

Airing Pain Programme 29: Fibromyalgia

Living with fibromyalgia, and the medical research offering hope for the future.

Fibromyalgia affects an estimated 2.7 million people in the UK, yet it is a condition which is poorly understood leaving the people with it often facing ignorance and prejudice. Presenter Paul Evans, who has fibromyalgia himself, talks with Lexy Barber about her experiences of coping with it. We also hear from Professor Ernest Choy and Professor Dwight Moulin about advances in medical knowledge of the condition and possible ways of managing symptoms.

Paul Evans: Hello, I'm Paul Evans and welcome to **Airing Pain**. A programme brought to you by Pain Concern; the UK charity that provides information and support for those of us who live with pain. This edition is made possible by Pain Concern's Supporters and Friends. More information on fundraising efforts is available on our Just Giving page at painconcern.org.uk.

Lexy Barber: What people think is just a general, minor knock when you are standing shoulder to shoulder with people, is very painful when they are... actually, it feels like they are just punching you in the arm repeatedly.

Professor Dwight Moulin: It is not primarily a psychological disorder, it is a chemical imbalance that causes a whole multitude of symptoms, but the primary symptom that causes the greatest disability is chronic pain.

Evans: Why should we on **Airing Pain** be even discussing the *validity* of a condition that affects an estimate of up to 2.7 million people in the UK? Well, I have fibromyalgia and I can tell you it is *very real*, yet, for years the condition was considered by the public, fed by an ignorant press and, I have to say some of the medical profession, as a psychological disorder – something in the imagination.

Even though fibromyalgia is now recognised by the World Health Organisation and the NHS (National Health Service), the spreading of misinformation persists. Only recently, a columnist in the UK tabloid press wrote that his new year's resolution for 2012 was to become disabled, nothing too serious, maybe just a bit of bad luck or one of those newly invented illnesses, which make you a bit pecky for decades – fibromyalgia or ME. Now, that is not only offensive and

damaging to people who have these conditions, but to people with all disabilities.

So let's put the record straight – what is fibromyalgia? Ernest Choy is Professor of Rheumatology at Cardiff University, he is also on the Medical Advisory Board of Fibromyalgia Association UK.

Professor Ernest Choy: Fibromyalgia in simple words means pain in the tissue and, in the main, a patient with fibromyalgia will have pain throughout their body in different tissues. It is very common – it affects something like two per cent of the population. It tends to be more common in women than in men. It can affect children as well as adults. The most common age of onset is round about the 40s and 50s. It tends to last for a long time. One of the most frustrating aspects of the illness, is that many patients do not have any outward signs of a physical illness, although they feel terrible in themselves, because they are in pain and often their friends, relatives, their colleagues at work do not quite fathom what the problem is.

But we have started to understand the condition a lot more over the recent years. First of all, the condition is not what I call homogenous – it means that there are different kinds of fibromyalgia. You can have different events and illnesses and factors can precipitate and bring on fibromyalgia, so in many ways, we do not always treat the patient in the same way – it really depends on what we think are the main factors that drive or cause fibromyalgia in the individual patients. But, in every patient with fibromyalgia, what they *do* suffer from, is pain throughout the body – it may vary in intensity from day to day and it may move from one place to another but it is uncommon for the patient not to be having pain somewhere in the body at some point.

Evans: Professor Ernest Choy. Now it is always good to talk with others who share your condition, to share notes and to compare coping strategies, so recently I met Lexy Barber and this is how it affects her:

Barber: It depends on whether it is a good day or a bad day and they tend to come in series – so it is more like a good week or a bad week. A bad week, a very bad week can be, particularly if I have gone down with a cold or something and I am recovering from it – then my muscles tend to go into flare and it is very, very tender and sore, so things like commuting on really packed trains is not very comfortable at all because what people think is just a general, minor knock when you are standing shoulder to shoulder with people, is very painful when they are... actually, it feels like they are just punching you in the arm repeatedly. They obviously don't realise that you are in pain and you can't just shout out at them to not, because of the situation

you are in – that can be really hard. On a good day, it doesn't matter quite so much, it is always there, it is always a bit painful – sometimes you don't know it is there, until someone bumps into you or you accidentally walk into the door frame, as I have a tendency of doing.

Choy: Pain is one of the most common and I would say, universal symptom, but there are lots of symptoms associated with fibromyalgia – fatigue, tiredness is very common; non-refreshed sleep – so people go to sleep, they may sleep for hours, but when they wake up in the morning, never feel that they had a good night's sleep. 'Fibro fog' also means that people also have problems with short term memory, they don't seem to be able to think clearly, people may have headaches, migraines, back pain, dizziness, sometimes even palpitations, anxiety, depression – all those are very common symptoms of fibromyalgia.

Evans: ... and irritable bowel syndrome?

Choy: Irritable bowel syndrome is a common occurrence in patients with fibromyalgia, yes.

Evans: Now that is a lot of symptoms, so what is causing this?

Choy: For a while, people don't understand why a fibromyalgia patient has this whole range of symptoms but it is now clear that one of the issues, in us coping with pain, is that all of us have an intrinsic mechanism in the brain that controls pain. So when we experience pain, we will naturally have a reaction to the pain because it stresses us, makes us depressed, it makes us upset, irritable. Normally, the body actually has a way of suppressing the severity of the pain, to make it cope-able and manage the pain – but what is clear, is that in a patient with fibromyalgia, some of these intrinsic mechanisms are not working very well – so they are less able to manage to cope with the pain, so they get quite frustrated, they get quite tired with the pain and not surprisingly because they cannot control the pain, they get more irritable, they get more anxious, they get more depression.

Another aspect of it is, that because the pain is inducing stress which is the normal reaction of pain – the stress also makes the whole body more sensitive because actually, one of the normal consequences of stress is to bring down the normal thermostat of the body, it is like a cat having his hair on end when he's stressed, that's how he responds. In a patient with fibromyalgia, the whole sensory threshold of the person gets lowered down, so they just become far more sensitive to where there is noise, where there is light, where there is movement in the bowel – the whole person becomes on edge. I think then you can start to understand why they have this

whole range of symptoms just from a single illness.

Evans: My wife describes it as when I get like that – she says ‘you need to be turned down’ and I say ‘my thermostat is not working’.

Choy: That is exactly the reason why the whole body seems to be on edge and in many ways, our way of managing the illness is by [finding] how to turn down that thermostat.

Evans: Ernest Choy. Now before that offensive article that I referred to earlier, was written, Professor Dwight Moulin, a neurologist at the University of Western Ontario in Canada chaired a session at the British Pain Society’s Annual Scientific Meeting in Edinburgh – it was under the heading ‘Fibromyalgia – is it a central neuropathic pain or a condition of psychological distress?’

Professor Dwight Moulin: There has been a perception that fibromyalgia is a primary problem of psychological distress and that’s been a mindset that goes back decades. Probably, where we are now with fibromyalgia is the way we were maybe a hundred years ago with epilepsy or, say, migraine or schizophrenia, because a hundred years ago – if you had seizures, you might be in an insane asylum and nobody understood migraine either. And you can look at the brain in individuals with migraine or primary seizure disorder and they look completely normal and we know now that these are conditions or so called chemical imbalance, so there is a chemical imbalance in the brain that can cause people to have terrible headaches, cause people to have convulsions, but you can’t see it looking at the tissue under the microscope.

And it is turning out now that fibromyalgia is another condition of chemical imbalance: it is not primarily a psychological disorder; it is a chemical imbalance that causes a whole multitude of symptoms. And one of the effects of this chemical imbalance can be to produce psychological distress, including anxiety and depression – and these are comorbidities – but the primary symptom in fibromyalgia that causes the greatest disability is chronic pain and that is part of this chemical imbalance. And in the past ten or twenty years, a lot of work has been done to show and validate the fact that this chemical imbalance is responsible for many of the symptoms in fibromyalgia including pain and an inability to sleep and the secondary anxiety and depression.

Evans: Let’s go back on that, chemical imbalance – what chemicals are we talking about, what should they be doing and how are they out of balance?

Moulin: The central nervous system is an interplay between factors that excite neurons and others that inhibit neurons. And there are neurons in the spinal cord that are responsible for

transmission of pain impulses. Normally if you stub your toe, or put your hand on a hot plate, you experience pain and that is important, because that alerts us to injury and so we withdraw right away and we do not hurt ourselves. In fact, there is a *very* rare condition where people lack awareness of pain and by the time they are teenagers, their hands and feet are mutilated because they do not have this protective reflex. So, that is good, that is normal, and that is physiologic pain that protects us from injury.

But there are conditions where a chemical imbalance occurs, where certain chemicals are not present in the central nervous system at levels that they should be to normally inhibit impulses. And the two primary chemicals that we are talking about in the central nervous system are: serotonin and noradrenalin. Levels of these chemicals in the central nervous system can blunt the pain response and prevent us from tipping over into a state of chronic pain.

We know now from many basic science studies, that individuals with fibromyalgia, are lacking in levels of these two chemicals, to the point where things that normally should just be pressure or light touch are actually experienced as pain, because they do not have the normal filter mechanism in the central nervous system to appreciate it just as light touch it actually comes through as a painful impulse. The clinical side of this, in terms of the bedside, is that there are drugs available, essentially they are antidepressants, but they are antidepressants that work as painkillers, that elevate levels of these chemicals that help restore that balance.

Evans: Well, I am such a happy man, I can take one of these antidepressants, if you like, and I will be cured?

Moulin: I wish that were true. It is not a cure, but it helps to restore that balance, not in every patient, but in a significant number.

Evans: How do you diagnose it?

Choy: We have certain criteria, we base it on the symptoms of the patient, typically a patient with fibromyalgia will have a *very* characteristic area of tenderness in the body, so if you press on certain areas they jump and scream a little bit, because they are increasingly sensitive to pressure, so light pressure causes a lot more pain than it should. We do blood tests, not because they are tests that will confirm their fibromyalgia, but, in the main, trying to exclude other possible causes of the pain. So it is not uncommon for us to do tests, in effect the tests are normal, they are really to exclude other possible causes of pain.

Moulin: There is no clinical diagnostic test. There are research studies that are not normally available to help validate fibromyalgia. One of the excitatory chemicals that is responsible for pain is something called 'substance P' – I guess maybe 'P' stands for pain, but I am not sure – but substance P is an important factor, in the generation of pain. If you do not have these inhibitory chemicals, levels of substance P are elevated. One of the most validating aspects of fibromyalgia is that individuals that have this condition, if they see a surface sample through a lumbar puncture, levels of substance P in patients with fibromyalgia are on average three times higher than they are in normal individuals. That is a research tool but it is a test that helps to validate this chemical imbalance.

Evans: Just tell me if I am right or wrong – substance P is a chemical that is present (it is always present) but at high levels, it is present when one is in pain?

Moulin: Substance P is a chemical that excites neurons that are responsible for generating nerve impulses. So, elevated levels of substance P means more pain, if you inhibit substance P you can decrease the amount of pain that a person appreciates. And many of the analgesics that we have including so-called narcotics or opioids – what we refer to as morphine-like drugs – they inhibit the release of substance P and that is a major mechanism providing pain relief because they decrease the release of this substance that excites pain neurons.

Evans: So, here is the billion Canadian dollar question... *What causes it?*

Moulin: I do not think anybody knows what causes fibromyalgia, but individuals with fibromyalgia they are pain-prone individuals. So patients with fibromyalgia have other manifestations of this chemical imbalance: they have a higher incidence of migraine; they have a higher incidence of irritable bowel syndrome; they have a higher incidence of depression... It is more common in women, as many pain conditions are, and often it will manifest itself in women in their thirties and forties.

These are individuals who probably are predisposed to this condition because they have inherited a deficiency in these two chemicals – serotonin and noradrenalin – and then they will have an event like a whiplash injury and it just tips them over the edge. And that is enough to cause the symptom to manifest. A typical story is somebody will have a soft tissue injury like whiplash, then they will have chronic neck pain and it spreads to their whole body and about 50 per cent of patients with fibromyalgia started with a specific injury. These are individuals who probably have innate... they are born with this chemical imbalance and over the course of a

lifetime of life events it manifests itself, not just with this generalised pain, but these are individuals who have other pain conditions as well like migraine and irritable bowel syndrome. It is kind of a nasty package.

Choy: Because of these different factors, one of the first things that we try to do is to understand 'what are the characteristics of the patient?' and 'what are the factors that may well be related to their specific fibromyalgia?' Just to give you an example, somebody who is a bit overweight, who sleeps very poorly, snores very heavily, may well be waking up very frequently at night and that, triggered off by chest infections, starts to develop fibromyalgia. So in those patients we try to make sure that their sleep quality is improved. Alternatively, in some patients if they have a very severe, uncontrolled depression, that is not well managed, then we will manage the depression. So I think that in individual patients there are different aspects that we try to address.

Evans: What I find very difficult, as somebody who has fibromyalgia, is explaining to somebody else how I feel. I could just say 'I feel rubbish' and that is the end of it. If I was sad enough to want somebody else to experience this, just briefly, how would I do it?

Moulin: One of the challenges of fibromyalgia is that people can feel horrible: they have chronic pain, fatigue and depression, but it is all subjective, there is nothing... you can look at a person who has fibromyalgia and they do not look any different than anybody else, so it is a very subjective condition. But individuals who do not have fibromyalgia, if they are sleep-deprived because they are shift workers, or they have another condition, things called sleep apnoea, other illnesses that deprive individuals of sleep or somebody who just... There have been experiments done where individuals as experimental subjects have been sleep deprived for days on end. Sleep deprivation in itself will produce chronic pain, these individuals are pain-prone, individuals, they become obviously fatigued, they develop secondary depression and they develop chronic pain. It probably leads to a chemical imbalance just with the fact that they are not getting normal restorative sleep.

Barber: I describe it as crashing fatigue. You could be getting through the day and suddenly you will just think 'I need to sleep, I do not care if it is on my keyboard I have to sleep', which is quite difficult to cope with when you hold down a full time job.

Evans: That word '*fatigue*'. I find that people do not understand the word 'fatigue', they think of it as tiredness. Now I describe fatigue as absolute exhaustion, being run over by a bulldozer.

Barber: Yes, that is definitely it. You can sleep for 12 hours and wake up and think you have not slept at all and feel like you need another 12 hours sleep. You stop being able to form sentences properly...

Evans: I noticed!

Barber: [laughs] You have not seen me on a bad day! It is not even forming sentences – I can often switch off midway through a sentence, thinking I have completed it and wonder why people are looking at me expectantly because they are waiting for the rest of the sentence.

Evans: Do you have those conversations with people, where you are in the middle of something and you stop, pause and say 'What was I talking about?'

Barber: All the time! I use the phrase 'My words have fallen out of my head!' because it describes what has happened. It is not just a blank mind, you could almost hear the words just tumbling to the floor next to you and you are just scrambling to find what you were saying, you completely lose your thread of conversation and then it is really embarrassing having to ask for prompts as well. I am lucky enough in that people who know me are now very familiar with this trait of mine and they will jump in before that happens. If they see me reaching for a word they are not afraid to jump in and tell me the word that I was looking for. That keeps me on my train of thought a lot quicker, than having to pause midway through a sentence.

Evans: And what about this thing we call 'fibro fog'?

Barber: Fibro fog, it can be a little bit like, if you've woken up in the middle of the night and you're still half asleep. Or it can be things – like the other day, I was making my breakfast and I was having a bowl of cereal and some peppermint tea and I put the boiling water on the cereal and the milk in the herbal tea, which doesn't seem like a major thing but you don't notice until you start eating the cereal or drinking the tea and thinking this isn't quite right. You have mental lapses where you [laughs], sort of, go on automatic and you don't realise that your automatic memory is not quite as accurate as it should be.

And it can also be where you are standing in the supermarket looking at twelve different varieties of cans of beans and thinking, 'I know I want beans. I know I normally get a particular brand of beans. I can't remember which ones they are and I can't remember why I want beans'. I have been known to stand in the same aisle looking at the same shelves for over half an hour because it becomes overwhelming when you realise, you don't know what you are doing there,

which is quite a scary moment when your brain just spaces out.

Evans: Have you ever had marmite on your porridge?

Barber: I'm lucky enough in that I hate marmite anyway, so it's not in my cupboard, but I've had similar.

Evans: I like marmite, but it doesn't go with porridge.

Barber: I can imagine not! [laughs]

Evans: My experience of fibro fog is on my commuter route going across a crossroads – which I did every day in my working life, twice a day, once there, once back – and stopping at the lights and not knowing where on earth to go even though it was straight on. It's like you've been using autopilot but suddenly the autopilot has failed.

Barber: Yes, the other day I had a social engagement and I thought it's Wednesday, I know that I *have* to do something after work, I know that there is nothing in my calendar, there is nothing in my email calendar, I haven't written anything down but I *know* I have to do something and I had to resort to posting my status on social media, saying 'I know I was supposed to be doing something with someone tonight, somewhere. If it was you, please get in touch because I don't know who I am meeting and why!' And that's *really* embarrassing to admit – you can't remember your friends.

Barber: Lexy Barber.

Now as we've heard, as yet there is no cure for fibromyalgia but it can be managed. Professor Ernest Choy of Cardiff University again:

Choy: First of all, I think understanding the illness is a big battle. So I think it's not uncommon for a fibromyalgia patient to get very frustrated, so we need to give them an explanation of what it is. We need to help them to understand what the role of, for example, exercise, keeping warm, the importance of medications – they are not cures, but they help – what they can do is when the pain is bad. And also try to reduce as much as possible, other factors that can make their pain bad.

Also to correct some of the common misconceptions – unfortunately, one of the natural consequences of pain is that when we get pain, we all stop and actually for fibromyalgia – it's

slightly counterintuitive – because if you stop, the muscle will become more deconditioned and over a long time actually make the pain worse. And initially, when people get told that they need to exercise, often the pain gets worse and naturally people want to stop, but actually if you persevere the pain will improve. So it is understanding that one needs to persevere through the pain: it's getting over, getting control of the pain that is the key and that can only be achieved with a combination of better coping strategy and medications.

Evans: Describe what you understand as exercise. By exercising, basically, I'm out of commission for five days at least, so are you saying that perhaps I should persevere – go through the pain barrier, if you like?

Choy: Yes, you certainly need to go through the pain barrier. Now, it's obviously easier said than done and I also appreciate that during the winter months, when fibromyalgia is at the worst doing exercise is not the easiest thing. But some things that are helpful are: that if you can find a local swimming pool that is nice and warm, it's very helpful to exercise in warm water and you don't even need to swim you just need to exercise in water.

The second thing that is actually quite easy to do – there are lots of video games, it doesn't matter if it's a Nintendo Wii or Xbox – there are some nice fitness exercises that you can do in the comfort of your own home. You can build up gradually. I'm not asking people to go to the gym and do an hour with a trainer – that isn't the idea. It is that you can gradually build up the level of exercise that suits your own pace. Something that is particularly helpful is that if you have those video games at home after dinner, if you do some exercise and then you have a warm water bath, it's much better than to go to sleep and it improves your sleep quality.

Evans: Consultant Rheumatologist at Cardiff University, Professor Ernest Choy. He is also medical advisor to Fibromyalgia Association U.K.

And this is a good point for me to reiterate Pain Concern's usual words of caution, that whilst we 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. He or she's the only person who knows you and your circumstances and therefore, the appropriate action to take on your behalf and I think that advice holds good for people with fibromyalgia starting out on an exercise plan.

Now, don't forget that you can put a question to our panel of experts or just make a comment

about these programmes via our blog, message board, email, Facebook, twitter and of course pen and paper. All the contact details are at the Pain Concern website which is painconcern.org.uk and, you can also download all editions of ***Airing Pain*** from there too.

Now there's plenty of good advice and support for people with fibromyalgia on the internet through charities such as Fibromyalgia Association UK, Fibro Action and UK Fibromyalgia.

So what's the future for the treatment for the condition? Are there any major breakthroughs on the horizon? Professor Dwight Moulin:

Moulin: I think because the mechanism of fibromyalgia is starting to unravel, that we will have probably more specific drugs available that will help to correct this chemical imbalance with fewer side-effects. But in the short term, what all of this has done – the evidence from the clinical trials and basic science research in substance P – the most important thing in the short term is that it has validated this condition to make us all aware that this is a real condition. These are patients who, with the associated anxiety and depression, they wonder if they are imagining it, you know, they can't get people to believe them and we know now that for patients in pain validation and acceptance that they have something that's real is just as important to them as the actual treatment.

So all this research in the short term, what's it done is help to validate that this is as real a condition as primary epilepsy, it's as real a condition as migraine and it's just a form of chemical imbalance that manifests with pain and fatigue and all these other symptoms.

Evans: What is your advice to people who are starting out on the fibromyalgia journey, if you like?

Choy: Well I think the most important thing is – don't get completely discouraged. There is no cure, [but] the disease can be managed positively. And there are instances where, you know, people who have stopped working for several years after they developed fibromyalgia, managed to get their life back together and getting back to work, perhaps not at the same level as before, but they're still able to manage a reasonable quality of life.

Evans: I have to say, I gave up work two years ago and now I'm making ***Airing Pain*** for Pain Concern and it's been an excellent feed back into the workplace.

Choy: Exactly! Exactly! Rethink about how you can adapt your life due to illness and people

sometimes don't believe me when I say that, actually work is quite good for fibromyalgia. It may not be the same job that you were doing before, but doing something, is actually quite healthy, makes the mind more healthy.

Evans: Taking control of your work.

Choy: Exactly!

Evans: ...would be my advice!

Choy: That's good advice!

Contributors

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