Airing Pain 150: Learn to live well with pain

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This edition of *Airing Pain* explores the transformative impact of pain education classes.

Click here for the episode

Featuring Dr David Craig, Joan Melville, Georgina McDonald, Mairi McWilliams, Lindsay McLean and Heather Wallace.

Transcript begins

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, our families, supporters and the health professionals who care for us.

I'm Paul Evans.

Heather Wallace: If you get a condition like diabetes, you are given education. It should be the same with pain.

Evans: That's Pain Concern's founder and CEO, Heather Wallace. Thirty years ago, she and her fellow graduates of a twelve-week pain management rehabilitation programme at Edinburgh's Astley Ainsley Hospital were asked to set up a support group for future attendees.

That support group grew into what is now this charity, Pain Concern.

Wallace: When we talked about what people with chronic pain needed, we all wondered why it had taken so long before someone explained to us how you can turn the volume of pain up, but you can also turn the volume of pain down. And if you can learn to turn the volume of pain down, you can bring back joy, enjoyable activities and an ability to participate in life and do the things that you want to do but you thought you couldn't do because of chronic pain. So, from twelve weeks, pain is officially known as chronic pain or persistent pain because it should have healed, and it hasn't healed.

The brain becomes very confused at that point, and it starts sending pain signals. You don't feel pain till it hits the brain, but the signals start firing in a confused way. So, your brain is confused, you are confused. You don't know how to manage your pain. It doesn't respond to medication in the way that pain should, but you need help to understand that. So, we thought that we should have education that was open to people, from twelve weeks of experiencing pain, to give them strategies to deal with the pain.

Evans: That's Pain Concern's founder and CEO, Heather Wallace.

Attending a multi-week pain management course for the over 8 million adults reported to be living with chronic pain in the UK is neither affordable for the NHS, nor is it convenient for every one of those persons living with chronic pain. But the key messages can be distilled in a way that's effective and life-changing. So, the NHS Greater Glasgow and Clyde pain service team, in collaboration with Pain Concern, have developed a programme that lasts just two hours and, crucially, these are delivered not by healthcare professionals, but by volunteer graduates of the longer pain management programme – those with lived experience of living well with chronic pain.

Consultant Psychologist Dr David Craig of the NHS Greater Glasgow and Clyde pain service —

Dr David Craig: These classes are designed to empower patients with chronic pain to understand more about the pain and how to manage it themselves. The power of these classes comes through the delivery of the information by people with lived experience. That takes the information to a whole other level – and a level that health professionals who don't experience chronic pain really can't take that information to.

Evans: David Craig of NHS Greater Glasgow and Clyde pain service.

So, I eavesdropped on one of those two-hour sessions at Clydebank Health Centre in Glasgow. The educators were Joan Melville and Georgina

McDonald, both of whom had attended the ten-week NHS Greater Glasgow and Clyde pain management programme.

Joan started the session.

Joan Melville: One of the first things that I learned on the programme was there's more than one type of pain, because I just thought that pain was pain, and I had lots of it. And I always thought I had quite a high threshold of pain, you know, I've had childbirth, I've broken a bone. I thought I was ok and I was managing it, but see, once my pain got to the stage that it was chronic and I was in pain constantly, I had no idea whether I was coming or going. I think I spent more time crying than anything else – and not so much crying because of the pain, but crying for me. I wasn't me anymore. The only way that I could cope with it was to go to the doctor's, get more pills.

Some of the pills that I got made me feel really numb. I didn't know whether I was coming or going. It was not a life to live really. I became a bit of an emotional wreck through it all. So not all pain's the same. So, I'm going to read this wee bit because it's a definition by the British Pain Society. It says that 'Pain is an unpleasant sensory and emotional experience with, or resembling that, associated with actual or potential tissue damage'.[1]

So, you break your ankle or you burn yourself. That's acute pain, and that's a type of pain that comes, you will heal, and things go back to normal.

Then there's what we call chronic pain. So, there's a number of different terminologies for that. Some people might say persistent pain or long-term pain. I was taught to call it chronic pain, and chronic pain is defined as 'a pain that lasts for more than three months'.

And, for some of us sitting here, it's lasted for more than three years, but it's less easy to explain.

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[1] https://www.iasp-pain.org/publications/free-ebooks/classification-of-chronic-pain-second-edition-revised/.

So, if you go to the doctor and you say I've got a pain here and it's happening every day, the first thing they're gonna tell you is what you've *not got*. So, they start doing tests to find out what you've *not got*, and it doesn't respond as well to drugs. You know, if you've burnt yourself or you've broken something, you get medication and it takes the pain away. Chronic pain doesn't work that way, it just happens all the time.

But the biggest thing for me was it turned my life upside down. It was the impact that it had in my life. All the little things. I love cooking but I found I couldn't stand in the kitchen. I couldn't stand and cook a meal. So, I stopped cooking. My husband became the main cook, and that was something I loved. You start to give up on the things that are important to you.

I stopped going for walks with my pal because it hurt too much to go for a walk. I stopped visiting other friends that had kids because the kids were too much hassle to deal with. And then I got grumpy and I got really tired.

And I was a nightmare to live with, and I think I took it out on everybody around me. I never bothered explaining to anybody how I felt. So, my family and friends clearly didn't understand what was going wrong. Now, if I'd turned up with a plaster cast on, they would have said 'Ooh – you broke your leg, you broke your arm'. It's something visible. They see it, and you get that empathy. But not when you've got an invisible pain that nobody – including you and your doctor – knows what it is. But then I learned on the pain management programme that we've got a thing called a 'nervous system', and that was a big thing for me. At school, I didn't do biology or anything, and I had no idea what a nervous system was. But once I understood what it was, I understood where my pain was coming from.

Now, I'm not a scientist but there's nerve endings. And then you've got your spinal column. And then you've got your brain stem at the back of your neck, and then your brain. So, effectively, if you damage a nerve, that pain goes all the way up and your brain sends a signal saying 'Help – you've been damaged'.

And, in chronic pain, when we see that your tissues have not been damaged, it’s because somewhere along the line the system’s got a wee bit confused and it just keeps sending the signal back and forward. So, there may well be no damage, like the broken leg, but your system says ‘I’m in pain. I’m trying to stop the threat of you being injured’, and that message doesn’t stop. And actually, it’s really hard to try and reset it. So, you constantly get that. It doesn’t matter how many drugs you take or how many devices you use. Like me, that message still comes – ‘I’m still in pain’.

There was a video we watched in the programme, and it was called ‘Why Things Hurt’ – have a look for it on YouTube if you can – and it was this Australian guy who told us that he had been out in the outback, he got a wee jab in his left leg, the nervous system sent a message to the spine, sent a message to the brain cell up to the brain and said ‘Ah, you’ve been poked by a twig’. He nearly died. He’d been bitten by a brown snake, which is poisonous.

But, the thing was, *the next time* he was out in the outback, he got jabbed in the leg and he immediately screamed ‘Aaah’, and shouted, ‘I’ve been bitten by a snake’ because his brain told him that – he was in the same environment, it was the same sort of sensation, so his brain, the memory in his brain, said ‘Hey you’ve been bitten by a snake’ and he hadn’t, he had been poked by a twig!

So, what helps these messages go back and forward is your memories, your expectations, your external environment, past experiences, beliefs – all these things are feeding into the message that the nerve endings send to the brain.

And that’s why it’s so difficult to change it, because all these things have to change. So, it means we need to understand that pain is an output for the brain. It’s the brain’s way of making sure that we’re safe. But the most important thing is that pain is not in the mind. Don’t ever let anybody tell you that your pain is in your mind. It’s just the brain’s interpretation of the signals that it’s received. It doesn’t necessarily mean that there’s damage to the tissue, but the pain is real. It's the hard bit, trying to change the signal but it also means that your pain is very unique to you.

So, if we accept that there's a pain signal jumping along the system. To get there, it's released by a chemical called a neurotransmitter. And there are good neurotransmitters and there are bad neurotransmitters. And I'm sure you've all heard that you get painkillers that give you good neurotransmitters, and there are things that make it bad.

So, some of the things that release the same chemical to make the neurotransmitters good are exercise, doing things that make you laugh, meeting up with friends – all the things we stop doing because we're in pain.

But there's also things that feed the bad neurotransmitters, and that's the depression, the feeling bad, the feeling low, excluding yourself from things that are going on. So, we need to focus on strengthening the good neurotransmitters. And that's what's in my toolbox. There's a whole set of tools. Georgina is going to start touching on some of those now.

Georgina McDonald: So, how do we live our lives when we have chronic pain? We start off often by wanting to do so much. We have a good day, so we think, 'It's lovely, I'll do all the gardening or I'll do all the washing, I'll hang it out'. You know, you do as much as you possibly can, thinking, 'It's a good day, I'm going to get this all done'.

But in actual fact, what happens is that our pain levels stay higher, but we haven't been able to achieve as much and, eventually, our activity comes down, and that is this 'boom and bust' cycle, which we're going to explain is not the best thing to do. So, there are ways that we can work this out, there are ways that we can change that, and that's what's in the toolbox. It's giving you some ideas as to what to do.

We have this vicious cycle when we have chronic pain. One of the worst things about having chronic pain is the fear. 'What's going to happen, am I not going to be able to keep my job' or 'Am I not going to be able to look after my family?'. For me, I was in a wheelchair for quite some time and it was, 'Am I going to have to stay in the wheelchair?'. There was this constant worry about the future, and because you're frightened that the more that you do, the worse it's going to be, you do less, and by doing less we lose fitness.

It's a well-proven fact that you have to keep active to stay active. And, I think, with chronic pain the vicious cycle works right round so that eventually, because of the pain, because of the way you think, you stop doing what you want to do and what you think you can do and you then lose fitness.

And there's another cycle where, if you think back to that pushing on, we almost try to ignore that we're in pain. So, we have the pain and we try to ignore it, so we just keep on doing what we're doing.

So, what's our options? Because, as I can honestly say, there have been times in the past where I was doing nothing and *could* do nothing but, through using a lot of these options, I've now got to the stage where I am today. That's not to say that I don't have chronic pain still – I do, and there are days when I'm quite low because of it.

If we look at this toolbox that we've been talking about then there are ways of actually managing your pain and managing your activity.

Spacing is where you break up a job that needs to be done, or break up something that you're wanting to do.

Doing what you can when you can and going with the flow. Some people will use that as an option. I don't because the thing with that is, you can't actually plan what you're going to do. So, if you're only doing what you can when you can, you're not sure when you're going to have a good day and when you're going to be able to do what you want to do.

Activity planning is, I think, very important, and I plan all my activities, literally from my housework through to seeing my grandchildren.

I have a written diary. I have a proper book diary in my bag and I write down on each day what I'm doing so that I can look at it and say, 'I've got something on three days next week. That’s not going to be good’. So I deliberately don’t put anything else in the diary.

I also look at what I’ve got to do. If friends say to me, ‘Would you like to go out for lunch?’ or – and that happened today – ‘Would you like to go for coffee?’ or whatever, I now ask if I can book it because I can plan to go somewhere that is safe for me and is accessible for me and I don’t have to leave the car in the car park and then walk for a mile. And don’t be frightened to tell people, ‘Actually, I’m not that good today, so can we do …?’ and describe the change, maybe what’s in your diary.

Mairi McWilliams: My name is Mairi McWilliams, I’m originally from the Isle of Lewis. I moved to Glasgow when I was 19 to study. And I’m a pain educator for Pain Concern.

I have been living with chronic pain since I was 17. It stemmed from a kidney operation that I had – pyeloplasty of the right kidney. The operation was a ‘success’, but it’s not improved my kidney, and I’ve had pain since then.

When I had the pain before my surgery, I was prescribed lots of different medications which numbed it. I’m 29 years of age now. It’s still the same, but I manage it better.

Evans: So, what has changed between now and then?

McWilliams: Educating myself on pain, chronic pain, learning ways how to manage it. I always talk about the toolbox, my toolbox. When I first discovered pain, the toolbox was non-existent, it was very much medication – like everybody goes to their GP. That’s the first protocol.

But the best thing that happened with me is not that my pain has got worse or better; I still have the same pain, but I manage it a lot better through education and adding more tools to my toolbox so that I’m in control of the pain instead of the pain being in control of me.

The biggest hurdle you’ll come through is accepting that you may have pain for the rest of your life. And that was really difficult for my family, more than me, to accept. My mum used to be very, very desperate to fix my pain and I say to her now, ‘The best thing that I ever did, mum, the best thing *you* can do to help yourself is accept the fact that I have pain and I am 29 and I might live to 99 and I will have pain and I’m ok with that because I’m managing it’. If we had spoken a few years ago, I wouldn’t have been able to do this ‘cos I was such a zombie. But over time, I’ve learned to be more switched on because I’ve managed my pain. But that doesn’t mean I don’t get flare-ups, and some days it's really bad and I can’t control that either, which is quite frustrating.

I’m easier on myself when I have pain, just to say, ‘Can’t work today, and that’s ok because I know I’m in pain. I don’t need to justify it to anyone else’.

Evans: So, people have to find their own way to live with pain?

McWilliams: Yeah, I would say it’s a very individual experience. Everyone’s pain journey is different. I think talking with people with chronic pain helps. I used to speak to people, anybody. At Tesco, ‘How are you today?’ ‘Oh well, let me tell you about this …’. But I was exhausting myself. See, now I’ve got a community of pain educators around me. And see, when we deliver the sessions to people, it’s not pain educators and participants. It’s one big community. We are all living with chronic pain. We get it. We’re seeing it in our feedback all the time. I did a session yesterday and somebody said, ‘Yes, the presentation’s wonderful, but the most important thing for me was the fact that I was with people that could relate’.

McDonald: So, we want to go back to pacing. So, pacing is where you have something to do or where you want to build your activity. But you do it in manageable steps. Even on a good day, we often have a bit of background pain. Our baseline is what we can do comfortably before the flare-up pain kicks in. Baseline is starting off very steadily and then building up something.

For me, it’s Braehead. I like to go to Braehead shopping. But it used to be that I could get out the car and go to Marks & Spencer’s and back to the car, and that would be my first line. And then I would walk to the next entrance at Braehead. And there's a coffee shop, and that would be the next step up. And so it went on till, on good days, I can go right along to Next and have a coffee at Next, walk back knowing that the car's at the other end. I can have a coffee or a seat if I need it when I get to the other end.

But that's not to say that there are not days when I get to Braehead and I walk in and I get along to where the lifts are and think, 'You know what …'. And it happened the other day, I was going to Superdrug to do all sorts of things, and I just turned and came back. But it just means that I start off again and build that up. And if you have goals in your life of things that you really want to do, then achieving them, it's an amazing feeling. So, all of that then comes through when I keep myself active and keep my mind active as well. It's not just about your body, it's the mind as well.

So, look for things that are important to you. Do a self-assessment. How much can you really do? Don't start off at the top of that activity level. Start off carefully, pacing yourself from your baseline, so that you're starting at a level that is good for you, and build on that because there's nothing worse than going at something and then not being able to do it, and you get all these negative feelings coming in rather than positive ones.

Develop a plan and aim to build it up gradually, so that may be anything from walking to swimming to cooking, knitting, gardening, whatever it is. Look at what you want to do and build it up properly – thinking through, 'How will I achieve that?'. Don't set yourself a plan that's going to be outwith your capability.

Reward yourself along the way, but be kind to yourself, because the one thing about chronic pain is nobody else knows what your pain is like. It's invisible. It's only you who knows exactly what the pain is like. So, when you've achieved something, reward yourself, and that gives you that positive feeling, and just say 'I've done well, I've done something'.

Lindsay McLean: I am Lindsay McLean, and I have lived with chronic pain for 15 years.

I went from being a very independent, energetic, social, active, employed person to having to leave work, having to depend on others for basic care. I became housebound and bedbound, and all my future plans – everything – just stopped, and that was just as I was turning 30. It was quite a bitter pill to swallow because I always thought as well that pain doesn't improve with age. The older I got, it would get worse. So, I thought 'Oh, that's me. This is my life now, and it's going to be a very miserable, lonely and just really restrictive life'.

Evans: And has it been?

McLean: No. I am very pleased to say it has not been.

I had a lot of medical appointments, a lot of medications, investigations with very little success. But then, when I moved to Glasgow, I was referred to the Glasgow pain management programme. I had these preconceived ideas of what I would expect at this group. I thought it would all be people above a certain age. I thought everybody would be judging me because I heard frequently that I was too young to have chronic pain.

And so I thought I would actually be told to leave the group, but when I got there, it was such a welcoming and friendly environment, the pain management team were so informed. And, for the first time, I just felt 'I'm not alone with this'. And these people get it. They took me through the science of pain, pain education, stress management, sleep hygiene, pacing – just lots of techniques and strategies on how to self-manage my pain and basically give me the power back, where I was in control of my pain and not the other way round. And it was a very, very slow process, but over time, I was getting my life back step by step, and it's just, even now, even after ten-plus years of doing it, I just felt it was fantastic.

Evans: Well, you mentioned one word, well two words actually – self-management.

McLean: Yes.

Evans: You're on your own. Get on with it. Is that what it means?

McLean: It’s really about informing the person with pain about how to manage their pain and how to put these practices into their daily life and how to challenge your own thinking, your thoughts, again, the limitations we can put on ourselves. Having the information helped me a lot because of the things I was trying to do.

For an example, I used to love going to the cinema, and that was something I had to stop completely because it just didn’t seem worth it for the pain I was getting. When I was on my elbow crutches and I thought, ‘Oh, we’ll try this again’, I would go and I would manage it fine with my friends and the support they would provide, but then I would start thinking, ‘Well, what happens if I have a flare-up and I can’t go out, what happens if I flare-up when I’m out and then I’m stuck, what happens if my friends think “Oh, you know, I’m getting annoyed with this”’. The fact that I had to make little adjustments like ‘Oh, can we stop here for a seat first?’ or ‘Can we go to a cinema closer to me so it’s not too much travelling distance?’. And I just got so consumed with all these thoughts and worries and fears that I thought ‘Do you know what, it’s not worth it, I’m better off just not going. I’ll try again on a better day’.

And then, of course, I worried that I wouldn’t be able to sit in the cinema seat for the duration of the film. But again, these fears became like a self-fulfilling prophecy because when I *did* try, it was like a shock to my system. My body *did* flare up in pain so I went away thinking, well I tried, I have pain so therefore it means I cannot go to the cinema anymore.

Now, that was not because of my pain. That was because of my fears and my thoughts, and that made me stop going to the cinema, and my body started to lose fitness, and I didn’t understand all that. So, I just thought chronic pain means no cinema. Whereas when I went and learned about pacing up and strategies and techniques and, again, challenging my thoughts and my fears and thinking how I would support somebody if they had chronic pain and what my attitude would be towards them, and things like that, I tried again and I was successful. Now I frequently go to the cinema, despite pain, and even times when I have flare-ups I can still go to the cinema but I make adjustments. But, again, it was having that knowledge and that guidance to self-manage in the correct way, because activity is very, very helpful for pain but you have to know how, and recognise your limits, and that's why the education was so vital to that because it really did show me 'Right, ok you've got the motivation, you've got the goal that you want to work towards, let's find a way to do it'.

McDonald: If I'm honest, fear is one of the biggest emotions that I have with regard to chronic pain. If I have a new pain, or if it gets a bit worse, I think 'Ahh' and the frustration of not being able to do what you want to do brings with it stress. It can affect our thinking. 'I can't cope' and 'What if' and 'I'm useless' – that's all coming into that anxiety and fear.

What has stress got to do with chronic pain? Well, pain is stressful. If you go to get up off a seat or if you go to do something and you're in pain, immediately your shoulders get tight, your chin goes down, and you feel that kind of 'pulling yourself in', that's a sign of stress. And all of that, the pain, the worry, the less activity, is in that cycle that we talked about earlier where the pain causes us to worry, so to do less – sensitised nerves – the whole thing goes round and round into a vicious cycle.

If you think about your behaviour when you have chronic pain – you stop doing things, maybe things that you've really enjoyed. You are so concentrating on, 'I've got to keep going but I've got this pain', then your thinking becomes the next step, 'I'm useless, I'm not able to do things, I'm getting worse' and your thoughts then almost take over and you will then end up with physical sensations of tummy upsets, perhaps a headache.

My biggest problem was I used to sit with the shoulders up because I was trying to protect myself. So, physical sensations come in and then you have the fear, all the emotions that you have, the feelings of being useless, the feelings of, 'What are people saying about me?', and that comes in with the thoughts as well, because if you have to cancel something, you know, you've maybe been asked to do something and you think 'It's a bad day – I can't do that' – your first reaction is they're going to think, 'Och, she's sore again'. You're feeling as if you've let people down.

So, there’s all sorts of things tied up in that, and all of these interact with each other, but if we can just find a way of altering one of them, then it breaks that cycle.

The more I could have positive thoughts and say, ‘Well, do you know what? I actually did such and such today, I’ve achieved this’, and the thoughts that are positive can break a bit of that stress cycle. There might be things that we can change, and there might be things that we can’t change.

So, feelings and pain aren’t easily changed but we can influence how we think, and we can influence what we do, and that’s your behaviour. If we’re thinking about what we do, it’s about not, maybe, cancelling something, but saying ‘Well could we do it in a slightly different way?’ and changing one or two of the parts will help all of them. It can influence the others. It can break that cycle. And that’s what we want to do, so that that doesn’t just keep going round.

So, sometimes we need to look for help. If you want to go out for a walk but you know you’re not keen on being on your own, then ask someone to go with you. I remember not telling people that I was in pain, and I would make all sorts of excuses, and I was giving myself more stress because I wasn’t actually being honest with other people.

Well, sometimes when we have chronic pain, it’s hard to sit down quietly and think through things. Later on we talk about mindfulness or relaxation, and that’s when you’re able to sit and think things through calmly and see things in the right way. A thought is just that – a thought.

McLean: I am confident in my own abilities now – how to manage my pain and when flare-ups happen. I’m still learning to this day because life revolves, it doesn’t stay all the same. I found my rhythm with my strategies in place and the education that I had, it got into a kind of rhythm and a routine, – but then, when I had my son, obviously having a child will throw that routine out the window, and you have to kind of evolve and learn and take a step back and think ‘Right, what do I need to work on?’. And, again, I’m a single mum to my son. Even when I was pregnant, I thought the only reason that I can have my son and keep up with him is because I have my partner's support. Well, again, I was putting limitations on myself and, having the education at my back, it really again reminded me to challenge my limitations and, again, now my son and I, we have a wonderful life, a very independent, active life, and even now I never thought I could do that myself. But again, I have all these tools and the knowledge and the strategy and the confidence and motivation. It's expanded my world, and I did not believe that that would ever be possible.

Evans: But it's a huge, monumental step from 'I can't do it' to 'I can do it'.

McLean: Yes, it's about kicking those 'buts'. 'I have pain but I need to go shopping' as opposed to 'I have pain *and* I need to go shopping'. Even just changing the words – just going 'Well, I have pain and I need to go shopping, I can do this' rather than 'I have pain *but* I need to go shopping'. It's again, just challenging the thoughts, challenging your thinking. It's just been a very life-changing experience.

Melville: Georgina spoke about overthinking things and changing your thought process. I don't need my brain system to tell me that there's potential for fear. I make it all up in my sleep. So, I can go to bed, quite the thing, and then wake up in the middle of the night and I'm dying because I start overthinking – one thing leads to another, leads to another, and I can't get back to sleep, and I toss and turn. And then I get upset, and then I start to worry, and then I get stressed, and we're back in that stress cycle – I can't get to sleep, pain wakes me up, and I just go round and round in circles.

I learned through the pain management programme to slow down my breathing. The mindfulness bit I was never very good at it. We had a guided mindfulness, and the guy that spoke, his voice went through me, and I've got a thing about symmetry, and he had done all of the guided meditation up the left-hand side of your body, but he didn't spend the same amount of time or touch the same bits of body on the right-hand side, and I was 'No, I cannae do that' [laughter], so that stressed me.

So, I went and I found somebody who had a voice that I *did* like on YouTube, and I used that. And, whilst it's not my favourite thing, what I did learn was how to relax. I learned what it was like to have your shoulders up and what it meant to relax your shoulders, and I had relaxed bits in my body that I'd never relaxed before. So, I do use that when I'm up during the night.

There is a myth about, you know, you need eight hours sleep – you don't, and you can't catch up on sleep because your sleep has to go through a number of different cycles.

So, you've got REM. Have you heard of that? That's when you start to dream. And then you've got your light sleep, and then you've got your core sleep, so your body will naturally balance out – if you miss it in deep sleep, it will fix it over the next couple of nights. So, you don't need to 'catch up' on your sleep.

Turning your bedroom into a living room [laughter] – I've got crochet at the side of my bed!! I've got several books because when I wake up, I used to do something because I couldn't get back to sleep. But you end up… you've got a TV in your room, so you put the TV on or you get your iPad up, and before you know it, you've turned night into day. So, you've been up all night doing things, and then you've slept all day.

So, what I found was trying to set a routine. I have a really strict routine, and this is how I get to sleep at night and how I stay asleep. I have an alarm that goes off at 10.45 pm each night that tells me it's time to go to bed, and I follow the same routine every night. I go to bed and I get up at the same time in the morning, every morning – weekends and holidays – because that's my routine now. That's what helps me sleep.

Now, when I set that up as my routine, that didn't mean to say that I was used to going to bed at 10.45 pm every night. I certainly was not. It could have been 3 am because I had been up or I had slept half the day. So, you set your watch ten minutes earlier. Go to bed at 2.50 am and, just as Georgina said about the pacing and spacing, pace until you get back into a normal routine. So, half an hour earlier, half an hour earlier, half an hour earlier until you get to bed at the time that you need to be in bed, and you can get up at the time that you need to get up.

So, I'm one of these people – I make my bed when I get up in the morning. So, when I go up to my bedroom, my bedroom *looks* like a bedroom. And I know that I need to go to bed and have that routine – 10.45 pm up the stairs, jammies on, toothbrush, hairbrush, all of the things that I do… plaster myself in cream hoping that I'll look younger in the morning! That's my routine. Takes me 15 minutes, and in that 15 minutes, I've told my brain it's bedtime.

So, when I wake up in the middle of the night because I haven't been able to get to sleep, my go-to is not to lie in bed and think and worry about it and then overthink things and get back into that cycle – I get up. I have a 15-minute rule. So, if you haven't fallen asleep in the first 15 minutes, get up for 15 minutes.

But, in the pain management programme, they told me not just to get up for the 15 minutes, but to go to a different room. So, it's all about the brain. So, I would go to a different room – that could be a walk downstairs and then a walk back up – and then I'll go through my same routine that I have to go to bed. So, I'll go back to the bathroom, brush my teeth, brush my hair, put my cream on because I'm telling my brain again, 'It's time to go to bed'. And then I start to feel sleepy. What I don't do is put on an iPad or a phone because the blue light will make you even more awake.

So, what are the sort of things that stop you from getting to sleep at night?

Tea and coffee, make sure it's quiet and dark. I've never had curtains in my bedroom – I like the sunlight coming in – but now I've got curtains up in it. I follow my 15-minute rule. I go to bed at the same time, so I've gradually got to the stage that I can get a decent night's sleep now. For me, it's 4 am, that's when I wake up. That's usually when my pain threshold's enough. And I get up. That's when I start to sit and worry. And that's when I'll apply some of the techniques that Georgina spoke about in stress. So, I will try to use my meditation to relax myself, not to overthink things and slow down my breathing. What happens to me if I wake up is that worry – I'm not gonna be able to work tomorrow, I'm self-employed, I'm gonna be overtired and can't work, that means I'll not get any money, but if I've not got any money, how am I gonna pay for the electricity bill? I need to turn the heating off, and it is just one thing into another into another.

So, one of the other techniques we were given was 'park it'. Park your worries. So, notepad at the side of your bed. If I start worrying about something in the middle of the night, I write it in my notepad and I deal with it tomorrow. And that allows me to clear my mind enough sometimes to get back to sleep.

Don't get desperate. So, if you can't get to sleep one night, then still try the next night to bring it forward by half an hour or get up and do the 15-minute rule. None of us can change things overnight. Everything takes time. Persevere. You'll find the thing that's right for you.

McDonald: So, life is still worth living, even with chronic pain.

You can have a different life but you can have a good quality of life, and I think probably Joan and I are evidence of that fact that, yes, it's not all sweetness and light, and we're not saying that it is. But what we're saying is there are ways of dealing with the chronic pain. There are days when I think 'I can't cope with this', but you do, you get on. You look back at what you've learned, and you think 'Yep, tomorrow will be better'. And look for the help that you can get, whether it be from your pharmacist, your doctor, your community nurse or your family, and get the support that you need.

And don't forget to be good to yourself. Be kind to yourself, be selfish. That's the only way you'll actually get through.

I hope you've enjoyed... Do you have any questions, or have you found it challenging or has it made you think? [fades away]

Evans: Georgina McDonald bringing that pain education session to a close.

Now, these in-person sessions are for people living within the NHS Greater Glasgow and Clyde Region. They take place at the Clydebank Health Centre between 5 pm and 7 pm on the second Thursday of each month and at Easter House Health Centre from 10 am until 12 noon on the last Thursday of each month.

You don’t need a referral, but you must phone 0141 355 1493 to book your place or to find out more information. That’s 0141 355 1493, or you can pick up an information leaflet at your local GP Health Centre.

This edition of *Airing Pain* was recorded in mid-2025, so do check for the current arrangements.

But for those not living in Glasgow, or unable to attend the in-person sessions, here is an alternative. Pain Concern’s Heather Wallace —

Wallace: We’re now working with the NHS to provide sessions online because so many people, one in five, have chronic pain. Everyone needs to take a role in trying to change that situation, and we’re just trying to widen access and allow as many people as possible to get access to pain education that gives them the tools that, with practice, enable them to live well with pain.

Evans: Pain Concern’s Heather Wallace.

For more information on those online sessions, go to the Pain Concern website, which is painconcern.org.uk, or just put ‘Pain Concern Education Session’ into your search engine. As in the NHS Greater Glasgow and Clyde in-person sessions, these are free of charge.

For more information or to book a place on one of Pain Concern’s online pain education sessions, call or text 07421 125638; or you can email pain-education@painconcern.org.uk; or go to Pain Concern’s website at painconcern.org.uk to book online.

And I’ll remind you, as I always do, 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 professionals on any matter relating to your health and well-being. They're the only people who know you and your circumstances and, therefore, the appropriate action to take on your behalf.

Now, it's important for us at Pain Concern to have your feedback on these podcasts so that we know that what we're doing is relevant and useful, and to know what we're doing well and maybe not so well. So, do please leave your comments or ratings on whichever platform you're listening to this on, or the Pain Concern website of course. And, once again, it's painconcern.org.uk. That will help us develop future editions of *Airing Pain*.

We'll end this edition of *Airing Pain* with pain educators Mairi McWilliams and Lindsay McLean. And, in case you're still in doubt as to why you should attend a Pain Education session…

McWilliams: There's lots of reasons why you should join a session, but the biggest one for me as an educator is the fact that we're all the same. It's just a big chat. It's not like you're the participants and we're presenting a presentation to you – a generic presentation. It's tailored, it's evidence-based. We talk about things like sleep hygiene, which I've never thought about before, stress and pain, activity and pain.

McLean: When people come to pain education sessions, they are maybe still in a place where they've not had very much success managing their pain. They've maybe perhaps started to distrust, maybe a strong word, but the health professionals or the advice that's coming. So, when they hear somebody that's been part of that process and going, you know, 'This information will help, it's not a quick fix, it's something you have to work to but it's something you can be supported with', you find a lot of people start to become more open, more receptive to it. I feel it gives them that bit of hope because I can honestly say I *have* been where you've been and I get it. Obviously, I never understand everything that that person's going through, but enough to know that it's not hopeless.

There are so many possibilities ahead, it's just a bit of encouragement.

McWilliams: I just guarantee that you'll come away with something.

Just do it!

End

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