

**Prepared For: Anna Hurley-Wallace**

 **University of Southampton**

**Recording Details: orange**

**Date of Transcription: 21 October 2020**

**Transcriber: Julie Winter**

**Recording Length: 72m**

ANONYMISED

Int[[1]](#footnote-1): So just to double check then that you’re still happy to take part in the interview, and that you’re happy to be audio and video recorded for the purpose of this?

R[[2]](#footnote-2): Yes, I’m still happy to take part, no problem.

Int: Great, so I’ll get started then.

R: Sure.

Int: Just to say, I might look over here when you’re talking, just to look at my questions, but I’m still listening to you, okay?

R: Okay. Yeah that’s fine, I know what you mean. Sometimes you have to check your prompts and things don’t you. Yeah, no problem.

Int: Yeah. Let’s start with the warm-up questions.

Firstly, can you tell me a bit about your experience of chronic pain and your arthritis?

R: Yeah, all sorts, where do I begin? It’s a real mixture of different kinds of pain I find, because obviously I know predominantly rheumatoid arthritis is about more to do with joint stiffness, or stiffness in the joints. I get a bit of everything really. To be honest nowadays it’s more kind of crippling pains or quite, what’s the word?, not paralysing, but when it’s sort of like... Oh I know, I’ve thought of it, and it’s probably going to sound really weird, but is just the only way again I can liken it to anything, or describe the pain, is sometimes it feels like whatever that particular area of body it is at the time, the experience of the pain, it’s like in a clamp, it’s being clamped. Almost like yeah, really crushed together.

 So that’s one way of describing one sort of pain. There’s sort of very crippling, and like sometimes when it’s particularly painful, it’s quite debilitating, like in the muscles it’s really debilitating, and it sort of kills all muscle strength literally. So it sounds far-fetched, but it will literally feel at that point, that part of the body dead for those few moments of experiencing the pain, because the pain has killed the muscle strength so much that it’s dead, it’s unusable for that moment. I mean ordinarily I’m actually quite strong, I’ve lifted some big things, heavy things in the past, but I suppose I’m just saying that to put it into context, because if I don’t have it, I’m fine.

 But as soon as I experience pain, then it will just like you’re a completely different person, and I’m the complete opposite, really weak, sometimes I can barely get up the stairs. So the other thing I was just going to say actually, just to finish on this question, I’ve remembered it, was with regards more specifically to the muscle stiffness and joints and what have you, I probably experience that more worse during flare-ups when this first started obviously long before I ever got on medication, and therefore had it controlled. So that’s when it was at its worst. Touch wood now it’s nowhere near as bad, and it’s more the crippling pains I experience and stiffness.

 I would say on that note, perhaps from time to time I was still experiencing – it’s only in a particular area which is my lower legs and around my ankles, swelling and quite a lot of swelling, but I think it is related to – I’m pretty sure it’s this, because I had it during the flare-ups anyway, where just lower legs, ankles, feet, one in particular were just really swollen up. Because with that it’s extremely achy, like this really dull aching, I don’t know how else to describe it, because I can’t remember until I actually have it.

 Because it’s not that often, but from time to time I will get that too, and I’m pretty sure that’s a symptom of it, because that’s everything I had during the flare-up and more. Yeah, so that’s just a snippet of it really.

Int: Yeah. So quite different perhaps to when it first started to how it is now?

R: Yeah, I mean there’s certainly less symptoms, but I mean I suppose that’s going to be the case, because that’s the whole point of the medication is to obviously tone the whole thing down, calm it down I mean. So yeah, touch wood that’s worked, but I still do experience a lot of crippling pain and quite frankly it’s really ironic, I’m actually experiencing it right now as we speak, and I’m not just saying that for the purpose of this, I actually genuinely am experience quite a bit of crippling pain right now at my arm, mainly forearm, and a little bit in the hands.

**Int: Yeah.**

R: Yeah, I mean it’s really frustrating because it’s a horrible, horrible pain and I think, “What can I do?” But then I think, “Well I’m already on medication and still getting it, so if I’m already on what I should be having to treat it, then what else can you do?” So that can occasionally get me down and be frustrating because it means I’ve got to live with that. Obviously, there’s far worse, so I don’t want to sound really precious about it, because there’s far, far worse in the world I know. I mean I’m pretty lucky, you know, some people have got multiple conditions at once to manage, and medication, so I’ve got it really easy in comparison. But still, as an individual, it’s still not nice.

Int: No – and you said it makes you feel down - can you tell me a bit more maybe about how your pain affects your mood and your emotions?

R: Well no pun intended, but it’s very up and down, so in terms of how often or not it may or may not affect. So sometimes not so much. I think in other words it’s more dependent on my mood at the time, like in general, so if I’m feeling particularly more, sort of like upbeat and positive, better mentally that day, then I’m obviously in a better position to handle it more. I’m in a bit more of a level-headed mood shall we say, to be able to suck it up. Like now actually is a good example, it really hurts, and it really bugs me self-consciously, but on the other side, luckily I’m in a bit more of a stronger, shall we say, mood mentally. So I’m able to deal with it more, fight it off, you know, the annoyance of it a bit more than normal.

 The reason I emphasise that a bit, is because more so that’s more of a thing at the moment is because I do also suffer other conditions as well so mentally really bad anxiety on and off. Sometimes with that touch wood again, hopefully not too much, because again I try and fight that off too as much as I can. But it will sometimes get the better of me, because the anxiety triggers it, which is something [inaudible 8:14] and occasionally panic attacks, it’s all interlinked. So that’s why I’m making reference to - it could be dependent on the type of mood I’m in, because in other words, experiencing that as well on the more down days in terms of mentally, that will, obviously affects my ability to then deal with the physical pain as well on those days.

 So yeah, really dependent on the mood, whether it’s better or worse, because I’m very up and down on the mental state. Yeah, as I say touch wood today, I feel better mentally. But at the beginning of the week, I felt awful, I find sometimes I think some days like mentally I worry non-stop, my anxiety is so, so bad actually it’s unbearable.

 For example I think on Wednesday it was really bad, Wednesday lunchtime, and I suffered a really bad anxiety attack. So the only reason I mentioned it was because that would be an example of a downer day, where the effects of the arthritis would impact on me more, because I’m not feeling, already lesser strong mentally. So I’m more susceptible to giving in to those feelings of frustration from the arthritis, whereas on a slightly more upbeat day, like today, yeah, I feel a bit better today. So I can cope with it more, shrug it off more I suppose.

Int: Yeah, yeah – that makes sense. You mentioned before about your being able to lift heavier things before perhaps?

R: Yeah.

Int: So how does pain affect your physical abilities?

R: Yeah, that’s a good question, and the real short answer is – obviously, I’ll elaborate - but it’s a whole mixture of things. So it’s very dependent on the type of pain because it can really vary in itself, parts of the body, when it is, how I’m feeling. So I suppose to go on a bit more from that... Oh and the strength of the pain as well or severity of it, so I guess maybe to put it into context, give it a worst case and better case scenario, worst case well yeah, would be the worst case at its worst. So probably the best example for that would be pre-medication treatment stage when it sort of, I guess first started, because that’s when it was at its worst.

 So it all flared up, experienced several flare-ups over days or weeks maybe, so that was at its most raw state, so completely untreated, so the worst it could be. So with that I guess I can only go by the symptoms I had at the time, so as I say, well swelling, so my feet and legs completely swelled up with that. So I’m having to retrace my steps a bit, because it was some time, it was about three years ago now, so I’m just trying to remember. So actually no, two years ago. So yeah, all the swelling took place, with that they also then became my legs increasingly much, much more stiffer, obviously the swelling causes the stiffness more in the ankles, feet.

 So yeah, it was incredibly hard to move, so I suppose sort of twist my foot, you know, which was ankles, legs were... Well for example I always remember one occasion I think because it was so significant, one of the most significant occasions when it happened, it was just so bad. At a time when I was just out and about one day, completely out of my area, catchment zone, the other side of [location] or [location] really, and it was a day where it wasn’t too bad to start, but I found almost the more active I was during the course of the day, the more that triggered it. So the more it flared up I could feel it coming along as the day went on, to the point that by the late afternoon/evening, well it was so great you could see it visibly, I could see my legs.

 I’ve got pictures as well I could show you as well if you’re interested? I’d taken them on my phone because it was so bad. In hindsight that helped because then it was a nightmare, by the time I did get the treatment, as you might imagine, that’s a long process to get from initial doctor stage, initial assessment, their thoughts and being their initial diagnosis, prognosis, and escalated to a hospital, it was specifically in this case the Rheumatology Department and a specialist. From start to finish, that whole process takes I think months.

 The thing is, the even more frustrating thing I found with this, is it wasn’t necessarily every day, it was very intermittent. Some days I’ll be honest, I could be fine. I found some of the activities I did would trigger it off, but it was still dormant in my body because it didn’t take much to trigger it off. So it was very up and down, so in other words sod’s law, but the time I got to the specialist appointment, because obviously the annoying thing with those, because they’re routine appointments, hospital appointments scheduled way in advance, with the arthritis I mean that will come and go as it likes you know?

 So it won’t necessarily be there on the random day I have this hospital appointment six months in advance.

**Int: Yeah.**

R: So that’s what I found so frustrating, I might be going off on a tangent, but it’s all relative, because yeah, so many times I’d have it so, so bad. Well actually start off the other way, the times I’d go to the hospital, I did actually be completely fine, I’ll be honest, totally fine, not have anything, nothing to show them, no symptoms anything. Of course they do a full body examination, so obviously testing the physical things like the joints and the stiffness and what have you.

 And of course because I’d be fine, they’d be fine, so it made it obviously incredibly hard to do their job in assessment with nothing physically to go on, and I’d still personally be experiencing plenty of internal pain. Of course they would never know that, they can’t tell, so other than my own description of that, they’ve got very little otherwise to go on. So that’s why going back to the photos, an example, and I didn’t at the beginning take it for this reason because it was all very early stages then. I found the whole thing a learning curve, so it was just luck that I took them more at the time for my personal reference, to look back on to remind myself exactly how bad it was, to almost make myself feel better that I’d got through that because this is how bad, what I’d experienced.

 I’m over it now to a point, but in hindsight it worked out really well because I ended up having to fall back on those appointments and ended up finding that really helpful to show them, so I could prove to them. In the end I felt like it was a game of having to prove to them what it was like, because I was so fine at the appointments, but you know that I’d suffered it really badly, there was plenty of other times in-between they’d never know about. It’s just so frustrating to think if only they could have been there at the times you were, I suppose experiencing a flare-up during those. And had they been there in the moment.

 So going back to this [location] occasion when I was out, so by the time the evening, it was so, so bad I could barely, I literally couldn’t walk. Of course I was on my own and driving, and where my feet were so, so swollen and as I say, going back to the point I’d twist them, it actually made it in all seriousness really, really dangerous. I could hardly drive. Well I couldn’t to be honest, probably if I’d have been stopped, I might have been told off. But I had no choice, so I thought at that point, “I have to take myself to A&E, because this is ridiculous.”

 So luckily, by sheer luck, I happened to not be that far at the time wherever I was in [location], well I remember, it was in [location] to be precise, because I remember every part of it so well, because it was quite an experience, especially on my own. So I got to the nearest hospital and got to A&E, I just about got myself there in the car, and then as soon as I got out... It’s starting to make me emotional, I’m ever so sorry...

**Int: It’s okay.**

R: ... because it was just the most awful, awful time, it was just so humiliating the experience, because they were so, so swollen up.

Int: Do you want to get a glass of water, or something?

R: Oh no thank you that’s all right, my eyes are also really sensitive, I’ve noticed lately the slightest thing, or as soon as I get tearful, they get really stingy.

Int: I know it can be difficult to talk about these experiences.

R: I don’t want to make you feel bad, it’s because it’s stupidness, and it’s raking it all up, and it’s a reminder. Because after a while even you forget how bad it was, and to be honest I have to a point, because life’s moved on a bit then. So yeah, sorry, it’s upsetting because of how debilitating it was at the time, because at that point I did feel, no disrespect to elder people, but it’s worse also because I think maybe because of my age too.

**Int:** **Yeah.**

R: Because I’m pretty young to experience this. It’s not that common I think in young females. So I felt worse more so because of my age, because I’m so young, yet so unable to do anything.

 It was like I felt either – no disrespect to the elder, I feel really terrible saying this, but I did feel like if you’re an elderly person if you like, where they’re far less, you know, they’ve slowed down a lot, they’re far less mobile or immobile, or otherwise shall we say like the – I don’t know what the correct word is, but like less abled, less mobile if you know what I mean? Because well I basically was that as well at the time, like physically disabled. So in other words, when it got to getting out the car, it sounds ridiculous now, I literally had to crawl out and I couldn’t, where my feet and ankles had swollen up so much, I couldn’t physically get my trainers on. I mean they were like twice the size.

 So you know sometimes where people have certain conditions, I don’t know, but their feet get really big and really swollen...

**Int:** **Yeah.**

R: ... and they were exactly like that. They’re not normally, so massive feet, I couldn’t get my trainers on. So yeah, and I certainly couldn’t walk, so I literally... Luckily, I’d parked reasonably close to the entrance a few feet away, but I had to crawl almost on my hands and knees on the ground into A&E to get there, because I couldn’t physically walk or stand up. So I think the moment I got there, they could see for themselves, it spoke for itself how bad it was.

 So they instantly got me a wheelchair and that’s probably one of the first times I’ve ever been put in a wheelchair in my life.

**Int:** **Yeah.**

R: Then from there on I was wheeled into A&E and I mean being a bit careful what I say, but the sort of area I was in as well, it wasn’t the nicest shall we say, and I was on my own, and I was just there randomly in that part of the country one day. So I felt a bit out of my depth, out of my comfort zone. So being on my own in a completely strange place, a dodgy place, in the state I was, I was quite vulnerable and stuck in a place in a wheelchair, and surrounded by quite weird and wonderful characters, it was definitely an experience I can tell you, waiting in A&E.

 I eventually got taken in to see the consultant there, and I had a whole range of symptoms, so swelling, stiffness, I couldn’t stand, the pain, so that’s going back to actually the types of pain, that’s a good example of the different types of pain. Because there it was different again, I think more to what I experience now, it was more due to the stiffness pain, rather than what I would describe now as, I can only really describe now as crippling pain, like where it shoots in and it’s really debilitating at that point. It’s like, I don’t know how to explain it, but yeah, it kills muscle strength.

 It’s all sorts of different types of pain and it’s so difficult to describe, put into words. So yeah, and to be honest I’ve gone on such a tangent I can’t remember what the original question was!

Int: It’s absolutely fine - I was asking about physical ability, but all of that is to do with physical ability, so that’s just fine.

R: Yeah, it’s quite a detailed example, but I suppose because I can only go by experience, so I’d hope that experience could cover it in its own way.

Int: You talked there about a few things as well, so I’d like to pick up one some of those. So you went to the A&E on that evening, can you tell us...?

R: Yeah, that’s not the first time, I don’t think it’s the first time, I think I might have been once before, but I can’t remember. But also, I’ve had to call an ambulance I think on at least one occasion as well. Sorry to butt in there.

Int: That’s okay. So a few times you’ve been to A&E?

R: When it was at its worst yeah, I’ve had to yeah. That was an extremity of example, I mean touch wood, I keep saying that, but it probably won’t really be like that again now I’m on the medication. I mean that was just the extreme of scenarios where I couldn’t stand or walk or put any weight on my feet. I mean that was just utterly ridiculous, I’ve never known anything like it. Yeah, that was crazy.

Int: Yeah. Do you think you could tell me about advice that you have had from doctors or nurses, anyone medical, be it in A&E or your GP? Could you tell me about some of the advice you’ve had?

R: Yeah, I’ll try, I’ve just got to recollect. I haven’t seen any for a while now, because – actually do you know what, very funnily enough, the reason I say is because yeah, I normally have routine roughly six-monthly appointments. I was feeling quite frustrated this year because I’ve realised, I haven’t had one this year, but obviously I’ve realised why, you know, because of the current pandemic and obviously all routine hospital appointments unless severe were mainly cancelled. It’s obviously down to that, but the funny thing was, I’ve literally just – I’ve actually got it right here, my letter came through yesterday for my new appointment, there we go.

 So yeah, for my new rheumatology appointment. It finally came through, I’m quite happy about that, because it must have been a good year since I last had it and it’s for like a month’s time. Anyway, so I’ve seen quite a few over the time between hospital specialists, rheumatologists, and doctors sort of more in the beginning really, and one-off sort of consultants at the times of visiting A&E. So thinking about those different ones, I’m trying to think of what the best example might be, it just all merges into one.

Int: What sort of advice have they given generally?

R: Yeah. Well obviously first of all some medication, [inaudible 25:04] but ensure you keep it up. Because I must admit I sometimes fall a bit by the wayside on that, for different reasons, that’s another story actually on the medication side of things, which I can let you know if you like?

 But with that, so I’m not very good sometimes at keeping that up and consistency. So that would definitely be one strong piece of advice is really vital you keep the medication perfectly consistent, no excuse, no missing any time really. Because obviously as soon as you start to miss at least one dose, it can sort of mess up, because I think it’s a process over time, it’s a build-up of it into your system. So it requires consistency to be working, so that’s that. As I say it’s been that long since I’ve had one, it must be a year.

Int: It’s okay if you can’t remember.

R: Yeah, I’ve genuinely just drawn a blank. I mean I’m really sorry, I’m sure there’s plenty. Actually I’ve got an idea sorry, I know I do try to keep notes each time I’ve had an appointment, and I’ve got them in my phone, which is right by me, and I can very quickly just skip back, because I know where I’ve kept them. So I can just find the notes and I might have something in there that might trigger my memory, hold on, because I want to try and say something [*searching for notes*] Oh yeah, here we go. So that literally was a year ago almost to the day, it was the 11th September last year, so just quickly I’ll summarise a few things.

 So for example, yeah here we go I’ve got some good things here. At the same time, it’s not quite related but I was also suffering with other conditions, well bad anxiety even then...

**Int:** **Yeah.**

R: ... so one of the things then she mentioned was that possibly the two could be related or the arthritis could be perhaps triggered by the anxiety. Or certainly it can help fuel it if you like, because I think arthritis from knowledge, from experience now that I’ve come to know, is that it’s very much an inflammatory-based thing, like inflammation, and I think probably just due to my sheer stress levels, that’s obviously increased the inflammation etc, so that’s one thing. The other thing underneath I’ve got something she suggested [*reading*], it was medication, but it was more related to the anxiety if I’m honest.

 It was indirectly related, because if it helped the anxiety it could help this.

**Int:** **Yep.**

R: Oh here we go, something she mentioned, she was worried if – I don’t know if this would mean anything to you or not, but if my sarcoid was affecting... Okay I did have another problem, it makes it sound like I’ve got a load of problems, I had another condition as well at the time with my eye, so that actually funnily enough was another inflammatory condition, so this is where I think it’s quite interesting, that was called uveitis. That came about last springtime, so about 18-months ago, which has really flown by, plus combined with the anxiety and the arthritis, they’re all...

 Well the eye and arthritis are both inflammatory conditions and I suffer the anxiety which is expressed - so you think that might be the underneath trigger for both of these two different things. So she mentioned sarcoid, she wondered if that was also affecting well, I think both of them, and she specifically requested certain blood tests which were called ESR bloods [*reading notes*], I don’t know if that would mean anything? But obviously linked to it. Because another thing I also experienced at the time was another sort of condition in my legs, but I think this could have also been related to it.

 I’ve had this quite some time, something called erythema nodosum, and it’s basically... Luckily that’s been kept at bay now from the medication, but a series of – I noticed in the beginning, and this was long before I started having the arthritis, so yeah, before that started and flared up, I was already experiencing this for some time. Then when the arthritis came along, I think they put two and two together and found a link there.

 It was like a series of lots of little, small red lumps and red bumps all over my shins. They weren't painful or anything, but just like I was fascinated by them, because I sort of experienced them for years through late teens and early 20s. It would drive me mad, I’d always see them. The worst time I’d see them was whenever I was in the bath, because it emphasised them a lot more. So I was really puzzled, but I went years experiencing them and not really doing anything about it, because they weren't painful, they were more of a visual cosmetic thing more than anything else.

 They weren't there all the time, they would come and go in just these random different places, these red bumps up my legs. It wasn’t anything like chicken pox or anything like that, it wasn’t that sort of thing, they weren't sore or itchy or dry, they were just round red marks, it was strange. I had those for years and years, and it was only when the arthritis started, and I still had the lumps that they possibly linked the two.

**Int:** **Yeah.**

R: I can’t remember the reasoning they gave because it was quite technical, but yeah, so that was something else.

Int: Yeah – so, that’s interesting. You mentioned quite a bit there about the linking in with your anxiety, did you see a psychologist about that? Can you tell me about any advice you might have had from a psychologist?

 Just a little bit about it...

R: Crikey. Oh my God I don’t know where to start. So I’ve had a real nightmare really with that...

**Int:** **Oh right?**

R: ... doctors trying to escalate it to receive proper treatment within the NHS, but obviously specifically for this. So in my case it was the local trust who did offer I suppose well specifically for this sort of thing, anxiety and depression, CBT, and counselling. So the local trust who did this, well [location] version of it, was talking therapies. I went through a whole process last year trying to, obviously seek that treatment out and oh my God, I’m not exaggerating when I say it was a nightmare. The ironic thing was it ended up exacerbating my problem more, making it worse.

 It was terrible and I hate sounding negative, or bad mouth an NHS institution, but this really was the most horrendous experience. I know the NHS are amazing in plenty of other ways, but this in particular, I almost felt I wasn’t even dealing with the NHS, it was more like a corporate company. So regimented structured, very robotic, and I mean I probably won’t go into too much detail on that...

**Int:** **It’s okay, yeah.**

R: ... because I’ll have you all day and it was quite a long thing. So in a nutshell it was a catalogue of errors, I went round in circles over a period of overall approximately nine-months. It began February of last year 2019, up until about it must have been August or September of last year from start to finish the whole process.

 I ended up going full circle, and in the end, I had to just give up, because trying to get anywhere with them from start to finish was just – well as I say, I came full circle. At one point I’d made progress, but in the end, this is how bad they were, I ended up right at the beginning again. I swear it definitely was not my fault, I did everything in my power in fact to make it work. That’s the thing, I was doing all the donkey work chasing them, following it up, and otherwise yeah, it was just terrible. So that was talking therapy, so going back to the original thing, as a result obviously of that horrendous experience, I had to just wash my hands of that.

 So reverted back to the doctor at the time in desperate need of some kind of help of that kind, CBT and counselling, and I’ve found it’s definitely counselling that’s like gold dust if you like, trying to get that out of the NHS, as I found through talking therapies and the doctor, they have a series of things I find at GP level, they’ll obviously recommend to you to help, like therapy, all sorts of different things. I sort of with all the different examples, not being big-headed, but I could say I’ve been there, done it, to some extent, and I could give examples of all of those on a separate note. But in summary yeah, so that was that. In other words, I exasperated all of those options.

 The one kind of more shall we say concrete kind of progress I could get out of them in terms of the therapy, so with talking therapy that was a whole new thing in itself that you got the crux of there. So apart from that, sort of running out of options. So yeah, without going into great detail, the different sorts of things I explored, and eventually got to the point I just was so desperate, as a last resort I had to resort to private counselling...

**Int:** **Right.**

R: ... which obviously as you can guess, is extremely expensive, because you have to pay for it and it was so specialist, it’s not cheap. I knew that all along, which is why I went to great lengths to pursue it obviously via the NHS.

 To be honest, if I am honest, quite disgusted really of all that happened there, but that’s a whole other thing, and that’s also something else that really upsets me, because really, it’s going off the subject now, it’s more of a mental thing, but I did go through utter hell really trying to pursue that to no avail.

**Int:** **Yeah, yeah.**

R: Which is funny, because the only reason I needed it in the first place was because I was quite mentally ill, and this made me more mentally ill. I still didn’t get the help I needed, so I was in an even worse place than obviously the beginning and probably further away from any help.

 So back to square one and worse. But now I am actually now [inaudible 36:54] because much to my disapproval. I mean the lady personally is fantastic and I mean in hindsight it’s probably a good thing, and they say things happen for a reason, maybe it did me a favour, because I found an incredibly great lady, or maybe that’s because I am paying for it, I don’t know, anyway. But I find that aside on a personal note, more on a just like out of principle it’s not the point, I shouldn’t have had to have done that. I only did it in the end on a personal level because I had to, and after exasperating all the NHS options, I should have been able to get further with them.

 I can’t believe it got to the point where I couldn’t get any further with them, I felt I had no other choice but to go and pay for it. Which I can’t afford, and to be honest, the only way I can pay for it is – I’m not actually to be honest, and I hate having to admit this, but it’s the benefit I’m on that’s technically paying for it, because I’m not currently working because of my condition. So that’s in actual fact, and that really proves my point, that I shouldn’t have had to do it, because in theory I can’t pay for it. I don’t personally have the money, it’s the benefit paying for it. So yeah, that’s not good.

[*Interviewee advised they want to eat a snack they made earlier whilst continuing the interview. Interviewer offered to pause and return in a few minutes. Interviewee said they didn’t want to come across rude – interviewer advised this is fine. Recording continued.*]

Int: So to summarise a bit what you’ve gone through, you’ve had a few in and outs of A&E, you’ve seen your specialist doctors who have said stick to the medication, it could be to do with the anxiety, go and see someone. You’ve gone round in a big circle which I think many people do, and you’ve ended up having to pay for counselling yourself.

So in terms of other things that you do yourself maybe where you’ve struggled to get the care you wanted, what kind of things do you do yourself to cope with your pain condition, like at home? You know, the example is kind of medication, exercise or relaxation, mindfulness?

R: Yeah, sure. Well obviously, I’ll start with the most obvious is medication, so I’m obviously currently on that, which is something called methotrexate, it comes in two forms, it’s an injectable form. I was originally prescribed it in oral form, but I think from the very beginning I’m not very good with medication for various reasons, so because of that in a nutshell I really struggled. So that was switched formats to the injectable kind. That’s once weekly injection. With that so obviously when I was first prescribed it by the rheumatologist, so when I first started seeing the specialist, so that was approximately a couple of years ago now, obviously I was started off with the course at the absolute lowest level. More or less like a test really to see how that worked - the effects of it.

 That was 17 milligrams once weekly. Obviously, I was on that for some time, I can’t remember the exact time, but maybe give or take a year. Then what happened was, and I remember this... Actually no it must have been under a year because I remember when it was changed, which was February of last year 2019, so it had only been nine months maybe I was on it. February was when I attended another routine appointment and explained that I still quite greatly experienced suffering from it, despite the medication, experiencing symptoms. So was there any chance then at that point of being able to consider increasing the dosage, you know to have a greater impact? They were really good, and they did actually do that, so it was upped to 20 milligram.

 I’m actually still on that now, so I’ve been on that ever since, which has been about 18-months. So that’s what I’m currently on with the medication, and I’m still very much experiencing a lot of the crippling pain. I will say the more physical or outside stuff, like stiffness, joint pain, that sort of thing, swelling, that’s almost completely calmed down. Not completely, because I do still experience it, but I would say quite rare, not that often anymore, once in a blue moon. I did I must admit recently experience recently quite a bit of swelling in my feet again, and that pain, that was quite a reminder of the night I mentioned to you at [location] I always remember that because that was so, so bad, that was the worst it’s ever been. The swelling obviously wasn’t on that level anyway, but it was the same sort of thing on a lower level.

 So I still do get that from time to time, but obviously nowhere near as much and severe, hence the medication coming into effect. But I still do get very regularly, I would say probably almost every day now, the crippling pains, which are quite debilitating at times, some worse than others. I’ve noticed I think more frequently of the latter months. So the reason I mention this, is because quite ironically, now I’ve had this new appointment come through finally, I actually just thought about it yesterday, I’ve made a point of thinking when I go next, it’s definitely ask if it’s possible to increase the medication again, especially now it’s been 18-months and I’m still getting the pain, I think why not increase the dosage there? So I’m quite glad about that, I’ve got a chance to do that, so that’s that.

 On a separate note, in terms of more like self-management, to be honest it’s going to sound bad, but not being unhelpful, but not really that much, because I’m not lazy, but I don’t really know – maybe it’s just really obvious things like I suppose – well for example with the swelling, the ankle and feet swelling I’ve experienced recently, when that did start to get mediocre bad that night, obviously not as bad as before, bit still very uncomfortable anyway and unpleasant, so I suppose what I could say with that is it was more because it was all I could do really at the time, was just to, I suppose relax, put my feet up.

 Luckily, our settee at home is one of those sorts of reclining where the seat goes up, which is great actually because I think a key thing with this sort of thing, or certain during flare-ups anyway, the thing with swelling is to then try and keep your legs more straight to even out the blood flow and stuff, help the swelling. So that’s one of the key things I do then, is thank God for the seat reclining, I can at least put my legs up and keep them horizontal in other words, otherwise I’d have to lie on the bed.

 It’s just to help then with that, because at that point it’s more that they’re just so swollen and aching so much, not that I can’t walk, I can physically...

**Int:** **Yeah.**

R: ... but very difficultly, very uncomfortably, and sometimes quite stiff, very slowly, very weak. Yeah, so I suppose relaxation would be the key thing there, more the choice has been taken out of my hands really. I can’t really do much else at that point physically because it’s like yeah, it’s just really painful at that point to do anything. And standing for long periods, that’s a point actually, they can start to, gradually the pain, the aching sets in more and more and I just ache so much more that it becomes almost unbearable.

 So that’s more like an aching pain, but it’s quite intense. Otherwise I suppose in terms of like mental wellbeing, I mean obviously because I have mental issues anyway on a separate note, I’m already - actually that’s quite a good question – I’m already trying to do things to help with mental wellbeing and what have you health, anyway just to help that, to help relax, because sometimes I’m very stressed and anxious. I funnily enough actually just very recently just found a new mobile game, I’ve suddenly become addicted to. But in all seriousness, it’s more helpful for the stress and relaxation purposes than it’s more about that than randomly playing a game because I don’t really have the time to, because I’m still quite busy with things. But I would do it just if anything to relax and calm me down.

 It’s the only thing I can try and do that will vaguely work, because you sort of lose yourself in it. So I’d say if there was anything to help relaxing it would probably be for the arthritis as well, possibly this game, because it is so addictive, it at least works as a good distraction. Because I get distracted very easily and sometimes find it really hard to just stick at something, concentrate and focus. It depends on the moods really, but just when the anxiety is at its worse, I do, because I’m so stressed and over-worrying, that I just become so restless. So in other words the game is great at keeping your attention because you just become so self-absorbed in it. So that applies to the arthritis pain, something to take your mind off it basically.

Int: Yeah. What’s it called the game that you use?

R: Oh, the game, well actually to be honest there’s a couple, but the one most recently, it’s really embarrassing to explain because it’s the sort of thing you play as a child probably.

 Do you ever remember as a child something called Colour By Numbers where you’d have a scene, and the colours are numbered?

**Int:** **Yeah.**

R: So it’s basically that, and obviously now the way the world’s changing in digital form, an app game, so yeah, playing that within the app. But it’s actually quite addictive, because they have a whole library of all these different scenes that you can potentially fill out, so once I get going in them... I’ve literally just discovered it this week and I’ve already nearly done 10.

 They do take quite a while to do, because that’s the other thing I love about them, first of all I’m quite creative, so they’re so creative, they’re amazing pieces of art, but they are also so detailed, there’s so much to fill out, so it can take quite a bit of time, it can take a good half an hour to fill one at a time. By the time you’ve done it they just amount to some amazing scenes. But the point is they’re so addictive you think, “I’ll just do a little bit more,” and you can’t stop. So that’s why hence it’s so helpful for this, because finally I’ve found something that really will distract me.

 There’s one other game I’m quite into, which is music-based, because I’m quite into music. That’s called Song Pop, and it’s just where you play opponents’ different playlists, whatever playlist you want to play, and it will obviously play the song and you’ve got to guess the song out of a choice of four different options. But it’s very much speed based, it’s a race against time as to how quickly you can do it, that’s what it’s really about. So those are the games.

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

R: Yeah, sorry certainly I forgot about those because there’s so many different resources now. Certainly in the past I have, I don’t know where to start as I’ve looked up a number of things to do with both conditions, so the anxiety and arthritis. Yeah, so at times when maybe I’ve been suffering more and been so exasperated by desperate measures, looked online for different things. So I suppose first of all online is your first port of call, it’s everyone’s port of call now, because it’s so easy to go on the Internet and just search anything. It’s just like an online encyclopaedia. So I suppose I’d sort of yeah, look at various websites specialising in it.

 Before I even do that, I mean it’s typical to do a typical Google search, to see what recommendations come up, but also the NHS is sometimes like a fundamental thing I’ll always start with, because obviously that’s like a Bible for health and it lists every single condition in alphabetical order. So I’ll go to each different section and it will give like a series of different links to forward you onto for specialist help in those areas. So stuff like that, even old school things like going to good old-fashioned leaflets, booklets, I’ve picked up some of those in the past when attending appointments on arthritis or rheumatoid arthritis.

 I’m pretty aware there’s some dedicated phone lines to them, support groups. Social media I must admit not something I have really. I’ve probably tried looking into it once out of curiosity, to see if there are support groups out there, and I’m pretty sure there are. I must be honest, I probably haven’t followed them up yet, not on purpose, because I’m certainly open to it, and it would be great to find a social group that you’re more on the same level, so you share common ground, albeit it’s not for very nice reasons.

 But at least – well it’s nice to know they’re out there, maybe that’s why I’ve not followed them up though, because I just know they’re always going to be there, so it’s more perhaps about time, I’ve just not felt quite ready. Or confident to do it at that point, or just not being in the right time...

**Int:** **Yeah.**

R: ... to follow it up if you know what I mean? But yeah, I’m definitely up for doing that in the future potentially, so yeah, I think there’s definitely some online, Facebook social groups, support groups even, and even ones more separate, external physical ones that probably could be recommended by health specialists.

**Int:** **[inaudible 52:30]**

R: Sorry!

**Int:**  **No, it’s okay, carry on.**

R: I was just going to say the last thing, because I haven’t attended an appointment for so long now, I’m a bit out of practice myself now with what’s available. I mean that was a whole year ago, and obviously a lot’s happened since then anyway, so there could be more available I’m not aware of actually.

Int: Yeah, yeah. It’s interesting what you say about social media that it’s something you’ve thought about but haven’t really...?

R: Yeah, I’ve dabbled in it out of curiosity, I’ve searched it sometimes. To be honest I think I’ve done it more for the anxiety/depression issues more than the arthritis. Because maybe the thought of meeting up with other people who suffer from it, it’s going to sound awful, but it doesn’t greatly appeal, because I mean other than that you might not necessarily have anything else in common. You might as well, but the point is you don’t know. I suppose you could say you don’t know until you meet them, and it’s not something I’m adverse to at all, I’m a really outgoing person, I’ll speak to anybody anyway. But it’s something you have to make specific time for, unless I’ve got nothing to do...

 The sad thing is I’m very busy at the moment but with nothing exciting, not socially, just a lot of personal issues out. So it’s probably just down to that too, it’s time. But yeah, I suppose if you met up with fellow suffers you could share... I suppose my only fear is, reservation, if I’m honest is just that because of the nature of what it’s about, obviously it’s a bit of a depressing subject. It’s a depressing subject for me anyway...

**Int:** **Yeah.**

R: ... and I’m sure it is for other people too, because it’s not very nice suffering with it and what it does to you.

 So if that’s all you’ve got in common, well it could act as a stepping stone to finding a whole load of other things in common with each other, but if you’re going there about that initially, so in theory it’s just based on that and talking about that, then I think, “Crikey what a depressing...” Because that’s it actually, it doesn’t help that I already struggle with anxiety and depression and mental issues anyway, so it probably doesn’t help it. Maybe that’s what put me off personally more, and if I’d didn’t, I might be far more inclined to go if it was just the arthritis I suffered from. But being on and off depressed anyway sometimes, I felt, “Crikey if I already feel like that and I go along to this, I might want to jump off a cliff by the end!” So perhaps that’s an underlying fear I have, I don’t like to commit too much.

Int: It sounds to me, you talk about social media and social interaction as a whole thing, and you’re maybe not inclined towards that at the moment?

R: Yeah, just at the moment, but not because I don’t want to, it’s more about time and matter of priorities, I suppose it’s not a priority at the moment.

Int: Yeah. And you picked up on two other things. We are coming to the hour now, but if it’s okay with you I’d like to carry on. I’ve only got a couple of questions left.

R: Yeah that’s fine [*eating snack- apologises about this*].

Int: That’s okay, you carry on. So you touched on a couple of other things in what you said, which I have here to cover anyway.

So the NHS website - do you think you could tell me about any particular experiences you’ve had of using the NHS website to find out about your conditions and potentially any other similar health advice websites like, for example Healthline, and what those experiences have been like?

R: Well first of all I’ll start with the easy one, you just mentioned Healthline, I must admit I honestly haven’t heard of them I don’t think. Or maybe I’ve seen them mentioned but they don’t instantly ring a bell to me. So with that no experience if I’m honest, but plenty of experience with NHS I must admit for all sorts of different reasons, the NHS website that is, different conditions. Yeah, I’ve definitely in the past, I can’t say possibly necessarily recently, because I know I already have done in the past and I might not necessarily have reason to, so soon, look it up again.

 Not to say I won’t, because I’m sure I’ll always need to look again at some point. But yeah, so looked up both the anxiety and the arthritis conditions, and I suppose experience of that from recollection is first of all, you know I said obviously each condition is divided up alphabetically, so you seek out your condition. I remember I know it’s divided into categories, which is quite good the way it, like the overall structure of the help on it. So it will obviously start off – and I swear I’m not looking at anything, this is just memory, so maybe I’ve looked at it quite recently, I don’t know. But it will start off with like an overview, like an introduction about the condition, then I suppose it’s common sense really, it’s logical, and then it will move onto a category-like symptoms. So summarising symptoms of it to ascertain if that’s what you’re experiencing. Possibly if you want to not self-diagnose, but self-research and get educated, then symptoms...

 Then the next thing, that’s it, I do remember it, the next thing is causes, so then it might then begin to give – and obviously, it’s never limited, everyone’s an individual, but a summary of some of the main causes as to what could cause it. Then after that I’m sure there’s something else in-between, but you’ve got obviously treatment, recommended treatment, and again it’s not limited, but some of the main treatments that can be recommended for that condition. Then finally the bit I remember, and this is what I’ve probably used in the past maybe, or looked for, is where it will then give like, or have a section of links to other third party external specialist organisations in this area to refer onto, redirect you to their website.

 So for example, I can think of a couple of examples, so if it was on the anxiety first of all, I know one of the ones they recommended was the charity Mind, and I’ve just remembered another one, it’s just suddenly come to mind, something called Heads Together. I think that’s a charity sponsored by royalty actually, because they sort of endorse the mental health. Then the arthritis side of things, I’m trying to think. To be honest I think because there’s so many different ones they all vary in their name. So like the Arthritis Society, I’m trying to think if I can think of any. I mean I’ve definitely looked at them in the past, but not for some time admittedly, but I know there are a lot out there. But it all lists sites dedicated to that, and then I’ll move onto that. So yeah, the NHS site is a great fundamental platform to start from, other than Google obviously or any search engine.

Int: So you say you’re looking for these kind of external links, would you say that’s the main thing that you go looking for?

R: I would say the point with the NHS a bit of everything, so yeah, external links for help to move on to, but also about the condition obviously itself as well. So just to see if there’s anything more on there, well yeah, more on there about the condition I don’t already know about, because I don’t know everything. And some things that are part of the condition I haven’t experienced or even some things it’s listed part of the condition I have experienced and not realised certainly symptoms, or didn’t know, didn’t put two and two together, that it might have been other symptoms I may have experienced, and I didn’t realise, necessarily think it was arthritis I suppose or whatever it is at the time.

 So then in other words, by reading this up on the NHS website it brings clarity, where you’ve seen them on there listed you think, “Ahh I know now, that explains why I had it, it was probably that linked to the condition.” So yeah, so certainly for self-education purposes as well, it’s definitely a good source of information. It’s like a health encyclopaedia is one way I could describe it, or a health Bible. It’s more at a basic level obviously, because they can’t obviously specialise in one thing, because it’s a massive institution that deal with everything as a whole, health as a whole. But that’s exactly why they’ll provide those links then at the bottom of ever different condition to refer you to specialist help.

Int: That’s really good that you do use the NHS website.

R: Yeah, I know definitely I have actively yeah, and even probably for other things as well, or other conditions in the past yeah, I definitely have, I’m well aware of it.

Int: Aside from the NHS website then, you said you put in the Google search and see to find out about things, what are you hoping to find maybe apart from the NHS website when you’re searching the Internet?

R: Good question. I’d say probably because I can’t think other than the NHS, any other generic site who might deal with it. So in other words I think the next best thing I think really anyway is, the natural best thing, would be websites or organisations specifically dedicated to the condition itself. I wish I could think of one, it’s annoying because I can picture the... Oh I might have it on me in all seriousness, I can picture the booklet, I’ve got a brochure, a booklet specifically all on arthritis and I think that’s been compiled by a particular organisation. I can picture it and I’m trying to think of the name. I might even have it here, yes I’ve got it, it’s here, I don’t know if you can see that at all? [*shows leaflet on webcam*]

Int: Yeah, so Arthritis Research UK.

R: This is the booklet I was talking about, one of them, I’ve got several because there’s all sorts of several different ones about neck pain, which actually I don’t really get. Well I’ve had it, you know when we mentioned about other types of pain before and you said about headaches and tension, I’ve had it in that context, but not with arthritis. But as I say, I’ve got several of these brochures anyway from the same company.

Int: Would you be looking online maybe to find their resource of the ones that you have on the brochure?

R: Potentially yeah, so obviously they have a website, so yeah, I’d probably definitely be inclined to go to the website. I’d probably first of all as I have the brochure, to be honest it sounds awful, I haven’t really looked at it much yet. But I’d be inclined to certainly look at that first because I have a physical copy. I’m a bit old-fashioned, I like a hard copy you could actually look through and flick through. So I would do that first, and then if I still wanted to, still felt it necessary to go to the website, if I need to for further information on stuff, and had a bit more time to invest looking into it.

**Int:** **Yeah, yeah. That makes sense.**

R: And because it’s live as well, it could be constantly updating with more things so yeah.

Int: So this way that you use the online resources, how has your use of those resources changed say from when maybe you were first getting pain to now? I know you mentioned about the games is more of a recent thing, but anything else that’s changed?

R: I’d say probably like less. What’s changed is I probably won’t refer to them as much anymore, because obviously I did more in the beginning when it first started when it was new, so researching the symptoms to try and find out more about the condition in general, causes, treatments and all that really. I suppose now it’s began to settle down and be under control with the medication and what have you, there’s a lesser need for it, because obviously it’s not quite as bad anymore. Other things in life have taken over. But that’s not to say I wouldn’t or won’t, I’m sure I will again at some point.

Int: Which Internet resources then would you say you found the most helpful, and why?

R: Definitely the NHS because that’s the first port of call that points you in the right direction. Other specific websites, I don’t mean to be unhelpful, I can’t remember any specific ones off the top of my head. Because yeah, I’m sure I’ve looked at them in the past, but it was so long ago, and I just can’t remember those names. But definitely it could well be one of the ones, the one I just showed you actually, so yeah.

Int: On the flipside then, which Internet resources have you found were maybe unhelpful and why?

R: Probably nothing really, yeah, nothing straightaway springs to mind anyway, I suppose because I haven't looked into it much of late anyway, I can’t exactly remember. But even when I did from a vague recollection, I don’t think there was anything. I might be more inclined to remember it if it was that unhelpful, so I don’t think there’s anything really that’s unhelpful in general. Provided obviously you’re going to a relevant site in the first place, but that’s kind of obvious.

Int: Yeah, that’s fine.

To close then, thinking about online resources, apps, websites, social media, is there anything else you think would be helpful, or would have been helpful in the past, for managing the pain associated with your condition?

R: I’m sure there are actually, and I’m sure I’ve probably come into sort of not contact, but I’ve come to see them in the past maybe when I have felt on the occasions where I’ve felt a bit more curious and inquisitive at looking up the condition, I’ve looked it up online.

 At the same time I might have researched it specifically through the App Store as well for specific apps on the condition too. I’m sure I have come into contact with certain ones that have popped up. Yeah, but I don’t think I’ve gone that one step further to the arthritis ones anyway to actually download them yet or look into them. Because I know I certainly have, and it’s not quite relevant, on a similar note, done so for the mental health side of things, I’ve certainly searched the App Store and downloaded some of those. A couple of examples I can think of straightaway one’s called Calm and Headspace, and there’s some others, but those are the two that straightaway spring to mind.

 So I have done, just so you know, I am app-minded, but just not specifically for arthritis yet. But maybe not thought about it, maybe I wasn’t that bothered enough at that time, which sounds awful, because I should be. Or maybe I just sub-consciously felt it was such a depressing thing, maybe I don’t really want to. I didn’t deliberately decide that, but it sort of swayed my decision at the time unknowingly. But I’m not adverse to in the future, after this session I might even go and look up now, because it’s made me intrigued.

Int: So there’s some things that you’ve seen that you’ve kind of saw them and thought, “Mm, not sure if I want to download that”?

R: Yeah.

Int: Is there anything that you’ve gone looking for that you wished was there and wasn’t there?

R: I don’t think so. I mean there’s bound to be on arthritis, there’s bound to be something there, I’ve just not gone the next step ahead to look. But it’s making me very intrigued to I’m tempted to look up in a minute. I’m sure that they’re out there, I can’t think that they wouldn’t be. Arthritis is really a very generic name because there’s lots of different forms of arthritis, I’m well aware of that too, because in the very beginning I think they first suspected mine was possibly psoriatic arthritis, and then of course there’s osteoarthritis and there’s some other ones. I know there’s lots of different versions anyway, so mine happens to be the rheumatoid, and I don’t really know the differences between them really. So yeah, there’s probably maybe one core app for just centrally for arthritis as a whole, and then hopefully within that different sections depending on the type.

Int: Yeah, right.

Unless you have anything to add to that, that’s the end of the interview itself. We’ve gone a bit over time I’m going to stop the recording now, and then I’ll read you a very quick debriefing statement, okay?

R: Okay yeah, certainly, no problem.

[Close]

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