

Airing Pain Programme 130 Pain Management Programmes & the Health Unlocked Forum

Scotland's Pain Management Programmes (PMPs) and what support is available after graduating

*This edition of **Airing Pain** has been funded by a grant from the Health and Social Care Alliance Scotland Self Management Fund administered on behalf of the Scottish Government*

What do you know about Pain Management Programmes (PMPs)? Do you know how they function? About the positive outcomes they have? Do you know if there are any PMPs near you?

In this episode of **Airing Pain** we learn about PMPs and the support networks that are being formed as a result.

With the help of [Health Unlocked](#) and [Alliance Health and Social Care Scotland](#), Pain Concern have created a small number of online forums. These forums are designed for PMP graduates in order to stay connected. They allow them to continue to support one another once the programme has ended. Graduates can communicate with one another on our Health Unlocked forums. Additionally, they can also communicate with the healthcare professionals who delivered their PMP.

So, for Pain Concern this is a test to see whether forums like these are useful! Also, should we create more?

Paul Evans speaks to Health Unlocked moderator and PMP graduate Louise Cromie about all things Pain Management Programmes. For example, how support networks can be key in someone's pain journey.

Issues covered in this programme include: pain management programmes, self-management, supporting one another in pain, pain community, pain education, the spoon theory, managing pain in a crisis, fatigue, burnout

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 those who care for us. I'm Paul Evans. And this edition of Airing Pain is funded by The Health and Social Care Alliance Scotland Self Management Fund administered on behalf of the Scottish Government.

Louise Cromie:

We had a message come via the pain team from Pain Concern saying we are thinking that these groups that you guys are making after your pain courses if we had somewhere central

that you could all go to then that experience and that shared journey and the shared wealth of knowledge from the eight of you could be bigger.

Evans:

Pain Concern in collaboration with the Scottish National Residential Pain Management Programme and the NHS Greater Glasgow and Clyde Pain Management Programme have developed two separate online communities that will provide ongoing support for those graduates of the two pain management programmes.

Lou Cromie is a graduate of the three-week Scottish National Residential Pain Management Programme and she's a moderator of that forum.

Cromie:

My chronic pain started just off as an injury when I was 13 and I dislocated my knee, you know you're 13 they put it back together and you kind of got on with things and things just got worse and worse as time went on. It dislocated, subluxed and we then discovered there was a reason for all this happening with the leg length discrepancy which they couldn't fix which, in time, caused my pelvis to be out of alignment which caused my spine to be out of alignment, which then just causes **all** of its own problems and I ended up with complex regional pain syndrome throughout my whole body as well as osteoarthritis in various joints, my pelvis, my spine, my knees ...

Evans:

So you've been on a pain journey from the age of 13 when your teens started?

Cromie:

Pretty much. And you don't realise at 13 that this is the rest of your life. You think at 13 you are starting out. My plans – you know I used to do running and everything, I loved it. And you push through these things when you're 13 and you're 19 and your 20s and your 30s but then you realise that you can't push through it any more and it's too much and it gets on top of you and life stops happening so you have to do something about it.

Evans:

At what age was it decided that you had to do something about it?

Cromie:

I had just had my children at 30 and I was maybe about 34/35 and things were getting unmanageable and when I realised I couldn't get down on the floor to play with my children, I couldn't run after them in the park, the pain was, it was more about, you know, what I could do to try and get out of bed to actually do anything rather than the joy of getting out of bed to have a day at work or a day with the kids. That was when I would say something needs to be done here and you do the whole bouncing round all the doctors and the GPs before you finally end up at a pain clinic.

Evans:

Having all those conditions what help were you getting up to that point?

Cromie:

My GP was good in as much as he would see me and he would listen and he would try to do what he could as a General Practitioner but he wasn't a specialist so he would refer me on and you would see orthopaedics, you would see endocrinology just in case it was something like rheumatoid arthritis and you got passed around the houses and passed around all the departments with the 'well your scan's clear, there's nothing on your scan' or 'well, yes there's a little bit of deterioration, maybe more than we'd think for somebody your age but it shouldn't be causing you this amount of pain' and I'm fairly certain everyone who's been on a pain journey has had this and you just whack up against every brick wall that the medical profession has. They can't fix it they expect you just to live with it.

Evans:

So, you were being treated for x number of conditions rather than one condition which is pain.

Cromie:

That's right, yeah. If they couldn't find a physical cause you almost felt like they were making you think it was in your head. You really start to doubt yourself and you think 'Am I imagining this, is this in my head?' but you know it's not because when you are physically blacking out from pain, when you are having pain spasms that are lasting 3, 4, 5 hours and you are in tears and gasping for breath you can't make that up. Your pulse goes through the roof, you break out in pain sweats and it wasn't until somebody finally says 'I think we're going to refer you to the Pain Team because there's nothing else that we can do'. And I thought 'There's a *pain* team! There's a team that actually deals with this and I'm only seeing them now!' [Laughs]

Evans:

That expression 'there's nothing more we can actually do'. That's a brick wall really, isn't it?

Cromie:

It is, it is and I think everyone who gets to a pain team has hit that brick wall. They have been banging their head against it for years. And I can see from a point of view the medical professionals on the other side of that wall putting it up. There is nothing that they can do because sometimes what is wrong you can't see on an X Ray, you can't see on a CAT scan you can't see on an MRI. Pain is very, very complex and it does take a certain, I think, mindset and understanding to work out what causes it, why it impacts the way it does and what you need to do to be able to manage it. And you're not going to get rid of it but it can be managed and you can live with it.

Evans:

So, you've arrived at your brick wall and they've referred you to a pain team. What happened then?

Cromie:

The first thing that happened then was apprehension, thinking how's this going to go, and then the utter relief and breaking down in tears, I can remember to this day sitting in my consultant's office when she said 'I believe you, I believe the amount of pain that you are in, it *is* real'. Just that acknowledgement, that acceptance, the validation that *everything* that I

had been saying to *all* these other doctors who were saying 'but there's nothing there'. No, it *was* real. And then she explained why I was feeling pain and explained why nobody else was picking up on it and that helped me understand and because I could understand it I could accept it. And because I could accept it, I could then move on in the journey to try to manage it.

Evans:

What did she mean by it when you said 'why nobody else picked it up'?

Cromie:

The mindset a lot of the doctors seem to have is they are looking for physical conditions, they are looking for a physical cause and sometimes in pain the physical cause is so small it doesn't show up. You could maybe catch it on a functional MRI scan and that's where you actually see the part of the brain firing off in colour so you can actually see the reaction in the brain to what's happening in the body. They are very, very, very, very hard to come by so because these doctors, who are *great* at their jobs, because they don't see lesions, they don't see a broken bone, they don't see a torn muscle, *they* are at a brick wall so for her to be able to say well actually what's happening is your brain is perceiving pain because it's getting flooded with pain messages coming from your nerves, and it's getting flooded with messages, rather, and your brain is interpreting it as pain. OK so there **is** actually something happening, it is going to my brain, my brain saying this is pain but nobody can see it because these messages are so small. They're tiny electrical signals.

Evans:

It's all very well for your experience of pain to be validated and to have it explained to you why it is pain but where does that lead you.

Cromie:

So, when you know it's real then you can do something about it. The approach that our pain team used in the Borders is a biopsychosocial approach so you learn a bit about the biology, you learn a bit about the psychology behind it and the social impact that it has. And when

you understand why these things happen the way they do and why we typically respond to these things the way that they are happening, we can then adjust how we react to things. So instead of having the days where, and you got them occasionally, the days when you'd wake up and you'd think wow I feel I could actually do something today and you go hell for leather and you're just out there and you do everything you can, you get the house cleaned, you go and do the shopping, you know, you go and see friends that you've not seen for ages and then the next day and the day after and the day after you pay for it.

So, this boom-and-bust cycle that you have of, you know, 'I'm going to go for it', and then you flop, that doesn't work. What you are looking to do with this whole biopsychosocial approach is trying to, instead of going from this roller coaster where we're sort of up and down and up and down, you want to go on a sort of merry-go-round. So, you're still going up and down like those carousel horses do, you are still going to go up and down but it's a smoother journey, you go round and round, it's a much smoother journey, you've got more control over it. So, you are maybe still doing things on the days where you're sore, you're not lying down to it but on the days that you're good you are pacing yourself, you're not going mad so that you know the next day you're not going to have to recover. And it just makes such a difference, you learn to manage your pain so it's not managing you and that gives you a life back and when you've had your life snatched away from you by pain for 10, 15, 20 odd years it's a gift just to suddenly have that understanding and the knowledge and the power to be able to say 'no I'm having my life back'. I'll still have my pain but I'm managing it, it's not managing me.

Evans:

That sounds absolutely great and it's fine but the biopsychosocial, the social side of it doesn't always fit a neat plan. Now I know that you were in a dental crisis with your child yesterday, that wasn't in the pain handbook. How do you cope with things like that?

Cromie:

Well, that's life, life happens, that happens to everybody whether you have pain or not and we all have a toolkit whether you have pain or not. We have toolboxes. When you've got pain you've just got to adapt your toolbox a little. So, for example, if I was a healthy, happy normal

working person I would phone my work and say, sorry I've got a crisis with my child, I need to take some personal time. So as somebody who isn't able to go out to work, I need to say to myself, ok, I can't do what I was planning to do today I'm going to have to put my energy and resources into this, which means I'm going to have to cut back a little bit later on from somewhere else. And there's a theory called the Spoon Theory which really helps with this and I'm fairly certain that anybody that has pain has heard of the Spoon Theory. This is one of these occasions where you borrow some spoons. You know you might pay for it a little but there are things that you have to make the judgement. It's worth paying for. Especially when it's comes to things like your child. [Laughs]

That can work for, you know, if you have a wedding to go to. You know that you might pay for it afterwards but the benefits you get from being able to have a little bit of life can get you through these little tough days afterwards. It is a balance, it's all about pacing and it's not easy. It's very much a case of putting it in to practice and finding out what best approach works for you and it takes time.

Evans:

All this stuff, all this pacing and booming and bust. How was that taught to you, how did you find out about that?

Cromie:

My pain consultant had suggested I go on a pain management programme. Now when she said this I thought OK tell me about it. So she says well we get a group of patients and we sit around and we discuss the theories of pain and we talk about how we manage pain and I am sitting there going 'Yeah. Not for me thank you very much'. I'm very much one of these people when you go on holiday and they have the organised resort activities to do on holiday and I'm like 'Yeah no I'll just sit at the bar thanks. Crack on'. So the idea of sitting in a room full of other people who were all suffering, all of us sitting whinging about our pain was not floating my boat at all. And my consultant tried for 8 years to get me to do a pain course. She never forced it. She just every time I saw her and we had our reviews she'd say 'have you given any more thought ...' I was like 'yeah, you know what it sounds good for some people

but not for me thank you very much'. And it took me hitting rock bottom to actually say to her 'look I need to do something. Give me this pain course'.

Evans:

Was that a residential pain course?

Cromie:

Initially the course that I'd done with the Borders General Hospital it was over ten weeks and it was maybe two hours, one to two hours a week every week for ten weeks. It was good because it wasn't overwhelming. You had time to process things during the week and it wasn't exhausting. But I did eventually go on to do a three-week residential course with the Scottish National Residential Pain Management Programme in Glasgow. So that was very much the same principles but they were showing you how to put the principles in to practice, giving you actual physical tools - you've dropped something on the floor you need to get down on the floor and you need to get back up. How do you do it? Simple things that we all do, or all need every day and it helped cement everything that I had learned over the ten weeks with the Borders team as well.

Evans:

That's overcoming sort of physical problems. Picking things up. But what about the psycho, the psychological, your mind. How did they help you put your mind in a different place?

Cromie:

Every team that's a pain team has a psychologist on it and they are very much aware of what pain does to us. Where pain puts us. And my psychologist knows I have absolutely no qualms. If I didn't have my family here I wouldn't be here, I would take the exit door because my family make my life worth carrying on with. That's how bad things can get. But they understand this and they listen. And they don't judge and they help us realise that, well maybe you need to find something for yourself, yes you're managing your pain or you're trying to manage your pain and you're trying to do it for your family but what are you doing for you because people with pain tend to end up putting themselves on the back burner because we get used to

putting a mask on for friends and for family. So, you walk around with this mask. My family are quite good. They can see when I have it on but you will see friends and they'll say 'oh wow I've not seen you for ages you're looking great, it's great you are feeling so much better' and you're thinking 'no I'm not really'. [Laughs]. But your psychologists on these teams help you realise that it's ok to lower the mask and it's ok to say, you know, it's not good just now but I can do this for *me*. So, for example, one of my things, I've started an Open University degree. At 45 I've decided I'm going to get a degree. I have something for me now. So, the psychology team help you put you in focus again, help keep you in focus and keep the balance.

Evans:

Lowering that mask, I guess, is a skill in itself because you could lower it and just be labelled a 'Moaning Minnie' - 'leave her alone, come on let her get on with it'.

Cromie:

And that's scary. When you have pain you find out who your true friends are and you find out the people that actually listen to what you say and it's not easy to lower the mask and to reveal what's really going on but the percentage of people in our country that are living with chronic pain is way higher than people realise. There are a lot of masks being worn out there. Wouldn't it be nice if we could all just see each other, realise, you know, they're struggling. What can I do to maybe help them a little bit, to make their day a little bit better, a little bit easier. And maybe if we didn't all have our masks on all the time, we might be able to achieve that.

Evans:

Well, I mean I have chronic pain. I have fibromyalgia and I've found that one of the worst things, that really annoys me, and I don't know how to cope with, is people saying 'how are you feeling' because the answer is 'rubbish'.

Cromie:

Well, the answer is *always* 'rubbish'. I have circles. My inner circle, my very core of my circle, I have my immediate family, and then my next circle out are my best friends, the ones who I

don't need to wear a mask around, and then the next group out I have people who, you know, maybe people I know from church that I'll have a little bit of a mask on. They know what my situation is but they try to stay positive, it's coming from a good place, you know I've got neighbours, it's coming from a good place. They'll do the, you know, 'how are you feeling' and you're like 'well you know, I'm here which is something that hasn't happened for a while' or, you know, well 'it's amazing what make-up can do'. I have little retorts. The further out my circles go the more my mask will stay on because there are sometimes you get people that are just, 'have you tried yoga?' or 'have you had this diet?' or 'I've 'well heard meditation works wonders' and those people you kind of keep the mask on and you think to yourself 'is it worth my energy getting riled up, getting in to a debate, getting in to an argument' - because that's exhausting – or is this somebody that I could just kind of say, 'look do you know what that's a great idea, I'll have a think about it' and move the conversation on gently. So you choose who you keep your mask on around, I think, and that's one of the things that I've learned on my pain course.

Evans:

That's a really good tip because the number of times somebody will come up to me, or other people with chronic pain, and say 'oh I've read an article in the Daily Blurb that says something about putting a pebble in your shoe. Have you tried that, I've kept the clipping for you'.

Cromie:

I know [laughs] and you just, inside of you, you just want to grab them and shake them and say 'it's not like that'. But you know [laughs] the beauty about having pain is that we have mastered an inner monologue when we have pain. I just need to remember sometimes I have to turn my inner monologue on and off. But yes sometimes we can have the inner monologue of 'pebble in my shoe, really? Tell you what I'll take the concrete ones off first and then I'll try a pebble' but you're like 'how very interesting'. Is this person actually worth this discussion, worth my energy or am I just going to say 'how interesting' and move the conversation along [laughs].

Evans:

I just need to say that having a pebble in your shoe is just pure fantasy from my little brain [laughs].

Cromie:

Well do you know if I could trade what we are, I'm sure you would be the same, if you could trade what you are living with to having to walk around for the rest of your life with a pebble in your shoe, I know I what I would choose. I'd have that pebble in my shoe [laughs].

Evans:

Well now you've broached on this as well. How does your family, your teenage children ... I mean who educates them about your pain and how to deal with you?

Cromie:

I have. And also, my pain team because we have sessions where they can come along and learn about pain. My son has done his Duke of Edinburgh Volunteering section for his Duke of Edinburgh Award with my physiotherapist as his instructor so that he can help me do physiotherapy at home. But I'm the one who has taught them about it. That was something I learned on my pain course because all they ever saw was mum's sore or my husband would say, you know, I'm really, really sore. They would see the results, the end result, the crying, blubbering mess or the person that couldn't get out of bed.

The other thing they would do is try and do everything for you which is coming from a good place. And when you've done your pain course you realise that actually you need to be doing some things for yourself. You know you can't lie down to your pain and having to say to them 'actually thank you but I'm going to go and try and make myself a cup of tea - would you like one? I might need you to carry them through'. 'Oh but mum, mum I can do it, you relax it's fine' it will be sure. Yes but I need to be moving, I need to be doing things so by educating them what I need to do, why I need to do it, they have then went [sic] ah ok so you are doing that for this reason, I'll support you by doing what? What do you need me to do? What would you like me to do rather than the brain of a child or a husband saying 'I'll do it for you' because it's easier. Tell them what you need. Communication is a big part and that's something you get very isolated on a pain journey before you take control. You don't communicate very well.

We like to keep it all to ourselves because we don't want to be the Moaning Minnie or the whinger.

Evans:

Right, you've been on the three-week residential pain management programme. What's on my mind is that being locked away, if you like, with like-minded adults for three weeks - at the end of it you're all wound up and 'yes' yes we're ready to go now' and then the gang plank is pulled away from underneath you. You have to go back to real life.

Cromie:

To real life. Well our particular course actually happened just before Christmas so we finished our course and we had Christmas, we had New Year and you know how everybody has that slump in January? We were all like, oh, we were exhausted after Christmas and New Year, everything just seems boring and blue and you know the pay check seems miles away.

Imagine having that after having had three weeks of positive 'we can do this' mentality. We were all just like 'ooooohhh arrrgh could we *get* any lower' but we reached out to each other because we had formed a little group, we kept a little Whatsapp group going and we'd be like, you know, 'I'm struggling, is anyone else having this struggle just now'. 'Oh gosh yes I am'. And the messages would flood in. There were only eight of us on this course and to just know that this is normal, this is ok I'm not the only one feeling this, this is real, this is justified and valid.

We kept each other going through that and because we had each other to lean on it wasn't a solitary dark January any more or a solitary dark life after pain clinic. We kept each other going and we had follow-ups with the pain clinics at three months and six months and that's something that they had said that they noticed that patients bond with each other, form a group and that helps keep us going because when you get to the stage of 'guys I need to do this and I've got no idea where to start, I'm so exhausted, my head is sore, I'm not coping well' somebody in the group has the answer. Or, at least, has an idea of where to send you for the answer so having that support structure the 'gang plank' wasn't really taken away. We actually had a bridge built so we had a message come via the pain team from Pain Concern

saying we are thinking that these groups that you guys are making after your pain courses, if we had somewhere central that you could all go to then that experience and that shared journey and the shared wealth of knowledge from the eight of you could be bigger. Your bridge could go from being a couple of metres wide to several Forth Road Bridge sizes wide.

We went along to have a meeting and a focus group and discussed what would work and what wouldn't work and what we would want to see and what we thought we would need and the project developed and the Board became in to being and we started looking for people to help keep it going in the right direction.

Evans:

Before we go on, I'll just remind you as usual 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 well-being. They are the only people who know you and your circumstances and, therefore, the appropriate action to take on your behalf.

Do check out Pain Concern's website at painconcern.org.uk where you can download all editions of *Airing Pain* and find a wealth of support and information material about living with and managing chronic pain.

Now the online forums we've been talking about in this edition of *Airing Pain* are restricted to those who've been through the Scottish National Residential Pain Management Programme or NHS Greater Glasgow and Clyde Pain Management Programme. So contact your pain management team to find out how to join.

Lou Cromie, who I've been talking to, is the Moderator for the Residential Programme Forum. What does that mean?

Cromie:

We try to keep the Boards flowing, we try to respond to every post that comes up, make sure that nobody feels alone - there's always a response there. We try to keep the Boards a safe place not just for if somebody is really, really struggling, you know we will reach out and try

and get them help that they need, but also if we see conversations starting to wind off, as you may see on other social media groups, you go down for six hours sometimes where the conversation waddles off into the realms of fantasy almost, we try to stop that happening, try to keep it real and accurate. Life isn't just about pain when you have pain. Sometimes we need to have fun and games too so, I throw in the odd fun thing on our Board, get some jokes and some little quizzes and things going too.

Evans:

I mean this is new to me because I'd assumed the chief function of a Moderator was censorship to stop all those barking pebble theories.

Cromie:

If somebody said to me 'I've got chronic pain and I've tried this pebble theory' I'd be like ok – as a moderator thing eh how accurate is that but right you can steer it but 'oh so where did you hear about it, do you know of any clinical research papers there are, let's see if we can find some solid evidence, some solid research and we'll put that on the Board and everybody can have a look at the research'. If it's something valid, properly conducted clinical research then why not leave it up there, let people have a think about it, let them read the research and make their own decisions. It's about directing. It's not about censorship, it's more about steering things in the right direction, keeping it out of the rapids.

Evans:

What control, if control is the right word, do the health professionals have.

Cromie:

They're effectively moderators as well. It's great having them there because they will probably be more aware of new research within the pain area so they'll share little snippets that they find but they don't censor anybody, they don't turn round and say you're doing this wrong. There is no real wrong. They help guide us when we really start to struggle but mostly it's patients helping patients.

Evans:

I think that's interesting as well because I'm sure lots of people with pain might think this – 'What if there's a cure and nobody has told me about it. What if there's a new treatment and nobody has told me about it'. I suppose keeping in touch with those in the healthcare, healthcare professionals, does keep you in touch with current practice.

Cromie:

It certainly does and they are as passionate about pain as we are. They are happy to shout from the rooftops when they hear about something new, that's positive.

Evans:

The great thing is that you can trust this forum - the worldwide web is a big place and you can get a lot of bad information. Your forum is to be trusted.

Cromie:

Yes, it's a safe place. We're not going to have rabbit holes that you fall down on the worldwide web. You know that everybody in this forum have all been on the same type of pain course. We have all learned the same thing, we all have the same basis and same grounding. We all have the same basic knowledge. We have professionals there to support us, we're all singing from the same hymn sheet which is great because that helps us all keep going in the same positive direction.

END

Contributors:

- Louise Cromie is a current Moderator for the Health Unlocked Forum. She is also a graduate of a Pain Management Programme.

More information:

- [Airing Pain 119: Working Together in Pain Management Programmes](#)

- [Sign up for Health Unlocked!](#)
- [Scottish National Residential Pain Management Programme](#)
- [Greater Glasgow & Clyde Pain Management Programme](#)
- [Airing Pain 51: At the Community Pain Management Programme](#)
- ['The Spoon Theory' & other self-help resources from Great Western Hospitals NHS Foundation Trust](#)
- [Pain Concern Health Unlocked](#)
- [Pain Management Programmes NHS](#)
- [Airing Pain 98: Excellence in Pain Education & North Bristol Pain Management Programme](#)

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- [Health and Social Care Alliance Scotland](#)
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