

Airing Pain Programme 32: Pain management programmes

What is a pain management programme? We find out more with the patients and staff on the Glasgow programme.

Airing Pain sheds some light on pain management programmes: what they are, and how they can help. Paul Evans pays a visit to the Glasgow Pain Management Programme where he talks to health professionals and patients. The programme's clinical leader, consultant clinical psychologist Martin Dunbar, explains how his team help patients rebuild their lives despite continuing to experience pain.

We hear patients on the programme speak about how they have benefited from sharing their experiences and gained a better understanding their pain and Lyn Watson, the programme's specialist nurse, talks about how she helps patients manage their medications and get the most out of medical appointments.

Paul Evans: Hello, I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us who live with pain.

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Evans: In today's edition of **Airing Pain** we're responding to questions Pain Concern received about pain management programmes – what they are, and how they can help. Not all pain management programmes are the same: some, like the one at Bronllys Hospital in mid Wales – featured in programme 5 and still available to download at painconcern.org.uk – are residential; others may be run on a day per week basis, say over several months. Now, the Glasgow Pain Management Programme is run over 12 weeks and I paid them a visit where the first person I spoke to was its Clinical Lead, Consultant Clinical Psychologist Martin Dunbar...

Martin Dunbar: It aims to improve the quality of life of people with pain and explicitly we understand we are unlikely to make much improvement to the pain itself. Often the rest of their life has to some degree fallen apart whilst they've been pursuing treatments and strategies to help reduce their pain and we help them find ways to kind of build their lives back up again.

We call it a 'values-based and acceptance-based programme', so the focus is on looking at things that matter to the patients, getting them to think quite hard about that and the way they're not living the life they wanted to live or that they would choose to live because of their pain. And then we help them set some goals to work towards getting some of that life back. There're physiotherapists and psychologists and some medical and nursing input and a lot of that is around helping reduce the barriers to getting those important bits of their life back.

Evans: So you're not curing them then?

Dunbar: We're not curing them, no. We have evidence to show that their pain doesn't actually improve – this is in line with our expectations – but what does change is that people are more active and we have evidence of that and they are more confident around their pain, they have a better understanding of it and they are happier and less anxious generally.

Thomas: I'm Christine Thomas, I've got neck and shoulder pain but it's never been diagnosed. It just came on spontaneously – initially I thought I was having a heart attack because the pain was down my left arm. I lost the use of my left arm – nerve pain – couldn't even hold a cup of coffee, let alone life it up to my mouth. That was two and a half years ago. I'm still employed, but I haven't worked since the day it happened and it's completely changed my life.

Evans: How did it start?

Thomas: I had pain across my collar bone and I was going to go to see my GP to get it checked out and that day everything just flared up and I got sent straight to hospital. They put it down to stress for the first six months, so I didn't get properly looked at until my own GP put things in motion.

I've had MRI scans, x-rays and nothing's shown up at all. They've said I'm one of the five per cent they'll never be able to diagnose. It's difficult because, particularly with neck pain, nobody really believes you. Officials don't believe you. I don't receive any benefits because I'm not sick enough, I'm not in enough pain. I can't get people to believe me, even though they can see that I can't do anything, they'll not say, 'right, you qualify for this benefit'.

Evans: So how did you come to be referred to the Glasgow Pain Management Programme?

Thomas: Through the Pain Clinic at Stobhill Hospital in Glasgow. They referred me.

Evans: And what is it doing for you?

Thomas: Oh, it's great. Meeting other people who have exactly the same side effects and knowing that it's not just me. It's made me more confident about explaining to other people that this is just part of having pain and that I'm not the only one. And that constantly getting pushed to see other doctors and other specialists by family... that they don't sort of realise that I've done everything that I can.

Lyn Watson: Last time we talked about the different types of medication, how they should be used, what they can be used in conjunction with... those kinds of things. This week, what we will do is we will talk more about how to manage your medication effectively and also to talk a little bit about if you were ever to rationalise your medication, 'cause very often, when we take medication for a long time, we almost get a wee bit kind of complacent – over the years things get added in and things get added in a little bit more... I think it's very beneficial every so often just to kind of have a review of what you're taking and what you're taking it for and how effective you think it is.

Watson: My name is Lyn Watson and I am the nurse with the Glasgow Pain Management Programme. My biggest responsibility, I guess, is to deliver some of the presentations, particularly more medically-orientated ones, medication-orientated ones, sorry, deliver a couple of talks on medication and how to optimise it. I give general information on medication as a whole. I also give some general talks on managing appointments. I see patients individually if they have any specific medication issues.

Evans: You talk about managing appointments, what can you tell people about how to manage appointments, surely you just make an appointment?

Watson: Past experiences have probably made people quite anxious about getting information and receiving information from the medical profession, whether that be that GPs, nurses, physiotherapists or consultants within the hospital. That can cause a lot of anxiety, which can mean perhaps they don't optimise their appointments when they have them. So we give them general advice – very basic advice – but it can often be quite helpful to enable them to get the most out of their appointments that they have.

Evans: What sort of advice?

Watson: Things like being prepared, having all the information they require written down. Very often when you go into an appointment, you get a little bit flustered, you forget things, so having things written down is very helpful. Particularly lists of medication – that saves a lot of time, which then means you have more time to discuss the issues you have. Taking people along with you if you find you're more likely to forget things or you want a little bit of

moral support. We say with that, make sure it's someone you trust, perhaps someone that's not going to take over the appointment for you, but somebody there to act as a support.

Very often you forget the information that's given and it can be quite helpful to have somebody there who can remember another part of the information as well.

Evans: I suppose it might be quite easy to misinterpret what your doctors told you.

Watson: Absolutely! And that's again where it's quite helpful to have someone else there. They might perceive the information that's been provided differently. Also, another way round is they can ask doctors, physiotherapists, nurses, whoever it is, to write things down for you, so that you can then go away and think about it with a more clear head. A lady gave an example of misunderstanding or perhaps misrepresenting the information – both her daughter and herself went in and heard exactly the same information from the consultant. She came out feeling quite downbeat, a little bit upset and her daughter came out feeling quite upbeat and when they discussed it, they actually realised that it could perhaps have been low mood, feeling anxious, all these things play a part in how we perceive information that's provided for us.

Caroline McRory: My name's Caroline McRory and I have fibromyalgia.

Evans: How long have you had that?

McRory: Three years

Evans: And how does that affect you?

McRory: It affects my whole life, the impact that it's had. I was working, I was employed, then I had an accident to my shoulder. After I got an operation on it, a year later after that I had widespread body pain, sheer exhaustion and I didn't know what was wrong. I had excruciating pain in my right ribs and I went to my GP and she referred me to a surgical doctor at the hospital who checked my kidneys, my liver, my gall bladder because of this right sided pain and everything was coming back normal.

Now this was very frustrating for me because I knew I had this wide spread body pain, sheer exhaustion and I do have arthritis in my back. I've had that for ten years and I could cope with that but this pain was different – it was controlling *me*, rather than me controlling it. The results coming back from the hospital was very frustrating, really depressing me and my family. Every test I went for, I came back home to my family and told them everything was fine. Don't get me wrong, I was pleased that my internal organs were fine and then it took a

year to say this is what is causing it – it was neurological pain, chronic nerve pain, polymyalgia but every one of these symptoms was related to fibromyalgia.

Evans: Can you describe the pain?

McRory: Oh, It's excruciating, it's like your whole skeleton is on fire – this is my personal experience – all my skeleton was burning. Shooting pains, stabbing pains – excruciating – I couldn't walk, I could hardly take any steps, I thought I needed a chair to get about. You couldn't get ready in the morning, you couldn't get undressed at night without help because the pain was so bad and I mean from head to toe, every part of your body, your jaws, your elbows, every part of your torso. It's very hard for me to accept, when I used to wear a pedometer and used to walk for miles, I can't do that now.

Evans: We're on the eighth day of the Glasgow Pain Management Programme – how is that helping you?

McRory: Well, it's helped me, because when I was diagnosed with this at first, I felt very isolated. I felt I was the only person with this condition, suffering with it and then I was referred here, to the pain management and I spoke to the other people, it was like a weight was taken off my shoulders because I thought well I'm not the only one with this condition. The staff you know, the advice given, the information, has been very helpful to me and I feel uplifted since I came here.

Evans: How do people get on the programme in the first place?

Martin Dunbar: We only accept referrals from the secondary care pain service – that's the hospital doctors who deal with pain... not just the doctors there, because it's a multidisciplinary team, so we accept referrals from physiotherapists, psychologists and nurses who work in those teams as well – and it's simply a case of filling in a referral form.

Evans: But should people ask for it?

Dunbar: Most certainly. We have had people approach us who are not in the pain service and we have to explain that they should go to their doctors and say they are interested in this self-management approach and I understand that I should go to the pain service first. We get their GP to flag up their interest in the self-management, so they don't get caught up in a lot of medical treatments that they don't particularly want, so maybe get referred to us more quickly.

Evans: How do you assess people to come on the programme?

Dunbar: We have a joint psychology and physiotherapy assessment – that takes about an hour and a half. Obviously, the referral, we get quite a lot of information about the patient from that so, we have a pretty clear idea of their history. We're looking for different things from the assessment than maybe others assessments have. We're trying to gauge people's understanding of what's happened to them, any unresolved issues they feel might be there, that might hold them back, people's willingness to try different approaches, to maybe set goals, even in the context of having a crippling painful condition. How physically able they are as well and one of the things the physiotherapy assessment does is to make sure there are no treatable muscular skeletal conditions, which could be dealt with as well. So we are trying to maximise people's benefit from the programme.

McRory: My quality of life is null and void as I feel I'm quite a sociable person and socialised at the weekends but now, because of the drugs, I can't do that. I take my medication in the morning and take it at night and come 9 o'clock I'm ready for bed as I'm so tired, so that's had a huge impact on my social life. Holidays, you think 'oh no, I couldn't sit on a plane for 2 hours or an hour, I'd be too sore, what about my medication?' The first thing you think is *pain*, it really controls your life and I worked in a healthcare environment. It's taken me up until now, two years to accept it because I couldn't accept it. I kept thinking one day I will wake up and it will all be away but it never goes away, this is a last resort for me.

Evans: It's a horrible phrase, the last resort. Do you think perhaps it should have been a first resort?

McRory: Oh yes, I think it's probably too expensive.

Evans: I heard the expression earlier that this was a last resort for many people.

Dunbar: Yes, I don't think it is. In fact, we've been encouraging our colleagues to refer people earlier in their journey. In fact, we've recently started a shorter programme as well for people who are earlier and as a consequence of not having pain for so long, they are usually less depressed and less disabled and limited by their pain and we have specific people to deal with people like that in the earlier stages. I think some of it is, there is a medical desire to diagnose, treat and cure people and those processes take time and patience frequently. If you can, obviously, get a diagnosis that will lead to a cure, obviously then patients are going to pursue that with all their efforts until coming round to the realisation and acceptance that maybe this isn't going to change and that maybe other things need to be addressed, like their quality of life.

Evans: So acceptance is an important word.

Dunbar: Massively important. It's a word with so many meanings, it has negative connotations for some of our patients and that has to be tackled head on. For some people see it as a sign of giving up. Our retort to that would be, you can continue to investigate further avenues of investigations and treatments but it really is diminishing returns. We demonstrate that to our patients by talking through their histories. There is another side of acceptance, which is more allowing the pain and suffering in and *not* getting caught up with that all of the time, and devoting all of one's time and energy trying to minimise that pain and rather accepting and seeing if that pain can be lived with. Often to patients' surprise, when they start to move down that acceptance road they realise, actually it doesn't get any worse but it allows me to do much more down other avenues that are important to me. So that's why it's so important, it's the initial stage really.

Evans: So do you find that the people who come on the course, have been to hell, I was going to say, they'd been to hell and back. They've come to hell if you like and now you are to find a way out of it for them.

Dunbar: Yes, *it is* about bringing them back into to life, I think, and our logo has this tree that's starting to flower again – that would be our approach, yes.

Lisa: I'm Lisa and I have been living in this country for twenty five years and I was a lecturer. I started having this terrible pain four and a half years ago, I think, and I went from one physiotherapist and one doctor to another. I bought loads of shoes and cushions and goodness knows what. I spent a lot of money on all different treatments. Then last year I felt I couldn't cope with my job and the pain was such a constant pain that I came to the point that I couldn't cope anymore. I took early retirement and I thought *that's it* and this led to quite a lot of depression because I didn't really want to stop work. I'm not that old and could have stayed a year or two.

I really have to say I'm very, very thankful for this course because it changed me. When I retired, I was hanging around the house. I didn't do anything so my body doesn't have to move – I put on weight, I became more and more depressed, I didn't go out anywhere. I was just stuck at home and thought 'I'm so old now' [laughs].

Vera Elders: I'm Vera Elders. I'm Assistant Psychologist on the Pain Management Programme in Glasgow.

Evans: You took a mindfulness session didn't you?

Elders: Yes,

Evans: Tell me what mindfulness is?

Elders: It stems from a Buddhist practice. It's really about becoming more aware of yourself, of your own physical sensations, emotions and not only gaining an awareness of yourself but also accepting all the physical sensations, emotions and not judging them. It sounds quite abstract in a way but I suppose in a day and age when we're all bombarded with lots of different stimuli all day long, I think quite often we forget to be in the here and now.

Evans: I don't understand what you mean by not judging your emotions and physical sensations.

Elders: It's a difficult one isn't it? I think quite often we get stuck in loops of 'I should be doing this' or 'I should be doing that' or 'what will this other person think about me?' And you can spend an awful lot of time struggling with those thoughts and expend a lot of energy, mind reading or fortune telling and sometimes by just allowing the thoughts to be present and not judging them, not spending time warring with yourself and just letting them be and moving onwards, can give you a bit of space to be here and now.

Evans: So the session you took with the participants of the Pain Management Course, that was very much being in the here and now with your breathing?

Elders: Yes, so we do a number of practices that perhaps take a little bit longer but of course we're all plagued with our own thoughts and our minds wander, so sometimes it can be difficult to bring our thoughts back to the exercise. I personally, find it hard to go straight back into an exercise if I've been wondering what I'm going to have for tea tonight so sometimes a breathing exercise is a nice way to anchor yourself back, as it's often easier to focus on the breathing first and once you've got back into that rhythm, you can get back to whatever exercise that you were doing.

We do everything from mindful walking, to mindful exercise to mindful eating. We do a body scan, a body awareness, which is a practice where you focus first on some of the unpleasant sensations of your body, followed by focusing on some of the pleasant sensations, which can be quite nice because if your focused on all the negatives, sometimes we forget that we have there are other parts of your body: 'actually my left arm feels quite nice today' [laughs]. So we're asking a lot from people to focus on the pain.

Geraldine MacVicar: I'm Geraldine MacVicar. The pain has been a problem for some few years.

Evans: What's the cause of the pain.

MacVicar: They say there's some sort of twist of the spine. I don't think they really know themselves but it's constant. It limits your quality of life.

Evans: And how long have you had this pain?

Geraldine MacVicar: Since 2007

Evans: And it's taken five years...

MacVicar: To get to here.

Evans: What are they teaching you here that you didn't know before?

MacVicar: Even to manage your anxiety, your mindset, how you approach things, not to be fearful as much as I had been. Though I find wee bits have been helping me just in my thought processes and that's been making a bit of a difference.

Margret Boyle: Hi, I'm Margaret Boyle and I've had pain for about fourteen years now.

Evans: So it's a twelve-week pain management programme?

Boyle: Yes.

Evans: And you are on week eight, three quarters of the way through. What have you got out of it so far?

Boyle: I can't say a lot, I'm still in pain every day. I had an accident. I did a back flip and tore all the ligaments in my neck and right across my shoulders. The mindfulness is quite good. I work full time as well, so I don't have a lot of time to practise all these things, so it's probably my fault as well, I don't make a lot of time.

Evans: Do you think it would teach you to stop saying it's your fault?

Boyle [laughs] I don't know, it's a positive wee course. I'll always say to people I'm not getting anything out of this but the people who know me, my family and friends say I am. They can see a slight difference.

Evans: So what can they see?

Boyle: I'm probably a bit more positive, confident. I'm probably a wee bit more outgoing than I was. It's hard to put your finger in it but you feel something.

MacVicar: I think maybe in the first few weeks the way they were talking, it was like: 'This is not really for me. I'm not really getting into this.' But in the last two weeks it's at a point that I'm picking it up but as you were saying, you think it's maybe not making big differences at this point in time but I think even being in work would make me really anxious and stressed on going home. Now, in the last two weeks, I think, 'I don't care'.

Boyle: My boss says to me and I work in customer services, we get a lot of cheeky people and the past couple of weeks she like 'you're very calm'. It staggered me because in the past I used to take it personally the comments that would say.

MacVicar: Were you a meek one?

Boyle: Very, very meek [background laughter].

MacVicar: We can all see a big change in you, maybe you can't, but we all can.

Laura McClaren: I've had back pain, chronic pain for about seven or eight years now.

Evans: You were saying you can see the difference in Margaret. What can you see at the end of week eight that wasn't there at the start of week one?

McClaren: Probably that she is willing to listen, 'cos you weren't in week one. That was the thing, in week one you knew it wasn't for you *at all* and out of us all I thought you might be the first one to go.

Boyle: Did you?

McClaren: Yes and the ones that have been and gone, I thought might have stayed.

Patient: You're always smiling, yes you are. It makes a big difference.

Evans: I was speaking to someone on the course earlier and I started talking to her and she said she wasn't getting much out of it. Then she suddenly said, 'Oh, but my family and friends do'. Partners suffer with chronic pain as much as the people with chronic pain.

Dunbar: That's definitely fair to say. It is something we address here. We address it in a number of ways, well the patients address it principally. Early on in the programme, we get people to think about what matters to them and as you might expect time and time again, family relationships come up as a part of that. People say to us 'that's the area that's not working very well in my life, it really bothers me it's not working'. We go on to get people to

set goals and kind of try to and set those bits of their life back on track. And that can be things like spending more time with their partners.

We had a lady recently – her goal was to have a weekly date night with her husband. She felt that her marriage had suffered so much because of her pain problem. So those kinds of things frequently come up like taking grandchildren to the park might be one of their goals; doing more for my husband, so that he doesn't have to do so much around the house. These kinds of goals are set by patients on the programme time and time again.

We have also recently started an information class for family and friends of people coming here. Principally, with the aim of helping them to understand what their loved one is going through and giving advice on how they can help them. But I'm sure they get some benefit from that contact with us as well.

Evans: Do you keep track of people after they have left?

Watson: Once they complete the twelve week programme, we invite them to return three months later for an individual review session, where we catch up with how their getting on, the different things that we've talked about on the programme but also to talk about any issues they have, any difficulties. We tend to troubleshoot any problems they may have had, point them in the direction of other agencies that might be able to help them.

Then we invite them back again, three months later, for a six month top up session which is a kind of refresher, if you like, where a couple of groups will come along and we will go over a lot of the things we've talked about, find out how people are getting along. It's also quite helpful and it enables them to see people from the group that they've been with and also people from other groups and learn from them as well.

Evans: Lynn Watson, Now before we end this edition of ***Airing Pain*** at the Glasgow Pain Management Programme, I just need to remind you of our usual words of caution, that whilst we believe the information and opinions given on ***Airing Pain*** are accurate and sound based on the best judgements available, you should always contact *your* pain professional on any matter concerning *your* health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

And don't forget that you can still download all previous editions of ***Airing Pain*** from painconcern.org.uk You can also get CD copies form Pain Concern and all contact details are on our website. If you'd like to put a question to our panel of experts or even make a

comment then please do so via our blog, message board, email, Facebook, Twitter and of course pen and paper.

So to end this edition of ***Airing Pain*** from *the Glasgow Pain Management Programme*, this is what some of the participants had to say about it:

Boyle: Oh I thought, 'nothing's going to help me'. But I did come and I have enjoyed it, as I say, meeting other people... the staff are excellent and the advice they have given has been very, beneficial.

McClaren: it's been fantastic, it's really made me change the way I think about things. The pain and mindfulness is really good, it help to calm you and take your mind off the pain, then you can go on and do other things and change the way I think about things in general. My family can see a difference in me and it's all down to the people here.

Thomas: I know the pain won't go but if I can just at least manage not to be as anxious, my pain level might just drop a wee tiny bit and maybe I'd have a bit more time for my son and some me time – not a lot because I know I can't do so much just a time in the month that's for me and that will be a big achievement for me.

Lisa: I hope that many more people can take part in this course, I really mean it.

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Contributors

- Martin Dunbar, Consultant Clinical Psychologist, Glasgow Pain Management Programme
- Vera Elders, Assistant Psychologist, Glasgow Pain Management Programme
- Lyn Watson, Nurse Specialist, Glasgow Pain Management Programme
- Lisa, Geraldine MacVicar, Laura McClaren, Margret Boyle, participants on the Glasgow Pain Management Programme

Contact

Pain Concern, Unit 1-3, 62-66 Newcraighall Road,
Edinburgh, EH15 3HS
Telephone: 0131 669 5951 Email: info@painconcern.org.uk

Helpline: 0300 123 0789
Open from 10am-4pm on weekdays.
Email: help@painconcern.org.uk

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