourself?

R: I mean I’ve tried massaging, I’ve tried like, I’ve tried like hot and cold kind of like creams and gels, like freeze gel, Deep Heat, you know I’ve tried that kind of stuff. I’ve contemplated getting a TENS machine but they’re kind of expensive.

I usually try and distract myself as well because like distraction can be really helpful. So, sometimes I’ll listen to music or like try and watch a video or something, like on Netflix. I always make sure that if I’m like having a hard time with pain, that I make sure that I’ve got everything kind of sorted in advance. Like for example, all of like my schoolwork is ready to go in the morning so I don’t have to kind of panic and worry and then like overdo it, make myself worse. Yeah, that’s all I can think of at the moment.

Int: That’s okay. What about things like relaxation or mindfulness, have you tried any of that to help with it?

R: Yeah, I’ve tried meditation. I do meditate from time to time - I just try and like clear my mind and relax. I usually do it at least once a week, just to like relax.

Int: Do you use any online resources or apps to help you cope?

R: Other than the Instagram community, no.

Int: Okay, I’m thinking things like Calm and Headspace, any of those?

R: No, I’ve never used any of those. I mean I did try a few years ago to use one of them, but I didn’t really find it helpful for me personally.

Int: Okay. And what about medication and managing that, do you take much medication for the pain or not really?

R: I don’t take any, I mean the NICE guidelines on chronic pain changed, not too long ago I’m pretty sure, so even if the pain did continue to get worse, I would actually be reluctant to ask, you know? Because I mean there’s already kind of... I do feel like there is a stigma especially with like EDS and stuff and it’s kind of difficult if someone wanted to fake it, so I don’t understand why there are so many professionals who just don’t believe it, you know? So, I feel like I wouldn’t cope very well with someone kind of saying things like that to me, so I just choose not to put myself in that position in the first place, so I’ve never really asked for any kind of medication or anything. Because I had like chronic headaches and after like the third time of speaking to the GP about it, they kind of gave me a week’s dose of Naproxen just to kind of shut me up basically, that’s what it felt like. So, I haven’t spoke to the GP since that actually... because it just kind of feels like I’m being dismissed, again.

Int: Yeah, did the Naproxen help you at all?

R: No, I don’t think medication would really help me. I mean maybe I just haven’t found one that’s right for me out of ones I’ve tried, but I don’t feel like it’s something that would help me a lot really.

Int: Okay, that’s understandable. You say you use heat and cold packs, do you find that helpful?

R: Yeah, I do get Raynaud’s in my hands though, so if I have hand pain, I can’t really use hot or cold because it does tend to trigger that and stuff, like I don’t do too well with temperature changes. So, there are kind of like contradictions with some of the things.

Int: Yeah, I was just about to ask you actually if you’d had any problems with any of the coping strategies you use?

R: Yeah.

Int: Any other problems that you’ve come across?

R: Sometimes when trying to do mindfulness, or like distract myself from the pain, sometimes it is just too much, and it is pretty much impossible to take my mind off of it, at all. So, sometimes the only thing I can do is try and sleep.

Int: And is that what you would do to overcome the problem, just try to go to sleep?

R: Yeah.

Int: Okay.

Moving back to internet resources, so the main one you’ve spoken about being Instagram, which internet resources have you found the most helpful and why? Although I think I know the answer to this.

R: Yeah, I think Instagram definitely because there’s like actual people my own age with similar situations who I can actually relate to, we can share kind of advice, strategies, support each other.

Int: And, what about internet resources that you’ve found, if you’ve found any that were unhelpful, and if so, why?

R: I can’t really think of any in particular. I mean if I click on one and I think it looks a bit dodgy I just won’t even bother, so I mean the only ones I really use are like the EDS website, NHS website, just the kind of main ones that I know I can trust, because I don’t want to be feeding myself false information.

Int: Yeah, okay, and thinking about any online resource, be it a website, an app or anything online, is there anything else that you think would be helpful or perhaps would have been helpful in the past for managing the pain?

R: Even if there was like a whole app just like for people with chronic pain, like a Facebook but for people with chronic pain. Because I mean there’s other apps for other things that are similar to Facebook for like specific things, like the neighbourhood kind of thing, I think it’s called “Nextdoor” and it’s literally like Facebook just for people who live in like a certain area. If there was something like that for chronic pain or chronic illness, that would be great because then everyone’s kind of on the same page.

Int: Yeah, and do you think any sort of chronic pain or more specific to EDS and hypermobility, what do you think?

R: To be honest I think any, because we all - the fact that all of us on the community have some kind of pain, we all kind of have that basic knowledge of what that’s like and I don’t think there’s like that many people with EDS and I feel like it’s kind of like, to separate people with different things, even though we all have chronic pain, I think it would just make things complicated.

Because I think it’s nice to learn about other people and their experiences as well, like I feel like I’m educating myself because I feel like prior to actually getting worse, I feel like I didn’t fully understand like certain things that can affect other people. Like for me, I think some of my friends who don’t have any issues, they struggle to understand why someone who looks young and healthy might need to sit on the bus for example. So, not quite that but people with other conditions who might have difficulties that I might not understand, it’s just nice to kind of educate myself so that I can try and be more inclusive with people who I talk to.

Int: Yeah, so a wider, much wider community?

R: Yeah.

Int: Okay, that makes sense.

Alright, do you have anything else you’d like to add to anything that you’ve said, either about your experience, or about online resources?

R: I don’t think so, I mean I think I’ve pretty much covered everything.

Int: Yeah, I think so too.

That comes to the end of the questions, so I’ll finish up there, and then I’ll switch off the recording. If there’s anything else you want to ask me off the recording then you can do. Thank you very much.

R: Thank you.

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