

Participant F19

I: There we go! So that's recording now. So, yeah, as I mentioned before, we're interested in understanding people's experiences of being invited onto the NERS programme, so what has worked well, and what could be improved. So could you talk me through, I guess, right from the very start, of when you found out about the programme, and then what happened from there?

R: Yeah. So we moved to Wales in - it was June of 2017, and I had - I'm trying to think - no, I had already been diagnosed with fibromyalgia, that's right. And it must have been a little while after that I went to my GP, because I wanted to get back into doing some exercise again. So I went to her and she said, oh, you can do this free exercise. So I thought, oh, great, okay. So she said, oh, you just need to phone this person and arrange to go and have a session and things. So I said, okay, great. So she didn't seem to know too much about it, but she just said, give these people a ring. So I phoned them up and arranged to meet them at my local leisure centre, and went along. And it just was a lot more complicated than I was led to believe, so it was I had to pay for it for starters, and it wasn't free at all. Which was difficult at the time, because we couldn't really afford it at the time. I mean, we would be able to now, but it was just too much. And also - I also was a carer for my son, who has a disability, so it would have been really difficult to have taken a lot of time out to kind of... I think they only had - they were quite strict on when they had the sessions, and I think it just really was just too difficult with my schedule with everything else.

And so I didn't actually do it in the end. So, yeah, I haven't really got a lot to say about it, other than I guess it wasn't the best of experiences. It didn't match up with my expectations, certainly from what the GP had explained to me, so yeah.

I: So you said you were referred by your GP, and what did they...? What did you understand as - so you were going to get more exercise from your GP, so what did you understand you were being referred [over speaking 02:38]?

R: So what I'd hoped, was it would be like someone who understood fibromyalgia, and would be able to help me to exercise safely, and build up at a pace that was suitable for my condition. Because I was really keen to get back active again and doing things again, because I guess I'm kind of that kind of person. And, yeah, I just hoped that it would really help me kind of feel better, be more healthy, be more fit and also control my symptoms as well. So my understanding was, from having the initial chat with the GP, that that's what I could achieve with this. Which I may have been able to, but, obviously, I never actually did it, so it's a bit hard to say.

I: So when you were having a chat with your GP, how well do you feel that they described or explained the programme to you?

R: I'm not sure they really understood it very well, to be honest. I think she kind of obviously knew what it was, but I don't, I'm not sure she could really answer all my questions. I think it was more a case of, well, have a chat to them and they'll tell you everything you need to

know. So, I mean, it's quite good that it's there in the first place, don't get me wrong, but it just didn't quite meet up with my kind of expectations, I guess.

I: What was those questions that you were asking the GP, that they perhaps couldn't answer for you?

R: Well, it was a while ago, so I can't remember all of the ins and outs of the conversation. I can remember sitting there, and chatting. I certainly would have mentioned the fibromyalgia, and would have very much wanted it to be something safe, because the last thing I want to do is have another flare up. Because someone has said, oh, you need to do all this exercise, and actually it's not, it's way too much for what I can manage. But also I wanted to get - I wanted to get healthy, really, because I've got quite... I'd not been very active for a while, and I'd hoped to get fit and healthy and build up my fitness levels, really. So I probably would have mentioned that to her as well, but I can't remember all of the conversation, to be honest with you, it was a wee while back now. It was probably - I reckon it must have been about three and a half, four years ago, possibly, although that might even be completely wrong as well, so I'm not actually sure.

I: Yeah. No, not a problem at all. And so you were having a chat with your GP, and so what were they like when they were chatting you? How encouraging or supportive were they of this programme, or getting you involved?

R: Well, I don't think they were quite as proactive as they could have been. I think it was more just a case of, well, here's a number, give them a ring. That's it, really, I suppose, and it wasn't - they weren't particularly overly trying to make me feel like I should go, or anything like that. It was because I did enquire, and it was like, oh right, okay, yeah, I know what to do here - here's the number. And I don't think they really knew huge amount about it, to be honest. So she wasn't, like, put me off for anything, but I don't think she was particularly overly-encouraging me to do it, I guess.

I: Yeah. Is there anything [unclear 06:17] that bit of communication with you before you went to call the NERS programme?

R: I think it would have been - it probably would have been a bit more useful, I guess, if she'd understood a bit more about how... Well, especially like the money side of things, because I was expecting not to have to pay. And, actually, whereas that would be fine now, in that situation, I had to recently give up my job, because of my caring responsibilities for my child with the disability. And we had quite a lot of money worries at the time, and that was quite a big thing, actually, when you think you're getting something for free and then suddenly it's like, oh no, you have to pay. And it's like, oh!

I: Yeah.

R: So I think that was probably the biggest thing, because I probably wouldn't have gone ahead. And, I mean, I probably had to arrange childcare for that day and things like that. So it probably did inconvenience me quite a lot to actually go in the first place, so if I had needed to, I suppose that would have been useful to have known.

I: And when you said that they were asking for costs, what were those costs? Was it - could you kind of explain a little bit about what they were charging you for, I guess?

R: I don't actually know, and I can't really remember all the ins and outs of it. In my head, I think it was like around £15 a session, but, again, that could be wrong, because it was quite a while back. I could just remember the guy talking to me, standing there in the corridor telling me about it and me thinking, oh! Yeah, I can't remember, and I'm really sorry, because it was quite a while back.

I: Oh no, that's okay.

R: I don't want to give you completely the wrong information, but I think he said something like about £15, but, I mean, I wouldn't like to say for sure. I don't know whether that was like - it was subsidised, I think, was what they said, rather than paid for, I think, but, again, I could have got that wrong, because it was a while back.

I: Okay. So I guess, do you think that they - did they explain what the cost... From your memory, did they explain what the costs were, or...

R: I don't think I can say.

I: ...what was that experience...

R: No.

I: ...of that conversation?

R: There wasn't really a lot to say. I think I must have said probably to them, oh, I'm not sure I can afford that. And he probably just said, oh, well, that's just how it is type of thing. So we just agreed to leave it there, I think.

I: Okay. And so I just want to backtrack a little bit, and you said that when you were referred, you had to call the NERS programme, so what was that like? So you - did you have any other contact from them, or did you just initiate the contact yourself? And how was your experience with that initial phone call from that programme?

R: I can't remember. I've got a feeling someone might have phoned me, but I don't know whether it was because I left a message on an answerphone. I'm really sorry, I just can't really remember all of the details around that.

I: That's okay.

R: I don't know whether I had to phone and then leave a message, and then someone phoned me. Ooh. Sorry, my thing has just decided to do a software update. I was like, no, don't do that now. So, yeah, I'm not - I can't remember, sorry.

I: That's okay. Just, I guess, a generalisation of the experience, do you think that that initial contact could have been improved in any way?

R: With the GP, or with the actual programme?

I: **With the actual programme, yeah.**

R: No, not really. I think it's reasonable whether - I can't remember how I did it, whether it was me contact them, or left a message, but we got in contact, I think, reasonably quickly from what I remember, and I think it was okay at that stage.

I: **Yeah. Okay. And when you are deciding to go to the GP and have the referral, and deciding to get referred onto the scheme, did you speak to any family or friends about this referral, and sort of [over speaking 10:49]?**

R: No. Yeah. Do you know what? I think that's where it came from, and I think my mum had done it. That's right. She'd - that's how I knew about it, actually, I think. Now, she - why did she do it? I think she might have done it, and she's got fibromyalgia as well. She's also got rheumatoid arthritis, and she had a lot of success on it. She did - I think, I can't remember... She wasn't based in [place], she's [place], and she was living down in [place], at the time, I think. No, I can't remember if she was - I can't remember. Anyway, wherever she was, I think she had some quite good success with it. I remember she went once a week, I think, and so I think from her I'd got a really positive idea of what it involved. So, yeah, my mum would have been the one.

I: **Okay. And did you speak to her as you were getting referred?**

R: No, I don't think so, I probably wouldn't have done.

I: **Okay. And so did you have any sort of appropriate resources, or support that would have helped you engage in the programme? So [over speaking 12:06]...**

R: No.

I: **...from the GP?**

R: No, because I had - the biggest barrier probably was, well, two things: the childcare, because it would have been specialist childcare, because my child has a disability; but also the financial side of things as well, so no, basically.

I: **Yeah. And so if - or what if there were any, what are the benefits if you... The benefits you could see of joining at the time of referral? So I know you explained a lot of your expectations at the beginning, of what you were trying to get out of it. But what, I guess, would you have seen the benefit, most benefit to you when joining the programme?**

R: Just kind of things, I suppose, like losing weight, feeling more healthy and getting more energy, hopefully. I'd kind of seen it as a cycle that if I did exercise, it would help me get more energy, help me sleep better. I'd probably started eating better, that kind of thing, just lifestyle changes, really. But also feeling better in myself, is what I'd hoped to get out of it.

I: Yeah. How do you feel about the way that it was going to be delivered? So you went to the GP, went and had the initial meeting at the leisure centre, and I guess when you were at the leisure centre, how did you feel about how it was going to be delivered? So what...

R: Yeah. I didn't really feel that confident, I'll be honest. I remember chatting to the guy thinking, I'm not sure how much you know about fibromyalgia. So, in some ways, I guess that added to the reasons why maybe I didn't push to go ahead. But, yeah, I wasn't feeling overly confident when I was chatting to him, I have to say.

I: And why did you think that perhaps it wasn't a good fit for you?

R: I just don't really think he really knew enough about fibromyalgia, chatting to him. He was kind of like saying, oh, we'll do this, that and the next thing. And I was thinking, that's going to be way too much. And he didn't kind of come back with, well, the reason that we're doing this is because X, Y, Z. He kind of like fobbed me off a bit, I felt, and I just was like, hmm, I'm not too sure about this. So, yeah, I didn't feel overly confident in the person that I spoke to. I don't even know who he was, to be honest, but I remember chatting to him in the corridor there, and he was showing me around. And I was thinking, hmm, I'm not too sure.

I: And when you were having these kind of thoughts, did you discuss it with anyone? And, if so, what were their thoughts on it? So this could have been maybe a family member, or discussing it with the individual that was at the NERS programme?

R: No, I don't think I did, actually. I don't think he particularly invited any comments. I think he was kind of, like, quite overconfident, and so I just kind of left it. I just thought, oh, it's easier just to leave it be. And also he'd already mentioned the cost and the timings and stuff, and I just thought altogether, it just wasn't really going to work out.

I: You mentioned a little bit that when you were referred, when you went to get the referral, you'd moved to Wales, and I was just wondering how maybe did the timings of the referral, and your decision to get the referral, impact on your decision not to take up the programme, or not to engage?

R: I don't think it was anything to do with timings, to be honest, I think it was more... I mean, in the bigger picture, I think it was more it wasn't what I was expecting, and it required a lot more flexibility on my part, that I could give, because of caring responsibilities, and also the financial side of things as well. So I don't think, really, it was anything to do with the kind of general, in a grand scheme of things, timepoint thing, to be honest. It was almost like a natural progression anyway, because I'd been diagnosed with fibromyalgia while I was living in England, and I'd already done the fibromyalgia coping skills course, which had really helped me, and given me a lot of, what's the word? I was keen to try and live well with it, shall we say. And so I suppose it was the next thing was to try and do some exercise, and my mum must have said something about the one she'd done, or I must have seen what had been going on with her and thought, oh, that's good. And that's probably how I ended up going to chat to my GP.

I: Okay. Yeah, that makes sense. Thank you. And I wondered if are there any circumstances in which you would have accepted the referral?

R: Yeah, definitely. Well, if it had have been free, and if I could be in a bit more control of the timings, I probably would have gone for it. And what I probably would have done, is if I was a bit unsure, I mean, I would have just said no if he'd tried to make me do anything too much. And I just thought, no, this isn't any good and I probably would have just said, hang on a minute! But I probably would have gone ahead and done it, yeah, I'm pretty sure I would have done. And even now, a few years on, I really struggle to find anything that I can do kind of exercise-wise, that's safe for me to do. And I kind of still think maybe there's something out there for me still, I can get involved in like this, I don't know. It was interesting when I saw that the link came up on - and it was on Twitter I saw it, and I thought, oh, yeah, I remember that. And maybe think, oh, I wonder if it's still going on now, and whether I could still leap back into it, I don't know.

I: Yeah. So if the circumstances were that, I guess, the cost and the... What was the other section, that you - what other circumstances you said that you didn't [over speaking 18:40]...

R: Well, it was...

I: ...flexibility?

R: Flex-... Yeah, it was more about kind of me being able to control the timings a bit more, because I am needed to do certain things at certain times for my child, and, well, my children, but particularly for my older child, who has disabilities. So, yeah, I guess a bit of flexibility, but more flexibility around that would have probably meant I could do it, really.

I: Yeah. And I guess kind of going on from that, I guess what would you say you'd want from the programme is to see you, I guess, or to suit other people in your similar positions that would benefit them?

R: I guess something regular, and something predictable with a clear something to aim for, I guess, because you kind of see progression, I guess, you go through, with a particular kind of time point at which you've hopefully got to a certain point, I suppose. And just someone very supportive, I suppose, that understands my condition, who is delivering the programme. Yeah, I suppose that's something [over speaking 20:00].

I: And do you feel that that person - that you didn't get that from the NERS programme, in terms of the person who was supportive, or understood your condition?

R: I think he had a very clear idea of what the programme - well, like what would be done in terms of, do this. And then I think he was - I can't remember whether he said weekly or something. I can't remember exactly what he said, but he obviously was going to build a programme up, like, put something together. But I guess I didn't feel - I didn't feel overly confident that he understood my condition, so it made me a bit nervous. But, as it happens,

I don't know, and maybe if I'd done it, he might have proved me wrong, I don't know. You never know, do you?

I: Mm. Yeah. So I guess those are all of the questions I have for you, and I just wondered if there's anything else you'd like to say about the experience, or say what you'd kind of like to have seen or improved on in all of your experience with the NERS programme, or anything else that you'd like to add, really?

R: I think, overall, it's a really good idea and I guess it's something, as far as I'm aware, that it's specific to Wales and the opportunity. I don't remember anyone ever doing anything in England, or I don't even know, it might just be our area. I don't actually know where it's delivered, if it's the whole of Wales, or whether it's just here. But I certainly never came across anything like it in England, so that's really positive. But I guess the idea versus practicalities may need a little bit of tweaking. I am in a slightly different, I suppose, situation than some people, but, I mean, a lot of people will be carers for people and need a certain level of flexibility. If I was asked to pay now, that would be fine and I'd pay. It's okay now, because I've got a job and I'm working again now. And my husband is too, so that wouldn't be a problem these days, but at the time, obviously... Maybe - and maybe if someone's earning under a certain amount of money that you could say, you don't have to pay, or something. I don't know, I'm not sure. I mean, that might even be a feature that I just didn't know about, I don't know. But, yeah, I never got to understand - got to really know enough about it, I suppose, I never really got to have a go. So, yeah, it's a shame, but maybe I'll go back and give it another try.

I: So when you said you didn't have enough information, was there any...? What would you like, I guess, to gain more information?

R: So I think it would be really good if there was a website that someone could... The GP could have sent me to and said, oh, go and have a look at this website or something, or a leaflet, or something like that maybe she could have given me, rather than just... She just wrote a phone number down on a scrap of paper, basically. Something like that would be quite good, and also, I suppose then you could have the expectations could be set out quite clearly, so everyone was, like, obviously, paid for it, really.

I: Okay. Yeah, that's really interesting. Thank you. And I just wanted to know if there's anything else that you were expecting me to ask you today?

R: No. I didn't know what to expect, actually. So, yeah, that's no.

I: Okay. I'm just going to stop the recording now. Stop.

R: No worries.

End of Transcription