

Airing Pain Programme 100: Glasgow Pain Education Sessions

*In this 100th edition of **Airing Pain**, Paul Evans speaks to Heather Wallace, creator and driving force behind the Airing Pain radio programmes, who discusses the inspiration that led to the programme and its continued importance for Pain Concern and the chronic pain community.*

Paul also attends a Glasgow Pain Education Session and meets Angela O'Neil and Georgina McDonald, two Pain Education Session Trainer Volunteers, as well as a number of attendees to the Pain Education Sessions, and finds how regular, community-based education sessions can help sufferers of chronic pain deal with pacing and self-management.

Lynn Watson, a Clinical Nurse Specialist in Pain Management Programmes for NHS Greater Glasgow and Clyde, discusses the role healthcare professionals can play in encouraging chronic pain sufferers to attend community education sessions like the ones in Glasgow.

Claire Mitchell, a Clinical Health Psychology Student at Strathclyde University, and a Pain Education Session Trainer Volunteer, explains how time management and good sleep practice has helped with her own chronic pain.

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 health care professionals. I'm Paul Evans, and this is a special edition – a landmark edition of *Airing Pain* because we've reached our century. Yes, this is the 100th programme since it was launched way back in 2010!

And like everything that's been achieved over the years by *Pain Concern*, it owes its success to a brainwave, but also the dogged persistence, conviction and the tireless, selfless hard work of Heather Wallace.

Heather Wallace: *Pain Concern* started as a support group for people who had done a 12-week pain management rehabilitation programme. The people knew how to manage their pain, what they had to do in their lives – the changes they had to make – to manage their pain well. And we were asked to run a support group to help them maintain these skills and keep them motivated.

And we very quickly realised that it was very hard for people to get to support group meetings when they were dealing with pain. Either they were housebound with their pain or if they were trying to go to work they were coming home so tired that they had no energy to go out yet again to a support group. So one of the things that led us to think about doing a radio programme was, 'how do we make it easier for people to get to support, given that so few were managing to make the support group meetings?' Although the feedback we got from them was, 'please, do it!'

And then it got the point that people were asking us to record the meetings because they couldn't come to them. So at that point we started to think that maybe, if we used media, we could reach more people. And we won first prize in the NAPS awards for chronic pain for the *concept* of a radio programme – and that allowed us to start to look for a professional producer who could help us do that, and introductions via a pain consultant who knew somebody who was working with the BBC, who knew you, Paul – and that's how you and I eventually had our very first phone call discussing this concept.

Evans: Well I can remember that very first phone call. I had just left the BBC because my own long-term condition had made doing my job very, very difficult. The last thing I wanted was to make another radio programme. So when I had this phone call from this mad woman in Edinburgh [laughter] who wanted to start making radio programmes about chronic pain I did not know how to react. I thought, 'well, OK, we'll give this a go for two or three [episodes] and then she will realise that it's just too difficult to do. But that didn't happen.'

Wallace: It's interesting because you didn't tell me you were thinking that. But from people who had any experience in radio [we were told] 'you won't really know what you're doing and you're going to find it's far more difficult than you think.' But you were *really* instrumental in making it a success. You've flung everything into making really good quality radio programmes and *that* was the inspiration to keep them going. That, and the fact that the majority of pain is managed in primary care by doctors and nurses and other health care professionals who have very little training in chronic pain, who don't understand it – who don't understand how people need to self-manage their pain, to manage flare-ups, and so on.

So, you know, one of the visions behind it was to allow people who couldn't get access to specialist care to *hear* from top specialists about how to manage that pain, and also patients who were benefitting from specialist care, and were managing to put things into practice. So you took that on.

Evans: But the eye-opener to me was that once I'd started doing this, and once you'd introduced me to all these specialists and people who genuinely knew about chronic pain and could help people, it was an absolute eye-opener that all this information was there. And having been managed for a good 15-20 years plus, this information was there, but nobody had told me anything about it.

Wallace: That's right. I mean, for the first 11 years of my life with pain – and I was very disabled by my pain – I had no help at all. And what made me really motivated to drive it forward as much as I could was the *difference* that actual access to a pain specialist had made to my life, and the turnaround. And then realising with excitement that there was a whole pool of knowledge there that could help people in this very difficult situation – dealing with this very difficult condition.

You know, it really was almost criminal that this wasn't better known to the many, many people whose lives were blighted every day by experience of pain. Once we opened that door it was really hard to close it again, I think.

Evans: Lots of the stuff is not rocket science. The self-management approach: that may have been suggested to me, but put over in the way that, 'listen, there's nothing we can do for you: get on with it by yourself. Self-manage yourself.'

Wallace: That's right. 'Go away and don't bother us in the surgery any more because, you know, you've had as many medications as we can give you, they're not helping your pain, you'll just have to go and live with it.' And the key to that is being able to tell people, 'well, this is *how* you live with it.' There *is* a way of managing this effectively that will let you have a life – not without pain, but at least where the pain isn't dominating every minute of your day and influencing all the choices you make. People talk about getting their life back.

Evans: When I asked you what we should be doing for this hundredth programme, you immediately said, 'the Glasgow Pain Education Sessions: that is what we are proud of.'

Wallace: Yes. The clinical psychologist in charge of the pain management programme in Glasgow, Martin Dunbar, is a very smart guy, and he runs a really good team of people. And they had a discussion about the future direction they should take: should it be in, sort of, getting involved in highly specialised pain management services, which help just a small handful of people; or should it be much more about getting pain management into the community? And let's face it, it's about preventing people's families from breaking up because of pain; helping people stay at work. So they made the decision to widen access in the community, and they did a pilot search project in West Dunbartonshire looking at the role the pharmacist could play in helping people manage their pain and also these pain education sessions.

So he and his team are the brains behind this, and they invited *Pain Concern* to be involved because they felt that we also were sympathetic to that approach.

Evans: That's Heather Wallace, the driving force and human dynamo behind *Pain Concern*. So, the Glasgow Community Pain Education sessions are currently run across six venues across Glasgow. They're for anyone who has had pain for more than 12 weeks, and the aim is to give a better understanding of pain and how to manage it more effectively in the long term. The two-hour sessions are delivered, not by healthcare professionals, but by trainers who have chronic pain themselves. The sessions cover the science of pain, how to manage activity, stress, sleep and flare-ups of pain. So, they're an introduction to help people develop ways of dealing with pain, to be able to do more and to enjoy life more.

The session I attended was in Eastwood and that's to the south of Glasgow.

Angela O'Neil [leading an education session]: ...My name's Angela O'Neil and I've got chronic pain. I'm a volunteer for the NHS and for *Pain Concern*, which is a charity. This is just a one-off, two-hour session, and I take it you've all had pain for longer than 12 weeks. A lot longer? Yeah, this is what we usually find – it might be a lot of years. So we'll get on because we've got a very busy session, we've got a lot of information to impart. I'm not here to advise you, just to give you information about pain and what pain is.

So, *Pain Concern's* a UK charity. It started in Edinburgh as a self-help group but it's gone on now to education, it's very much into education people what pain is – not just patients, but the medical profession as well. Because people don't understand pain, I don't know if you've found that when you've gone to the GP and things – that that little 10-minute window you've got with them, it doesn't always cover what you want to say about your pain and they don't always appreciate the full impact that pain has on your life, would you say? It impinges on everything, doesn't it? ...

O'Neil [in conversation with Evans]: I had 11 operations in a year; they didn't really know what was wrong and why I wasn't getting any better, and eventually they ruled everything out and said that it was chronic pain, and there was nothing they could do. And that was 12 years ago.

Evans: How did you feel when they said, 'there's nothing more that we can do?'

O'Neil: I was absolutely devastated. I didn't believe it, I was still looking for a cure. I couldn't accept that there was nothing more that they could do. I was on the internet looking for information; I was trying to find different cures; I was talking to different people, asking questions about different drugs. I really could not accept that there was nothing they could do for me.

And I think I now accept that there's no cure available. I wouldn't ever lose hope that one day somebody would take my pain away, but now I do much more myself to put my pain in perspective and live as normal a life as I can.

Evans: Explain that – what do you mean by 'putting pain into perspective'?

O'Neil: I've learnt to accept that my pain's there, but there are things that I can do to make my pain easier. I've got lots of strategies in my bag now – or in my toolbox – to use when my pain's at its worst, and to carry on doing the things that I should do every day. And I'm much more positive in my outlook on life. And I'm now helping others to use these tools and learn about the strategies and educating people in pain, and that also helps me with my pain as it gets me out – doing things, meeting people.

Evans: What are some of the strategies that you use?

O'Neil: Pace has been exceptionally good for me. There were things that I thought I'd never be able to do again and by pacing I've managed to be able to swim again, which I never thought I could do. I now walk – I pace my walking up and I can now walk 10 kilometers, and I couldn't walk to the end of the street two years ago. I've paced my reading; paced my concentration; paced my ability to sit and concentrate for longer.

I think people that come along to the sessions, and seeing that we actually suffer pain and hearing our stories and similarities between them and us, that it gets the message home a lot better.

Georgina McDonald [leading an education session]: ...If anyone needs to stand up and stretch please feel free to do so, you'll find often go walk about – not out the door for a coffee [laughter] – but we do try to move about.

I often say that when you see these two words together they don't really go together, do they: pain and activity? And you, probably, like me, will have reduced your activity...'

McDonald [in conversation with Evans]: My name is Georgina McDonald and I suffer with chronic pain, but I am a pain trainer with *Pain Concern*, working alongside our colleagues and other pain trainers who have been trained to deliver the information evenings.

Evans: So what did the training [needed] to deliver one of these sessions involve?

McDonald: Well, originally, because I had chronic pain I was referred to the pain management team and underwent a 10-week course of pain management. I had had an accident a number of years ago and after years of chronic pain I was offered this resource which I found to be particularly helpful in my situation. At the end of the 10-week course I was asked if I was interested I becoming a pain trainer, which was still in its early stages at that point, and I then underwent training with the pain management team – two-day intensive training – then was monitored and helped by them before we were let loose with patients and people who came to the information evening.

Evans: I presume part of the training was keeping you on-message?

McDonald: Yes, very much so. We have very strict guidelines as to the fact that we're giving information and not advice. We're giving out how we have been helped by the pain management strategies which we are giving information about, and we're also letting those who have come to the sessions know how helpful we have found different aspects of that course – and especially things like pacing, which I had never really heard about before or hadn't taken on board. That's one of the things I find most helpful and we do stress that in the two-hour session we do here.

Evans: Pacing is one of the easiest things to explain and one of the hardest things to do.

McDonald: The whole concept of pacing is that you build up your activity to the point where you don't have extra pain, or don't have the pain increasing, in your activities. So anybody with chronic pain has background pain which is there all the time – and I certainly have a lot of sensitization in my legs, so therefore I can have additional pain from that. But when you're building up and you're using pacing then you start getting to a level which is comfortable for you, and if you start to feel additional pain then you know that you have to go back to that comfortable level and try increasing the activity again perhaps the next day or the next week.

Evans: But the games the mind plays – when you've come to that comfortable level, the mind sometimes will say, 'maybe I'll do a bit more.'

McDonald: Yes, and I think that's human nature, that you try to push on. And I think that's one of the things I think we try to get over through these sessions is that you have this either boom-and-bust or you have this 'pushing on' scenario where, on good days, you want to do so much – whether it be the garden, golfing, cleaning, whatever – or pushing on, which I tended to do when I was working. I tried to dismiss the fact that I was really not able to do the level of activity that I was undertaking at that time and so was incurring further pain, which, perhaps if I had known about pacing at the time, it might have prevented even having to stop work when I did.

My GP is exceptionally good and she's very helpful and supportive, but what I've learnt through the pain management course has helped me to structure my life and to get my life back together again.

Evans: Had you been to one of these sessions that you're running tonight at the very beginning, how different do you think your pain journey would have been?

McDonald: My pain journey would have been totally different. I do have to say that. I've spoken to my GP about this and she has referred people to these sessions because she knows, I think, and I know that I would have benefitted so greatly from this at the beginning. The activity planning, the pacing, the knowing when to stop, when to be more active, how to address your medication – I think I would have had a far better understanding of my body and the pain journey, although there's still lots to learn. I would have had a better understanding.

Britney: I'm Britney, I'm 24 and I deal with chronic neck pain mostly. I've also been going through surgeries for endometriosis and chronic pelvic pains – kind of a mixed bag of the high and the low [laughs].

Evans: You've got the works? You've got the whole lot!

Britney: Yes [laughs]. Yeah, I guess it's kind of learning to – one of them is an older thing to deal with and one of them is new, so trying to find the right balance of things that worked with me with my neck and things that now can help me with the pelvic pain; I've been trying to find a good balance.

Evans: So why have you come here today?

Britney: I guess to kind of work on that, exactly: to just kind of find out what would be the most beneficial way to keep moving forward with work and school and getting married soon and, you know, just trying to maintain healthy relationships and a health life while, you know, not letting the pain bog me down or put me on bed rest too much.

Evans: So far, what have you learnt?

Britney: So far I've learnt the pacing method – I've been able to not take on everything at once. I have a tendency to stockpile my weekdays during business hours and then it makes for a pretty awful evening [laughs], awful weekends. So I'm trying to make sure that I can enjoy time with friends and things as well as my work.

Evans: I was quite interested in what Georgina was saying about if you are planning for some big event, don't plan not to do that, but take the day after as a recovery day.

Britney: I think that that's a really good strategy, because what I've run into is sometimes I'll have multiple events booked out day after day after day, but then if I have a flare-up then all of a sudden it's like my entire week's plans have just gone out the window. I'm leading up to a few big events so if I can now plan to take it gradually, leading up to that, rather than just trying to pack everything in then that may work better than what I've been doing.

Evans: If there's just one message you'd take out of today – there's more messages to come, I know that just one message, pacing – which I find very difficult, actually, but very worthwhile. That's a great thing to take away.

Britney: Yes, absolutely. Pacing definitely so far has been what stands out and what I'll take away.

Claire Mitchell: My name's Claire Mitchell, I'm a student at Strathclyde University and I help to deliver these sessions for *Pain Concern* as part of my placement for my clinical health psychology masters.

Evans: And what part are you going to deliver?

Mitchell: The 'stress and pain' talk and 'pain and sleep.' And I also suffer from chronic pain as well.

Evans: Can you tell me something about your chronic pain?

Mitchell: Well I have ME so it's chronic fatigue and also pain in all my muscles.

Evans: How does that affect you?

Mitchell: It affects my mobility and it cognitively – my thinking, you know, you forget your words [laughs]. Your brain just does not function at the same capacity as it usually would. Concentration is low, you get stiff, you have to move around a lot.

Evans: When did you start having your ME?

Mitchell: When I started university, so five years ago.

Evans: So how did you cope with university and ME?

Mitchell: It's mostly about time management and working with what you can, and accepting that you have limits and you have to stick to them. You have to manage your time affectively.

Evans: It's a form of pacing, isn't it?

Mitchell: Yeah, it is, I guess.

Evans: So how does taking part in these classes help with your condition?

Mitchell: For me particularly the information on sleep really helped me, because you're kept up at night from your pain. And for me I would spend a lot of time just lying in bed, I haven't slept, and I can't do anything so I'm just going to stay in bed anyway and try and catch up on sleep. But, really, what's important is establishing a routine and *not* lying in bed all the time [laughs] because you can't catch up on your sleep – you know, it's not like a bank.

Esther McFarlane: I'm Esther McFarlane, retired for the last 10 years, nurse for 40 years. As my pain began to increase I began to shift my job.

Evans: So what brought you to this pain education class tonight?

McFarlane: It's really interesting to know the changes that have taken place in pain management and pain education and pain knowledge since I taught it about 20 years ago or something.

Evans: Ah, so you taught it pain management? So how has it changed?

McFarlane: I mean, most of the things have changed but what's got me is the fact that now they accept that chronic pain is [actually] *there*, and that it's different to acute pain. Because chronic pain used to be, 'oh it's just neurotic,' you know? And it used to frustrate me, that idea; people would say that about folk.

Evans: It's all up there in the head?

McFarlane: Yeah. Aye, that used to really frustrate me. And it's quite good to hear that there *is* evidence to show that persistent pain is different from acute pain, and it's not just something that's in your head; it's to do with neuroreceptors and things like that, which is really quite interesting. It's great for folk that are, you know, stepping out on that road of having chronic pain, it's good to know that people are going to listen to them now.

Evans: But is there stuff you're learning today – learning about in this session – that will help you with your pain?

McFarlane: Yes. So many times you're really not good to yourself. So many times you start to think, 'maybe I am making this up.' What I've learnt tonight is that, no, it is there. You deal with it, you know – I suppose it's acceptance. Acceptance that you have it, and deal with it in a sensible way, instead of sort of pushing your own boundaries all the time.

Lynn Watson: My name is Lynn Watson and I'm a clinical nurse specialist who works within the pain management programme in Greater Glasgow and Clyde.

Evans: This is bringing pain education into the community, rather than taking the community into the hospitals, if you like?

Watson: Absolutely. What we discovered within Glasgow, in line with the Scottish Service Model for [Chronic] Pain, [was that] we were quite well served within Glasgow at some of the levels for education within the service, but that's what we call level 1 service, which was education and information for people within the community. There wasn't really any service available at that time, and so as part of the pilot that was what we looked at.

Evans: And what's the take-up like of these sessions?

Watson: [In] some areas the take-up has been really good; however, some of the areas it's perhaps still not as well-attended as we would like. And I think that can be for various reasons. We're certainly looking within the service and, more importantly, though *Pain Concern*, at how we can allow it to become more accessible for people; that people know about it; that people are encouraged to attend, perhaps by the professionals that they might see in relation to their pain.

Evans: It's one thing to advertise them; it's another thing to convince people that this is the sort of thing that will help them.

Watson: Absolutely, and I think there is certainly a role for us, as professionals, to play in that. I certainly think that it is given more validity if, say, a person's GP, practice nurse, physiotherapist et cetera is encouraging people to go along to it, then I think that makes it more valid – that the information they're getting is going to be suitable for them, it's going to be appropriate for them.

Evans: But the primary care, I guess the GPs have to buy into the scheme?

Watson: Yes, and that has probably been a struggle. There are huge pressures on all primary care services. Obviously I work at the other end of people's pain journey – that sort of level 4 commitment, which is a pain management programme, and what people time and time again say to us within that service is, 'I wish I had known this before.' And that was something we were hearing regularly.

And I think it is invaluable to give people that confidence to realise that there are things that they can do themselves, and manage themselves, and empower them to make choices themselves.

McDonald: I think, certainly in the west of Scotland, we've been brought up with that almost Calvinistic attitude that you don't matter, that we have to think about everybody else and that we aren't really important. But actually, you *are* important, and you have to – as Angela said – pat yourself on the back when you achieve something, and you have to do what is good for you. And so in self-managing, as well as the medication, it means that *you* take control of some aspects of your chronic pain to try and help yourself, so that you're not relying on absolutely everybody else.

And I think Angela said at the very beginning of today: one in six people have chronic pain, so we are not alone. Lots of people have chronic pain, and we hope that this evening have been a help to you on your journey.

Evans: You can find out more about the Glasgow Community Education Sessions from *Pain Concern's* website which is www.painconcern.org.uk. As always, I have to read you the small print that whilst we in *Pain Concern* believe the information and opinions on *Airing Pain* are accurate and sound based on the best judgements available, you should always consult *your* health professional on any matter relating to *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.

Don't forget that you can download all 100 editions of *Airing Pain* for *Pain Concern's* website which is once again www.painconcern.org.uk. And you'll also find on the website *Pain Concern's* extensive resources to support living with chronic pain.

Well this 100th edition of *Airing Pain* – or the previous 99 – would not have happened without the vision and dogged persistence of Heather Wallace, so she can have the last words.

Wallace: There's no doubt when we've done evaluations of *Airing Pain* that for some people it has had a major role in their getting their life back. The other thing is, I mean, why do we keep doing it? Why don't we just a set of videos or radio programmes explaining self-management and then cut people loose to just get on with it? It is about the role of support groups – people need constant reminders. Because you have to do this every single day of your life: that's tough, and people get

demotivated. Incidents in their life come into play – maybe a family crisis or something – and they forget about their self-management skills and then they get a flare-up.

So it's about keeping people motivated, keeping people on-track. And if they get flare-ups, realising 'oh yeah, I understand why this has happened; let's get back to managing the pain better.' And I think having a regular source of support like *Airing Pain* does help people do that.

Evans: So from that very, very strange phone conversation from seven or eight years ago, there are now 50 hours of broadcasts about pain and self-management and how to live with conditions. And all I can do is thank you for how it's helped *me* and thousands and thousands of other people.

Wallace: And I would say it's helped me too. You know, there's always new knowledge to learn about how to refine the way you're managing your pain; there's new science coming forward. So I hope that in another few years' time we will be sitting down celebrating the 200th radio programme. Yeah.

Evans: I'll take you up on that.

Wallace: Ok, good!

Contributors:

- Heather Wallace – Founder of Pain Concern
- Angela O'Neil – Pain Education Session Trainer Volunteer for NHS and Pain Concern
- Georgina McDonald – Pain Education Session Trainer Volunteer
- Britney – Pain Education Session Attendee
- Claire Mitchell – Clinical Health Psychology Student at Strathclyde University and Pain Education Session Trainer Volunteer
- Esther McFarlane – Pain Education Session Attendee and Ex Pain Management Nurse
- Lynn Watson – Clinical Nurse Specialist in Pain Management Programme for NHS Greater Glasgow and Clyde

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