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ANONYMISED

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

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

Int: Great thanks. You can probably see from my glasses, my screen is over here with my question prompts so if I’m looking over there, it’s not me answering emails or something, it’s me looking at the questions. I’ll still be listening to what you're saying so don’t worry if I’m looking between the two.

Do you think you could start by telling me a bit about your experience with the chronic pain that you have?

R: Okay... I think to begin with the chronic pain, it was bad, but it wasn’t, it got worse as I got older and... not just having the chronic pain, but the chronic pain, EDS actually caused me to have more like problems with my body as well, like for example, because of the EDS, it’s affected my eyesight, which is... recently I had eye surgery.

I think probably one of the hardest things with EDS and any chronic kind of pain is the experiencing and not – because it’s invisible, nobody can see it, and no-one can tell you, “you look ill” or when you feel unwell, so it does lead to a lot of misinformation and... judgement.... and I don't think that there’s enough kind of education for people who don’t have it, and don’t understand it, about it because I had like friends and family, people that don't think I’m ill, I can even say “I have this, this and this” but because I look healthy all the time and okay, they would believe but they wouldn’t really believe it was up there, was that serious.

Int: Yeah, yeah. I think a lot of people do experience what you're experiencing with that, you're certainly not alone in that.

And, how old were you when you first started getting the pain?

R: I think I was around 7 or 8, maybe. The memory, I remember the first time it all went downhill with the pain was when I was at a friend’s birthday party, I was on a trampoline and I was bouncing on the trampoline, and then my ankle just sort of semi-dislocated and then, after that, it just got worse, more joints and ankles dislocating and went downhill from then.

Int: Okay, okay. Remind me when it was, how old you were when you ended up being diagnosed with EDS?

R: That was, I think, 15/16 and that was by the paediatrician. And a lot of, with the diagnosis, a lot of the doctors had no idea, didn’t know what… it was only really because me and my mum and my family, we did research about my symptoms and everything like that and then we just asked the doctor, “Could it be this? We fit all the symptoms, could you investigate that?” and when they did investigate that, it then turned out to be that.

Int: Okay. You said a little bit before about friends and family and people not understanding...

R: Yep.

Int: Would you say pain affects your social life and if so, how so?

R: [*laughs*] It affects it a lot to be honest. There’s been so many times where I’ve missed going out with friends, constantly just because I’ll wake up and, in the morning, I’ll be in so much pain. Sometimes it would last the whole day, sometimes it would just be in the morning, and it’s bad, it’s really bad.

Int: Okay, and... How about your physical abilities more generally, apart from just the pain itself, how does the condition and the pain affect your physical abilities to do things?

R: It does affect it, it’s weird because it does affect it and not drastically, but it does affect it to some amount. I’ve been to... My hands are one of the things that really hurt a lot and I have kind of like arthritis type pains in my hands, I’ve been to physiotherapists and tested my hand strength with them and they’ve said, “nothing wrong with your hands”, it seems strong enough for them but for me, it’s really weak and… yeah.

Int: Yeah, painful?

R: Yeah, so much. I wake up every morning, maybe 99% or 95% every morning I have to click some of my joints back into place and it is painful.

Int: Yeah. How do your pain and your symptoms compare to when you very first started experiencing pain, to how you are now?

R: I think.... I think at the time when I was younger, it didn’t feel so bad and I kind of gave in too early I feel now, I feel now that I could have… maybe tried harder but I just kind of thought, “I’m in pain, I’m not going to do anything, I’m just going to rest” but I feel like now I’m older, I could have maybe tried more and, even though I was in pain, I could have done more to try and feel better.

Int: Yeah, yeah. Okay. Do you think that pain’s affected your school and university or work life and how so?

R: A lot. I missed so much school to the point where I had to have meetings with teachers because if I didn’t start attending school or sort something out, they would actually refer to prosecution because I’m not going to school. I think because... It was really frustrating because there were other people at school that didn’t have the same, any chronic fatigue problem, but they had some problems like one person had cancer and stuff like that, and the school kind of went with “if this person can come to school and do this, then you should be able to and there’s no real excuses”.

So, I missed so much school, a few of my GCSE exams, I had to take some of them at home and I didn’t get the best grades in them, because I missed so much school. I didn’t do any A Levels as well. It’s drastically affected my education.

Int: How about your mood and emotions? Not even independently as a result of everything else or on its own, how does pain affect those?

R: A lot, like with motivation, with the pain, it drastically affects motivation. When you're in so much pain, you just don't want to do anything, you just want to lay in bed. If I had zero motivation, I would probably just be in bed.... all day almost just because constantly I’m always in pain. If I could just do nothing, I would do nothing and rest because even though it doesn’t help so much, it just... it feels more bearable than doing things because doing things, little things, even that puts more strain on my body and more pain.

Int: Yeah, yeah. Do you work or anything like that?

R: I don’t, no.

**Int:** **It’s okay.**

R: It’s quite hard for me to work with all my joint pains and also the last two years, two years ago I had a sleeping condition as well, no idea if it’s related to EDS or chronic fatigue, but I was sleeping almost all day a lot of the time and I just couldn’t wake up as well. I went to hospitals and they did sleep tests and all sorts of stuff like that.

Int: Okay, okay. So possibly related but you're not too sure?

R: Yeah. It does definitely, the EDS does affect my sleep to some extent... because I do feel a lot of pain in the night and it is hard to sleep.

Int: Okay. You mentioned physiotherapy before, can you tell me a bit more about advice that you’ve had from doctors, nurses, physios, psychologists, any healthcare professional that you’ve seen about it?

R: I think with physiotherapy, it’s a lot of hard work, and I think at a young age, I should have... gave more effort? With physiotherapy, but it is very hard work. The first physiotherapist I had was really great, encouraging and helpful... but there’s other physiotherapists which are helpful but they’re also, they do push you a lot and it can be quite hard.

I remember when I was, I think, 13 or 14, I went to [hospital] for a physiotherapy rehab kind of thing, where they had loads of people who had chronic fatigue issues and stuff like that, where they had a kind of group physiotherapy and that was good, but it was really hard work. Really hard work. I do feel like if I had that, could have that more regularly, it would be a lot better because it is really hard to motivate to do physio and also when you're in pain, it’s even more hard to do it.

Int: Mm. Is that the one where you stayed nearby the hospital for the physio?

R: Yep, in London, yeah.

Int: And you found it quite intense…

R: I found it intense, well it was really rewarding by the end of it and I kind of wish I didn’t have to go, if I could do more, because it was really good and helpful, it’s just a lot of hard work. It was almost like a kind of bootcamp, workout, because they’re really strict on you and forcing you to, yeah.

Int: Okay, okay. What about advice from other doctors and nurses, psychologists, anyone like that?

R: A year or two ago, I went to see a physiotherapist about my hands because they were really bad and I was a lot disappointed with... their kind of help because they did do tests and stuff like that but not that much, just like strength tests and things like that. By the end of it, they were just like, they’re really sorry but they can’t really see what’s wrong and that’s it, pretty much. Nothing else, no referral or anything like that. I was kind of disappointed at that because I was hoping maybe they could refer me to rheumatology because that’s to do with the hands, that could maybe help more, or even an x-ray or anything like that, but they just said, “Your hand strength seems fine” and that’s it. That was disappointing.

There was also with my eyes, the vision is really bad, because I have a condition called keratoconus?

**Int: Mhmm.**

R: And that basically means the shape of my eye is not right, it’s like a cone shaped, I think or something like that and I went to [hospital] for an eye exam because the optician recommended it and the doctor that we saw there, I don't know how he came to his diagnosis but he said my eyesight was fine, even though I had 50% vision, he did eye test after eye test and said it was completely fine.

It was just kind of worrying how that doctor got into that job if they can’t even tell that, because immediately, we asked for a second opinion and they diagnosed me with keratoconus and said I would need surgery, cross-linking surgery, and in the future, I’ll have to probably have a cornea transplant.

Int: Mm. So that was recent as well, the eye surgery?

R: The eye surgery was recent but that was a different surgery, when I spoke to the doctor at [hospital] which was the doctor that said I was perfect vision, that was five years ago maybe. I’ve had cross-linking surgery three years ago and then a few weeks ago, I had eye surgery to remove a ‘kero’ ring in my eye.

Int: What about in terms of someone like your GP or your paediatrician, in terms of helping you with the pain, have they prescribed you anything or given you any other advice apart from physio?

R: GPs, I find it’s kind of almost like pot luck, some can be good, some can be not good and even there’s some of them that can be good, it’s frustrating because with chronic fatigue, I feel like you don’t get strong enough painkillers for it because I’ve had it for so long and all the painkillers I’ve had, haven’t really helped and the only painkiller that’s just about helped... I only managed to be able to take that two years ago, still taking that.

I don't know if it’s in the rules of the GPs or they’re powerless to prescribe anything stronger, because the best they could prescribe is naproxen or codeine.

Int: Yeah, yeah, okay. What about someone more like a psychologist or psychotherapist, have you seen anyone like that about the pain?

R: When I was maybe 12, 13, I went to CAMHS?

**Int:** **Mhmm.**

R: Just because the pain was really bad and it was getting me depressed, of course, and yeah... my way when I was younger of coping with the pain was kind of hurting myself but not like anything like cutting, or anything like that. Just if I had pain in my wrist, I would like, punch my wrist or put pressure on my wrist, because my thought in my head was that if I put pain or pressure on that spot, then I would feel that pain that I’d just put instead of the pain that was hurting constantly, and that would be better than...

Int: Yeah. I’m with you, I see what you're saying. What did the psychologist you saw, do you remember the advice they gave you or how they tried to help?

R: Um... They tried to encourage me to stop doing that and eventually, I did. Even though I stopped doing that, I was a little bit disagreeing why I should stop, I understand it’s not good to hurt yourself but at the time, doctors weren’t really helping, nobody was understanding the pain. Medicine was pretty much useless because it was so weak, it would do nothing and so yeah, that was pretty much my coping mechanism. They did encourage me to stop doing that but other than that, they couldn’t really do that much.

Int: Have you ever tried to seek advice from an alternative sort of therapist or specialist?

R: Yes. I remember, apparently when I was at school, there was another girl that had some sort of illness, and... she went to this alternative therapy thing and the school recommended us that, so we tried that and it was kind of [*laughs*] where you would go, close your eyes and they would talk to you, a bit like hypnosis therapy but not really hypnosis, more like... I’m not sure, she’d be like, “I’m taking the pain away from your body”, stuff like that. It didn’t really, it didn’t help at all and it was ridiculously expensive. The first session was free but... it didn’t help at all. Yeah.

Int: Some sort of hypnosis, meditation type thing? Yeah?

R: Yeah, it was just them talking and “I’m taking the pain away from your body” and stuff like that... whatever that’s called!

Int: Okay, that’s interesting!

In the past, when you've been trying to find out how to deal with the pain that you're getting, where is it that you’ve turned to first in the very first instance?

R: Definitely online, mostly because no-one that I knew really had any either idea of what I was going through or had someone who had something similar or anything like that, so I turned to online.

With online it’s... when I was younger, I didn’t really feel there was much information about it or there was much... there was a lot of things I saw wrong with the information, or I would kind of feel like it was downplaying what I had. And that made me wonder maybe that’s why other people don’t understand why I’m in so much pain because when they search what I have up, online, they don’t see it as bad as what I’m experiencing.

Int: Mm. How old were you when you started searching about stuff?

R: Really young... I think probably around... maybe 10?

**Int: Okay, yeah. Just so I’ve got an idea of that time period.**

R: When I was 9 or 10, I wasn’t diagnosed, I had no idea what I had so it was just searching the symptoms and there was so much stuff, that it didn’t really help much.

But as I got older and I knew what I had, it did help more because I saw things that people would comment saying they had this same thing, and what they tried, and things like that.

Int: Do you think you could you tell me a bit more about the internet resources that you've used to find out information about pain? What resources have you used?

R: So ... the main things I used was places like Reddit or you know, those sites where you can just write things in a thread and then people can search it, and see, and read about it and stuff like that. That was the main thing I used. There was things like WebMD. There was also a lot of medical journal publicised things that came up but when I was quite young, it wasn’t so easy to understand.

I didn’t really... because the NHS have their own thing about EDS, I think it was quite late until I discovered about that and when I discovered it, most of it I already knew.

Int: Right. So, let’s talk about the Reddit, and I think it’s online forums that you're talking about, is that right?

R: Yeah, exactly that.

Int: Yeah, okay.

Do you think you could you tell me a bit more about your experience of looking for information on things like Reddit and the online forums, what sort of things do you do and how do you go about searching?

R: I would usually just search either symptoms I have or EDS itself or both symptoms and EDS, and then I would scroll through the pages on Google, looking for... looking for more, not so much doctors or web page stuff, I wanted to see more what people had to say about it. It did take a while because I had to go through so many different pages just to find people that were relevant to what I had.

I mean, none of the stuff was really that helpful in the way that, “Oh I did this and it helped”. It was more I guess frustrating because it was more people who had things that I had but no luck with doctors or anything like that, and then occasionally there would be say one person who had good luck with this doctor, who actually prescribed him strong painkillers and they would say how their life completely changed with having that.

That was hopeful, but also disappointing because that was in America and I know how strict the UK is with stuff like that, so I was like it’s good that this person, it was like I knew that would help because I was thinking if I just had stronger painkillers when I was younger, I would be a lot better. It was good and bad to see that.

Int: Yeah. It sounds quite mixed …

R: Yeah.

Int: Why do you like the Reddit and the forums? Why do you think it is that you're drawn to them?

R: I guess, just because in my experience, a lot of doctors get a lot of things wrong, a lot of doctors have been either completely wrong or it seems like they don't know what they’re doing. Whenever I’ve said to a doctor about stronger painkillers or anything like that, it would just be shrugged off and they would never be willing to try or anything like that.

I guess that kind of made me anti-doctors, in a way, a bit because a lot of them were unhelpful and it was like when I was younger, I knew what I thought would help me, but the doctors would never like prescribe it.

Int: Okay, okay. What about other social media type resources, things like Facebook, YouTube or Instagram? Have you had any experiences of looking for information about pain and EDS on there?

R: Yeah. With Facebook, I didn’t really see much information about EDS until quite late, now there’s EDS support groups on Facebook and stuff like that, which is good, and people share what they have and open to people’s suggestions and things like that, which is really good.

With YouTube, yeah, it wasn’t so much helpful, but it was more like… just like “oh I have that, I know what that’s like”, comparing to the people talking about their own pain and problems like that and these kind of videos, I would watch some of them, I’d be like “I want to show my family or my friends” so they would more understand what I go through.

Int: So maybe useful for sharing with other people, the YouTube videos?

R: Yeah. To help them understand because there’s not really much other resources. I think unless... unless you’ve been to most of or a lot of my hospital trips or unless you have it as well, then you're probably not going to be able to understand, that’s pretty much what it is.

Int: Okay. You did mention the NHS website before as well, but not particularly drawn towards that, what’s your experience of looking on there for the information about pain?

R: I guess it just wasn’t that so much useful in a way. It did tell me stuff about the other types of EDS, which I didn’t know, but in regards to treatment, help with that, it didn’t really seem useful at all because, yeah... the most thing they would say is physiotherapy and I think that’s about it, that’s all the treatment they do, they don’t have a particular drug they prescribe to people with chronic fatigue stuff. The most they’ll probably go up to is naproxen or codeine.

Int: I know you said you don’t use them too much but what about other health websites like Healthline and WebMD, have you looked on any of those and what was that like?

R: I haven’t looked on Healthline, but I have looked on WebMD. When you go on there, it can be very scary in a way.

Int: Sorry, you cut out for a second, but I think I got what you said …

R: Yeah, just that you have to take what WebMD says with a pinch of salt because it can be very, it can be a trip on a scary adventure because it’s “you could have this, and this, and this could be life threatening” and stuff like that, it wasn’t really helpful.

Now, when I’m older, I’ve seen more stuff that’s helpful from the doctors’ side of things, where I’ve seen doctors use different types of drugs to help, different types of therapies, all sorts of things like that, but... WebMD before, when I’ve looked on it, it wasn’t much helpful.

Int: Okay. I’m going to skip back to talk about something else for a minute.

R: Sure.

Int: When you're by yourself or self-managing, what kind of things do you do to cope with the pain?

R: Um... I use hot water bottles a lot, drastic levels of heat or cold, they kinda help. If something’s burning hot, that would help, I’d use that on my body just to help in the same way as the ice cold. I find the really high end of each temperature doesn’t magically help but it helps a little bit, but also because it’s either so hot or so cold, it adds kind of a distraction in a way.

Int: Right, okay. What about other things like exercise or relaxation and mindfulness? Do you do any of that to help you?

R: I tried mindfulness when I was younger. It didn’t really help so much but I think maybe I was young, so I might not have paid much attention to it, to be able to really focus on doing it. With exercise... it’s hard because whenever I do exercise, the next day or the day after that, it can very likely put me bedridden for a day or two because after exercise all my joints are just kind of dead afterwards, even an hour or two after exercise, all my joints feel dead but the next day it gets really worse and I won’t be able to move much. I do like to exercise... I used to do a lot more when I was younger, but now I don’t do so much because... it’s really draining afterwards. Yeah.

Int: Okay. Have you tried to use any online resources, apps or websites to help you with coping by yourself?

R: Um... Yeah! I’ve used websites and apps to talk about mental health because it is quite a- it affects mental health a lot with chronic fatigue.

Int: What apps have you used?

R: I used one a while ago called Talk Life, I think?

**Int: Uh-huh.**

R: It used to be quite good when it started. I say that - it was okay when I started - it was helpful for me but it wasn’t the greatest app because it did have like people who weren’t there for the right reasons basically, and it was really helpful to be honest because I met people, some friends from there and it was good... but after a while, they tried to monetise it more and show ads in it, that’s probably the only app that I’ve used to help.

Int: And you don’t use it now?

R: I don’t use it now, no.

**Int:** **Okay, alright.**

R: But if I needed to use it now, I can always go to it, I do say that to myself.

Int: Okay, yeah. That makes sense.

With the coping strategies that you use to help manage the pain, have you had any problems with any of the ways that you’ve tried to manage?

R: Um... I mean, well, people have been opposed to some of the ways of me hurting myself in a way, for example, when I wake up in the morning, my hands are so painful and I have to click them back into place, when it’s so painful, the first thought what I want to do but I don’t do but what I want to do so much is grab a hammer and hit my hands and fingers because that’s the first thought that I think would help it.

Int: Mm. So, a few issues with those thoughts you're having about what you want to do, and then trying to retract away from that.

R: Yeah.

Int: And, what stops you doing that?

R: Uh... I guess the therapy I had when I was younger, and I guess maybe all the people telling me not to do that. It’s kind of built up some sort of common sense, in that sense.

Int: Mm, yeah. Okay.

Your friends and family more generally, have they given you any advice about how to deal with the pain?

R: Yeah, I think... well there are only really two members of my family that help in that sense, my mum and my sister [name]. My other sisters and my dad, they don’t really… understand what I have and a lot of times when I was younger, they would think I’m pretty much faking everything.

Int: What do your mum and sister, have they given you any practical advice?

R: Yeah... lots of things like try to... breathing stuff, try to calm me down, lots of different techniques to calm me down. It could be something, when I was younger, as simple as I Spy, something distracting. There might be more but I’m struggling to remember! [*laughs*]

Int: That’s fine, that’s fine.

I’m going to move back to internet resources. Just a few questions we missed before.

R: Sure.

Int: You talked about a few different online resources, the Reddit forums, talked about websites and the app that you used to help with the mental health side of things.

How would you say your use of internet resources and social media has changed from when you were first diagnosed, compared to more recently?

R: Um... I guess when I was younger, I was using it a lot more. Just because when I was younger, I felt I was pretty much all alone, nobody I knew had what I had, it was pretty much, yeah, an isolating battle against my pain. I guess now, I use it if I need to, if I feel down, or it’s too much. If I need to, I will use it. There’s different things like the Facebook EDS group, I will use, and things like that, but yeah, now that I know that I’m not the only one and that there’s more people and more... people are kind of slowly getting to understand.

Int: Yeah, okay. Which, out of the internet resources, which have you found the most helpful?

R: I would say... I would probably say - would the Talk Life app be? [*nod from interviewer*] Yeah, I would say that, just because a lot of people on there either have something with physical conditions or mental conditions, or both, and I guess having people to talk to about stuff like that, that know, is a lot helpful. The forums are okay for finding information but with Talk Life, then when you have information, you have someone to talk to about it pretty much.

Int: Okay, on the forums and on Reddit, do you actively comment and post on there or do you more just read?

R: I more just read, to be honest. Yeah.

Int: It sounds like with the Talk Life, you interact more with people, is that right?

R: In the past, yeah.

Int: In the past, okay.

Which internet resources, if any, have you found were unhelpful and why was that?

R: I would say that... there’s a charity for EDS and I found that quite unhelpful when I was younger. Yeah... it just didn’t seem that helpful and when I was younger, because I was missing so much school and when I saw the EDS charity, I thought it could maybe help, because I think I wrote to them saying that “I’ve missed so much school, is there any support that the EDS thing can do”, because I want to try home schooling or something like that, and it was just like “we don’t offer that kind of thing” and looking at some of the stuff on there, I mean, it may have some but it just, maybe that when I was younger - not getting any kind of help back at all - maybe that clouds my judgement. I’ve been on there a few times, doesn’t really help, so I find that unhelpful.

I guess I would find certain websites and stuff that kind of downplay EDS, they don’t really explain just how hard it is with EDS. I feel like if someone goes online and searches about it, back then, or even now, they would see it’s just a condition like asthma or something but it is a lot more worse than asthma.

Int: Yeah, okay, okay. You mentioned that as well before, at the beginning, about websites that downplay.

R: Yeah.

Int: Thinking about any online resource, is there anything else that you think would be helpful to you or perhaps would have been helpful in the past if it was there, for managing the pain?

R: Um... maybe something, like a place where people with the exact same condition as me could interact and like, yeah, understand what they’re going through and you can share what you're going through, supporting each other in that kind of sense. Because a lot of people who I have spoken to with EDS, they have said that they’ve had not a great time with doctors because they just... I don't know, maybe they’re powerless to do anything effective enough. Yeah.

Int: So, some way of connecting on social media?

R: Yeah, to more people that have it. One thing I forgot to mention... because of my conditions over the years; I had the sleeping condition, the eye, all the other joint pains and stuff like that. When I was younger, I used to have really head pains and they found something in the back of my head, they didn’t know what but like an anomaly, off topic, but anyway. Because we went through trying to get government support with, I’m not sure what it’s called, I think it’s DWP where they help people who suffer, who have conditions or health problems or stuff like that. I had quite a bad time with that, with the first person I saw, they were very kind and nice in the interview but when I told them all the things I couldn’t do, because again I look like I can do everything, when they wrote and said the result, they said “You said you can’t do this, but we think you can do this, you can do that” and I think in that case, unless you really have EDS or know enough about it, then you really have no clue what people with EDS go through. When we tried to get a re-interview with that, we actually got someone to come to the house to do it, because I was getting worse with my health, and this person who came to the house, he actually had EDS as well, and him having EDS, talking to him, he understood everything, and he said he was shocked that I wasn’t put on the health benefits years ago. So, I really think it makes a difference if the person treating you... or deciding something about your life has EDS. Yeah.

Int: Yeah. And you said before about generally, how it would be better if there was a bit more information for people who don’t have it.

R: Yeah, because a lot of times they just think you're faking or it’s not as serious, they just have no clue.

Int: Okay. I’m glad you’ve got the support now, that’s good.

Is there anything else you'd like to add to anything that you've talked about?

R: I can’t think of anything, no.

Int: That’s okay. That’s the end of the questions, thanks very much. What happens now is I turn off the recording, and if you have any questions for me, feel free to ask them off the recording. And then we debrief.

R: Okay, sure.

[CLOSE]

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