Programme 109: Fibromyalgia

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Fibromyalgia management's revised recommendations, walking as self-management, and one person's journey living with FM

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Fibromyalgia (FM) affects around 2% of the UK population, with 80-90% of those being women, and being a widely misunderstood condition its exact causes are unknown. Widespread pain is the major symptom; but people with FM may also experience fatigue, difficulty sleeping, memory problems ("fibro-fog"), muscle stiffness, and many others.

In 2016, EULAR (European League Against Rheumatism) published its Revised Recommendations for the Management of Fibromyalgia. In this edition Paul Evans speaks to Dr Gareth Jones, reader in epidemiology at the University of Aberdeen who was part of the study group.

Paul also speaks to Dr Kathryn Martin and Fiona Rennie about their work with Walk With Ease, a programme that encourages walking as a self-management technique for arthritis and musculoskeletal conditions like FM. He even has a go himself!

We also hear from Diane about her experiences being diagnosed with FM and her journey using swimming, yoga, and mindfulness as self-management techniques.

Paul Evans: This is ***Airing Pain,*** a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain, and for healthcare professionals.

I'm Paul Evans. And this edition of ***Airing Pain*** has been supported by the Women's Fund of Scotland.

Diane Edwards: It's a pain that can just appear out of the blue at any particular moment, in any particular part of the body. And it's not just the pain, it's the other symptoms that go along with it.

Evans: Fibromyalgia affects around two per cent of the population, and of those who have it, 80 to 90 per cent of them are women. And just some of those other symptoms that go along

with the pain are fatigue, muscle stiffness, difficulty sleeping, problems with memory and concentration, and the list goes on and on and on. As Diane Edwards, a long time sufferer, explains.

Edwards: My first symptom of course was the irritable bowel syndrome, and that was when I was 18 years old. I used to get a lot of stomach cramps, a lot of diarrhoea and constipation, and I was tested for lots of different conditions at that point, and it was called irritable bowel. It all sort of came a bit to a head when I went through the menopause. That was 12 years ago now. And everything just sort of kicked off, everything just went a bit wild. I started experiencing lots of other symptoms, acute abdominal pain - I've got three children, of course - but it actually felt like I was in labour, the pain was as extreme as that.

Evans: Gosh it was as bad as that?

Edwards: Yes. In fact I actually got taken into the hospital in the middle of the night by ambulance. My blood pressure had gone up, my heart rate had gone up, I was in such excruciating pain it was like spasms. There was something gynaecological going on, that's what it felt like. That was at the stage where I was going through the menopause. After that there was all the things like night sweats, and those are quite indistinguishable from the symptoms you would get with the menopause. So you get a lot of sweating, a lot of freezing cold, hot cold kind of thing. Also got hypersensitivity to things, that's a very big issue, bright lights, strong smells, loud sounds.

Evans: It's a very strange illness or syndrome, because people can ask you, 'how does it feel, how do you feel?' And I'm speaking for myself now, and I'll just say, 'well I feel awful, you know'. 'How do you feel awful?' 'just feel awful, I'm aching in every joint in my body, my brain doesn't function, I get absolutely exhausted'. And then people say, 'oh yeah I get tired as well' I say to them, 'no this isn't tired, I described it as like being hit by a torpedo, it comes from nowhere'.

How did you get a diagnosis?

Edwards: I had all these symptoms where I was getting the very severe pain and they were putting it down to the IBS, they did lots of different tests for like Crohn's disease, celiac disease, and it came up that it said normally if you want to get a diagnosis you need to see a consultant, usually a rheumatologist. And he said nothing shows up in the blood you've had done with your GP and things like that. And then he said, I'm going to press some points on your body and I want you to tell me how it feels. So he pressed certain points in my shoulders, my neck and various places, and they were really sore, really tender, even with the slightest pressure on them. And he said the fact that these points are really tender, he

actually called it pain amplification disorder, because I think at that time a lot of people were quite sceptical about this term fibromyalgia.

He didn't give me any leaflets, any advice about any medication, any advice about what I should be doing to help myself. He didn't give me any leaflets about how to cope with it. He said, 'I'm going to tell you if you don't go out' – I remember this because it was quite upsetting at the time – 'if you don't go out and get a life you will end up in a wheelchair for the rest of your life'. That was the only information he gave me, so I thought I'm going to have to work out for myself what to do here.

Evans: That's Diane Edwards.

Well, in 2016 EULAR, that's the European League Against Rheumatism, an umbrella organisation of national rheumatology societies, including the British Society for Rheumatology, published its revised recommendations for the management of fibromyalgia. Revised that is from the previous study of 2005.

So, a multi-disciplinary group from 12 countries assessed research studies into the management of fibromyalgia - pharmacological and non-pharmacological - and graded them, percentage wise, from weak to strong.

Doctor Gareth Jones, who is a reader in Epidemiology at the University of Aberdeen was part of that study.

Gareth Jones: The previous incarnation of these guidelines was largely expert opinion, there actually wasn't a big scientific evidence base. So a lot of the guidelines were based on what people thought, albeit experts in the field, or what they thought was appropriate management. Since then there has been quite a lot of randomised trials demonstrating that treatment A is more effective than treatment B, or not.

Evans: It goes through just about everything I've ever heard about fibromyalgia, all the medications and things like that, hypnotherapy, massage, meditation, everything. It seems to me, to cut to the quick, that there is only one positive view of what is good for fibromyalgia, and that is exercise.

Jones: Yeah, so exercise was the only treatment that we looked at for which we came up with a recommendation of strong for, as in the recommendation strongly for exercise. That's not to say there aren't other therapies for which there are trials that have shown benefit. Actually, there are so many trials, we were looking for reviews of randomised trials, so we were reviewing the literature that has already pulled together a lot of evidence. And so when we came up with a recommendation for being strongly for something we were satisfied that

there was enough of a body of evidence demonstrating that this treatment is effective. Where we didn't recommend strong for, it might have been that there was evidence suggesting it wasn't effective, or it might have been that there wasn't evidence. For a number of therapies, especially newer therapies, it's the same with new drugs, actually it takes a while for that evidence to build up.

Evans: But there's exercise and there's exercise. Now I remember when I was diagnosed with fibromyalgia 25 plus years ago, I was told to go and buy a pulse monitor watch that sportsman wear and really max out on exercise, make sure that I really thrashed it, if you like. It didn't work for me, and others have said exactly the same thing.

Jones: And obviously I can't comment on precisely the advice that you were given. You're absolutely right, there's exercise and there's exercise. And so what we found is that there is good evidence that patient outcomes in fibromyalgia, and they may be pain, they may be function, they may be whatever, are improved with exercise versus not.

The trials that have looked at exercise, some of them have done aerobic exercise, some of them have looked at strength and conditioning, some of them have looked at exercise on land versus in water, hydrotherapy exercises and so on. And that's where it gets a little bit more difficult to determine whether there is a benefit or not. When planning a trial of course the expected benefit, or how you might power the trial and determine how many people you need in the trial, is based on what you expect the difference might be. And to say "let's assume people's pain scores might improve by two out of ten in the exercise group compared to a non exercise group". But if you're comparing one kind of exercise with another kind of exercise, then the improvement is going to be much smaller, and so actually the trials would have to be bigger, they tend not to get done.

So actually there's very little good evidence comparing different kinds of exercise. So it's not possible to say it's strengthening which is beneficial, as opposed to aerobic exercise, or the other way around, because that evidence is just not there.

Evans: I think the danger is with advice like that, I'm not the only person who has had advice like that, I think many people have had advice like that, the only danger is that it could be, and I suspect it might be very beneficial; but exercise as a prescription is not enough. There is cognitive behavioural work that needs to be done to help you get there, you don't go straight at it, it's not a therapy in itself.

Jones: I think having the psychological support, where necessary, is absolutely important. It's not a treatment such as taking a drug, where if you take a tablet you have ingested the chemical that has the beneficial effect. What's exercise, is it walking, is it running, is it

swimming, is it doing it for five hours a day is it for 20 minutes. So the dose of exercise that you can take, or that you can do, is highly variable. And not only variable in terms of what's possible, but probably also variable between what people require, and indeed what they are able to do.

Evans: That's doctor Gareth Jones.

Doctor Kathryn Martin, also at the University of Aberdeen, focuses her research around physical activity for people with arthritis and musculoskeletal conditions like fibromyalgia.

Kathryn Martin: Exercise is something that's structured. And it's marked by things like what type of exercise you do, what type of movement. Usually it's around moving large muscles and joints, doing it for a certain amount of time and thinking about the intensity level; so not all activity or lifestyle activity that you do can be considered exercise. And people often find that from wherever they are, whatever their baseline is, they are able to do more or less of a different type of activity or exercise.

Evans: Well you've been working on a project called Walk with Ease?

Martin: Yes.

Evans: Explain that to me.

Martin: Walk with Ease is the Arthritis Foundation's activity programme that was developed specifically for individuals with arthritis. And it is a six week community based walking programme. And when I say it was designed specifically for folks with arthritis and musculoskeletal conditions, it takes into consideration the barriers that individuals often have around fear of movement, fear of pain on exercise. It tends to some of the concerns that people have about reengaging with activity, if they've been inactive for a while.

And so individuals can do this either in a group with an instructor who's been trained in Walk with Ease, and leading the Walk with Ease programme, or they can do it on their own with a guidebook. The guidebook is there for all individuals taking part in walk with ease, but there is that element where you are able to do it on your own, in case you maybe have care giving responsibilities, or if you're still working, and so if you aren't able to take part in a group, especially since it's meant to be three times a week for about an hour or so, so it can be quite a time commitment. But folks really enjoy being part of a group and having that social aspect. So there's both elements, individual or instructor led.

Evans: Well, I don't have arthritis, but I do have fibromyalgia, and I'm going to join a Walk with Ease group. What do I need to know, will I start at a sprint, or a crawl?

Martin: You won't start at a sprint. It depends, I suppose, whether or not you'd like to start at a crawl. But we'll do a small warm up, getting limbered up, getting the muscles warmed up, so taking just a little bit of a walk, stopping and doing some stretching exercises, cause that's really important. And that's not often found in other heath walks or walks. And then once the stretches are done, there's a set of five that we'll do, we'll get into the main bit of the walk. And that's really to get up to a moderate pace, as well as you can do. But we'll probably aim for at least 10 to 15 minutes, and if you need to have a slower pace you can hang back, there's always another person who is willing to walk alongside you. But then once we've finished with the main walk we'll do a little bit of a cool down, and then do some stretches at the end.

Fiona will probably also at the beginning talk a little bit about the goals for the day and she'll bring along her lecturettes, so just a bit of a conversation about activity - so each of the sessions has a different topic to focus on and get the group thinking about for the day.

Evans: But I won't be embarrassed if I have to slow down or stop, that's the important thing.

Martin: No, that's the important thing, absolutely, that's part of it. It's recognising the limits and knowing where you are able to set your goals to for that day, in terms of your intensity and the amount of time that you're able to walk for.

Evans: Alright, let's go for it, be gentle with me.

Martin: Absolutely.

Evans: This seems like an appropriate time to remind you that whilst we in Pain Concern believe the information and opinions on ***Airing Pain*** are accurate and sound, based on the best judgments available, you should always consult *your* health professional on any matter relating to your health and wellbeing. And that of course includes starting a new exercise regime. He or she is the only person who knows you, your circumstances and therefore the appropriate action to take on your behalf.

…

Ok Katherine, we've left your sumptuous office in Aberdeen University, just tell us where we are now?

Martin: Right now we're in the Westburn Outdoor Sports Center, that's run by Sport Aberdeen. It was a location where we held our physical performance assessments and it was also one of the areas where a walk, for Walk with Ease, actually went out from. So, it's a

nice community centre, there's a nice size park, it's a great, beautiful day out. And with us is Fiona Rennie, she was one of the Walk with Ease leaders that we trained to deliver the Walk with Ease walk as part of the research study. She also does health walks as part of volunteering with Sport Aberdeen.

Evans: Fiona, you're going to put me through my paces today are you?

Fiona Rennie: Yes, I'll just get started?

Evans: Yup, please do.

Rennie: Ok, so we usually start with a lecturette, so I'd just like to make you aware of making a doable personal walking plan with realistic goals for improved fitness. And this is a very important one - the two hour pain rule. So your pain should not be worse two hours after you exercise than before you started. If it is, cut back. So that's saying, like today when you go away from here you might have pushed yourself just a little bit, you might get home and you're fine. But you might still be sore in two hours time. So, next time please come and say to me, or if you're out for a walk and you do too much, calm down for the next day. It's a build up rather than 'I've got to do this now'.

Evans: You say two hours for arthritis, two hours for maybe other conditions. For me personally it might be two days later. But as long as I can read those signs, then it should be fine.

Rennie: It's to do with awareness. So now we go on to exercise dos and don'ts because we will be doing exercises before we start our walk. So *do* build a programme that includes the three different exercises of flexibility, strengthening and cardiovascular. Cardiovascular is when we are walking. *Do* walk when you have the least pain and stiffness. *Do* walk when you are not tired. *Do* walk when your medicine, if you are talking any, is having its greatest effect. *Do* always include a warm up and a cool down whenever you walk. *Do* start at your own ability level, move slowly and gently and progress gradually. *Do* avoid becoming chilled or overheated when walking, like today we've got a brisk cold.

Evans: Brisk?

Rennie: [laughing] Up here in the North-East. *Do* use heat, cold and other strategies to minimise pain. So when you go home and you are having that pain. *Do* use aids, this is the most important thing I would say, cause you're coming to a group you might be embarrassed to use your walking stick or your poles to help, but you normally have them.

So that's all the dos, but we've always got don'ts. *Don't* do too much too soon, start slowly and gradually. *Don't* hold your breath when doing anything – because that's when people count to thirty and take a deep breath in. *Don't* take extra medicine before walking, unless prescribed by your healthcare provider. *Don't* walk so fast so far that you have more pain, and as by now I think you'll get, two hour pain barrier. And that's all your exercise dos and don'ts. So the next thing will be we'll go out and it'll be like a slow walk, then we'll have our exercises, then we'll have our walk, we'll kind of pace it up a bit, then we'll slow it down, then we'll have our exercises. And that's the programme ahead.

Evans: Well I'm looking forward to it. It's a lovely day in Aberdeen, ice on the pavement, so we should be a little bit careful of that, shouldn't we? It's very cold for my soft, southern body, so we wrap up warm.

Rennie: And the other thing that we do is we chat and have a laugh.

Evans: Chat and have a laugh.

Rennie: Yes, because like we said, it's fun as well.

Use your surrounding area for the exercises, so as you see we've got a bench, if people wanted to do that there.

Martin: So you can do them seated, is that what you're suggesting? Some of the exercises can be done seated?

Rennie: And a lot of people like going up against a tree. People wonder how we're outside doing exercises, but it's to be at the same temperature. If we did it inside you'd be too warm coming out into the cold.

Evans: So we've done a short walk, just to acclimatise to the temperature, get our muscles into the cold if you like. [laughter]

Martin: So shall we grab a tree then?

Rennie: Yup, wherever you want to.

…

Evans: On the same subject, of the revised recommendations for the management of fibromyalgia, I'd be very cautious as a patient in reading this, because the medicine that I take it says is not particularly effective, although it does some stuff for me. I'd be very

cautious as a patient, for other patients to read through something like this, just in case it skews your mind into something that has been working for a long time.

Jones: I would caution patients about reading it and I'm not saying that they shouldn't read it, it is not written as a patient facing document, if you like. There are other documents that are written specifically for patients. To say that certain treatments don't work is difficult. Clearly, in a study where you're testing a new drug, let's say, you want to test it against a placebo, you want to test it against existing therapies. And if you're testing it against an existing therapy, and maybe in that existing therapy 50 per cent of people show improvement, and with your new drug 60 per cent of people show an improvement, then this would be heralded as an enormous success. But you have to remember that there is still 40 per cent of people who are not showing an improvement with the drug.

So a lot of the trials are really just looking at is it better than a placebo, is it better than what's already there. But of course if you give the drug to 100 people and 60 are responding, there is still 40 who are having inadequate pain relief, and will need something else. Even drugs and therapies that we say are effective, there are still people for whom they won't work. And there will be therapies that we say actually the evidence isn't great that they are effective, but there will be a sub group of them for whom it does work.

…

Evans: We're using the tree, which could be anything really, just to support us, and we have one leg in front of the other, and we're just gradually stretching what feels like to me my calf and my upper thigh.

Rennie: As long as it's not just your calf, that's good it's your upper thigh.

Evans: See I'm falling into the trap again, I'm really pushing hard to get it to, almost to hurt. I shouldn't do it.

Martin: Do you find sometimes Fiona people get impatient with waiting their 30 seconds on each side?

Fiona: No, they're impatient if they don't feel that stretch.

Evans: Ahhh.

…

Maybe I was a little bit negative about patients reading this. The plus side is that many patients, myself included, with something like this, is many people have expressed surprise to me that there is so much work going on into fibromyalgia. Somebody just this morning said, 'I didn't know anybody was working on it, it's like we're a condition in a vacuum'. There is a lot of work going on with it.

Jones: There is an enormous amount of work, internationally. It's a sad fact that some conditions will, I don't want to say become 'in vogue', that sounds terribly patronising, but money that charities, research, councils, that fund this work have finite pots of money, and this year money will be going towards x, next year money will be going a bit more towards y. But across the board there's quite a lot of work going into chronic pain and fibromyalgia for a number of funding bodies.

…

Evans: So we're at a decent pace for me now, but we're not ambling. Watch the ice. Too much time talking, not looking where I'm going.

Martin; It is an important feature, thinking about where are you going to walk, what are the conditions like. Especially if you were to fall, walk with these programmes and walk independently, so when you're with a group you have other people around, but you always want to make sure that you're safe and you understand the conditions of the pavement and if there's any trip hazards and things in your local area, wherever you like to walk.

…

Evans: It's not the responsibility of a researcher or a healthcare professional to manage somebody's pain for life. People with pain have to take ownership of something at that point, and that's the important thing isn't it, that they have to take ownership of it?

Martin: Absolutely. I think that a lot of individuals want to be able to self-manage their condition, and have those skills to be able to do so. We operate in a world where there are a lot of different medicines or things that can be given to cure things instantly. But being active even without any condition like fibromyalgia is important to be able to maintain good physical health. So that is one element that all individuals can take ownership of and try and increase their activity over time and maintain it as well. So yes, I think that that's an important aspect of self-management of a long term condition.

Evans: Kathryn Martin, of the University of Aberdeen. She's the researcher behind the Walk with Ease programme in the UK, which is funded by the Arthritis Foundation and Arthritis Research UK, now going under its new name Versus Arthritis.

You can find out more about how to Walk with Ease, be it in a group or by yourself, from the website arthritis.org. Just put Walk with Ease into the search box at the top of the page, all the resources are there.

And don't forget that you can download all editions of ***Airing Pain***, including videos and resources on self-management, from Pain Concern's website, which is painconcern.org.uk.

Now, on that subject of self-management, you'll remember that I spoke to Diane Edwards at the start of this edition of ***Airing Pain.*** I'll just remind you of what the doctor who diagnosed her fibromyalgia told her.

Edwards: He said, 'I'm going to tell you if you don't go out' – I remember this because it was quite upsetting at the time – 'if you don't go out and get a life you will end up in a wheelchair for the rest of your life'.

Evans: And her response.

Edwards: So I thought 'I'm going to have to work out for myself what to do here'. So I went back to my GP and she said 'we're going to try and work out how we can help you'. So she started me on the amitriptyline, but I just felt like a zombie so I decided, no I'm going to find another way to get round this.

We then tried hydrotherapy, and that was lovely, it was really nice, nice warm water in the pool' and we did gentle exercises, I would say, in the pool. And then I thought, I always used to go swimming a lot when I was younger, I really enjoyed swimming, so I thought 'I'm going to try and keep this up'. So I started going swimming just once a week after the hydrotherapy sessions had finished. The water is really good because it supports your body, so you're not putting a lot of pressure on it. And I now going swimming once a week. And I thought I'll build up, I did a couple of lengths and went up to five lengths after a little while, up to ten lengths, and I can swim up to 40 lengths now in one session. Takes me about 35 minutes.

Evans: You've built up to that 40 lengths?

Edwards: Oh yeah, over the years. From the hydrotherapy that I had to start with I guess. And then I thought, right I'm going to explore other things that might help. First of all, we went and got a dog. That gave me the encouragement to go out for short walks. Not hikes

up mountains or anything like that. Just like round the block kind of walks, at my own speed. At one stage I was doing three walks a day, but I'm down to two now, cause the dog's got quite old and she doesn't like walking as much anymore.

Evans: Your dog can't keep up with you.

Edwards: [laughing] Not quite. And then the other thing I explored was yoga, because I know yoga is very good for gentle stretching your muscles, but it's not intense like running on a treadmill or lifting weights or anything like that. It's called Hatha Yoga, which I think is the gentlest form of yoga.

Evans: Ah, ok yeah.

Edwards: It's not these things where you tie yourself up in knots, it's very gentle. Maybe I'll do five or ten minutes at home every evening as well. I force myself, maybe if the televisions on I'll just think 'I can do these things'. I can still touch my toes and my daughter can't do that. [laughing]

Evans: I didn't know I had toes.

Edwards: So, yoga's been really good because it keeps you very flexible, very supple. Even though some evenings I might think 'I don't want to do this'. I don't force myself, but I think, 'this is good for me, I'll do this, this is good'. So it is about managing your time doing all these things. You wouldn't go on a three mile hike, you wouldn't go and run 20 miles or anything like that. So I don't pretend that I'm particularly good at anything, but I just maintain a balance that my body can manage at this particular stage in my life.

Evans: So you've learnt how to self-manage your condition?

Edwards: Oh, definitely, yes. And I also think it's not just the physical exercise, it's also mental exercise as well. I think you've got to keep your mind quite active. So I like to do things like sudoku puzzles, crosswords, there's an online site where you can do courses which are set up by different universities. And you can enrol on them. Some of them are four week courses, some are six week courses. You don't get any qualifications at the end of them, but they are really interesting, and you can interact with your fellow learners. So that keeps my mind quite active too.

Evans: Exercise for the mind and body?

Edwards: Yeah.

Evans: For more information about fibromyalgia I suggest you go to the Fibromyalgia Action UK website, that's at fmauk.org.

So, to Fiona Rennie, my personal Walk with Ease leader.

…

Rennie: Back here just to see how you got on, how you're feeling just now before you go. Is there pain just now?

Evans: No more pain than I had when I started.

Rennie: That's good to hear.

Evans: And I'm very surprised, because the walk I normally try and do is more physical than this, and I found this better today, because I've been held back.

Rennie: Yeah. What will you be doing before the next time I see you, so I don't want you to just do the walk today and then the next time it's the walk then, what are you doing in between?

Evans: Well, the one thing I've learnt today is the stretching, the warming up and cooling down, the stretches are really worthwhile. And they are the things that really go, that you would ignore completely, come on let's just get at it.

Rennie: Just think, professional football players, they warm up, they warm down.

Martin: They do their stretches.

Rennie: Yup, so let's be professional, we're walking.

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