Airing Pain Programme 1: Introduction to pain

What is chronic pain and how can we manage it? We talk to health professionals and patients to find out more.

*In this first **Airing Pain** programme we introduce the subject of pain and its management with contributors with a variety of expertise and experience. Professors Blair Smith and Richard Langford take us through the causes of chronic pain and conditions associated with it, while Sherrill Snelgrove and Kiera Jones talk about the challenges faced by patients in being understood by the health professions. Dr Beverly Collett explains the importance of the patient's own understanding in managing their condition and keeping active.*

We also feature short interviews with some of the experts we'll hear more from in later programmes: Professor David Walsh discusses the importance of multidisciplinary approaches in helping patients to manage their pain, Professor Nick Alcott and Claire Rayner encourage older people to get help with their pain and Nicole Tang talks about how people with pain can improve their sleep, and finally, Pete Moore give some words of encouragement based on his own experience of learning to live well with pain.

Lionel Kelleway: Hello, and welcome to ***Airing Pain***, a programme brought to you by Pain Concern, a UK charity that provides information and support for people who live with pain – people like me, Lionel Kelleway – and for those who care for and about us.

Dr Beverly Collett: There are 7.8 million people in the UK with chronic pain. That means one person in every four households has chronic pain.

Kelleway: Each fortnight in ***Airing Pain***, we'll look at the topics that affect us.

Dr Sherrill Snelgrove: There are reports from patients that they're not understood very often and they feel they are given a low priority in the health services.

Kiera Jones: I've been through the whole rigmarole of doctors, specialists, and having MRI scans, x-rays, ultrasound scans, the lot.

Kelleway: And we'll look at how dealing with pain on a day-to-day basis affects the way we live.

Dr David Laird: On a good day, we want to do things. We want to achieve things. That means that we overreach. We're overactive. We want to live our lives without the pain interfering. And that's part of the whole aspect of the loss that pain induces.

Kelleway: We'll look at the coping mechanisms, medical interventions and therapies that might help us regain control of our lives.

Dr Steve Allen: More and more, we're beginning to understand what goes wrong with people who have pain and, more and more, we can do something to fix that.

Kelleway: And just to prove that you can live with pain and keep smiling...

Claire Rayner: One summer night, I had gone to bed early. I was lying in bed, stretched out starkers, reading glasses on the end of my nose. My husband comes in. He stands beside the bed, and he says: 'Look at you – you've got artificial shoulders, artificial knees, you've got a hearing aid, you've got a pacemaker, you've got glasses – I don't know whether to plug in or switch off!'

Kelleway: More from Pain Concern's patron Claire Rayner later in the programme. But first, a few words about ***Airing Pain***. This is the first in a fortnightly series of programmes produced by Pain Concern, a UK charity that provides information and support for people who live with pain. So those are the people we are making the programme for, along with our families, friends, carers, and supporters, but also for health professionals who either wish to have a better understanding of those suffering pain conditions, or the experts who wish to hear and share their views and strategies with colleagues and patients.

But first a word of caution, that whilst we believe the information and opinions on ***Airing Pain*** are accurate and sound, based on the best judgments available, you should always consult your health professional on any matter relating to your health and well-being. He or she is the only person who knows you and your circumstances and, therefore, the appropriate action to take on your behalf.

In this, the first edition of ***Airing Pain***, I'll give you a taster of some areas we'll be covering over the coming months. But we'll start at the very beginning. What is pain?

Well, there are two broad categories: acute pain – that is, the pain that gets better, for instance, from a broken leg. It hurts, but as the body heals the injury, so the pain diminishes. Or so it should diminish.

And then there's chronic pain.

Prof Blair Smith: By definition, chronic pain is pain that has lasted beyond the time that the body should have healed, so chronic in this sense means: 'long-lasting' – nothing to do with severity. So it is in itself, by definition, an illness.

Kelleway: Professor Blair Smith is Professor of Primary Care Medicine at the University of Aberdeen. So how many people does this affect and what causes it?

Smith: Depending on how you define chronic pain, at its loosest definition, up to half of the population actually have chronic pain. But at a more stringent definition, at the most severe end, about one in twenty people have chronic pain. People who have this level of severity talk about pain being the overriding feature in their daily life and it tends to be… more likely to be women and more likely to be older people or people with other health problems. But of all people with chronic pain, it is maybe about a third of people who have chronic back pain, a third maybe have arthritis and a third have pain caused by other illnesses or diseases.

Often, we don't know the ultimate cause of pain. Sometimes it's obvious, like an operation or an injury. Sometimes it's a disease that we can diagnose. Actually, very

often, it's something else that is happening to the nervous system. In neuropathic pain, there are abnormal signals being sent through the nervous system up to the brain, and it causes a particularly unpleasant sensation which is there all the time.

Kelleway: Professor Blair Smith of Aberdeen University. And neuropathic pain is a subject we'll be returning to in greater depth in a later edition of ***Airing Pain***. The idea of pain as an illness in its own right, rather than as a result of some other injury, has not always been taken seriously and, indeed, there are still pockets of ignorance, not just in the medical profession but in the community at large.

Professor Richard Langford is a consultant in anaesthesia and pain management, and is president of the British Pain Society.

Prof Richard Langford: Sometimes because you can't see that there is a diseased part – there's nothing that looks inflamed or broken or has recently been operated on – you can look at the arm or the leg or the abdomen or the chest or whatever and it looks, to all intents and purposes, normal. Even investigations may be pretty normal. It can, therefore, seem a bit of a mystery as to why somebody still complains of pain. Sometimes somebody can have a pretty bad-looking x-ray of their spine, for example, and they have no pain at all. In other people, you struggle to find an anatomical defect, and yet, they have really debilitating pain.

So I think there is an understanding now that there are various ways that pain is generated. The biological mechanisms: when nerves may be trapped or firing pain signals spontaneously, not in relation to an injury but just because they're diseased nerves. On other occasions, you may have actual anatomical defects.

And so there's this whole spectrum. There's pain that can well be generated or certainly amplified by psychological mechanisms. We know that low states of mood, depression etc. – anxiety states – worsen pain. This isn't something which one should be unsympathetic about – tell them just pull themselves together – because actually these are working at a level below the conscious level. This isn't in any way wilful. This level of

understanding has been greatly increasing amongst professionals and, indeed, the fact that those patients then respond to various types of therapy.

Kelleway: Professor Richard Langford, President of the British Pain Society.

One of the many difficulties that chronic pain sufferers seem to share is how to describe their pain to their doctors and to feel believed by them. Sherrill Snelgrove teaches psychology, including communication skills and the management of chronic conditions, to undergraduates and graduates from a range of health-related backgrounds. She is also a registered nurse and a member of the Welsh Pain Society.

Snelgrove: Patients want health professionals to understand what they're going through more than anything else and to believe them. So why do people perhaps not believe or are skeptical about people with chronic pain? Pain of any sort is very often difficult to articulate, the type of pain you're in, and that may be a cause for misunderstanding very often.

I think that also it's to do with the approach that health professionals may have to chronic pain, now their own perspective of chronic pain. For instance, if a health professional has a view of chronic pain as being mainly a biomechanical dysfunction, they're not going to consider people's feelings, their beliefs, or the wider social context in which the person resides, their lives, and how that impacts on the pain. It's partly, as well, to do with the fact that it is invisible. The only way you're going to understand what people's pain is, is by listening to what they say. Pain is what the patient says it is. And I think that's a good basis to work from.

Jones: If someone says they are in pain, they are in pain – they are hurting, they are suffering. Just because you can't see something, it doesn't mean it isn't real. Some people seem to think that if there's no physical problem, if you can't see that I've got a plaster cast on or missing a limb or something like that, they don't think that there can be any pain – there's no visible cause, so it's not real. I think the worst thing that I've had was actually from a nurse. I went to a walk-in centre for a different problem and the

nurse was just saying to me: ‘Well, why don’t you go and get a job?’ Implying I was just some lazy scrounger who was sitting around not doing a great deal out of choice.

Kelleway: That was Kiera Jones, and we’ll be broadcasting an edition of ***Airing Pain*** on the subject of how best to communicate with your health professionals and how best for them to communicate with you in a future program.

You’re listening to ***Airing Pain***, presented this week by me, Lionel Kelleway, and brought to you by Pain Concern, the UK charity providing information and support for people who live with pain and for those who care for and about us.

Collett: We should be trying to encourage GPs to measure pain.

Kelleway: Dr Beverly Collett is a consultant in pain medicine and an assistant medical director in the pain management service at the University Hospitals of Leicester. Amongst many other positions held in professional pain management, she is past President of the British Pain Society and Chair of the Chronic Pain Policy Coalition.

Collett: One of the things that the Chronic Pain Policy Coalition is trying to encourage is to get pain recognised as the fifth vital sign in the UK. And what we want to do is we want to do this not only in hospitals, but also in primary care, so that if you go along to your GP with a pain problem, he will not say: ‘How bad is your pain? Okay. Take these painkillers and come back in a month.’ He will measure your pain so you can give him an accurate answer as to how severe your pain is. Then, when you go back for a follow-up visit, he can ask you again and see if your pain has diminished in any way.

The other thing that we want to encourage GPs to do is educate people about their pain and to realise that often, with persistent pain, hurt does not mean harm, i.e. you will not do yourself any damage if you maintain your functionality. We know that, actually, people often get worse if they do not remain active.

I think that the other thing we want to do is to encourage close relationships between primary and secondary care so that some of the techniques that we offer patients today

in secondary care can be offered in primary care, especially so that we can educate patients using some self-management techniques, using booklets such as *The Pain Toolkit*, which helps people to manage their own pain at an earlier stage. No, you don't need these relatively simple interventions when you've had pain for four years. You need them right at the beginning of their pain.

Kelleway: That's Dr Beverly Collett, Chair of the Chronic Pain Policy Coalition.

We've already heard that 'chronic', as in 'chronic pain', describes the longevity of the pain rather than its severity, although by no means, as many of us can testify, does that mean that the chronic pain cannot also be severe. So what approach does a specialist in pain management follow if, as we've heard, he or she may not be able to cure us?

Dr Steve Allen is a consultant in chronic pain management based at the Royal Berkshire Hospital in Reading.

Allen: You can't be a good pain doctor without, I think, being a mixture of being very empathetic – not sympathetic; patients don't want sympathy, they need empathy – you also have to be a little bit hard. I will have to tell you that I'm never going to make you any better. I'm going to have to tell you that you're going to have to live with some pain for the rest of your life. That's really hard, and you need to be a bit compassionate to do that.

Kelleway: So is there a pattern to the conditions that get referred to Steve Allen's pain clinic and how successful is he in treating those conditions?

Allen: There's no doubt that musculoskeletal pain is the most common thing that's referred to a pain clinic – back pain, neck pain – huge, huge problem. What is it – 1.5 million people a year are diagnosed with back pain? Something like that. Now many of those end up with us at a pain clinic. And I would have thought that most people's clinics – fifty per cent, at least, of patients that we see – will have musculoskeletal pain, probably more.

How successful are we at treating the pain? I think – if I'm going to be honest – fifty per cent of the patients I see, I can make no better than when they first came in, irrespective of what we've done. Around about twenty per cent are made moderately better, twenty per cent made very much better and occasionally cured and perhaps five or ten per cent are actually worse off.

Now that's not a reflection of me being a bad doctor – well, I hope it's not – but it is a reflection of how difficult the syndrome of chronic pain is. That it is something which changes from one day to another, from one week to another, and that very often is not just the fact that the physical things have changed – as indeed they may do – but it's also a reflection of the very complex nature of everybody's life and the psychosocial factors that are involved.

If one of our patients comes in and says: 'Dr Allen, I'm so much worse off than the last month'. Rather than immediately reaching for my x-ray pad or whatever and charging huge amounts on investigations, my first question is: 'What's changed in your life?' Because if you're not coping well with the rest of your life, because of extra stresses, then of course you're not going to cope with the pain either.

Prof David Walsh: All these chronic conditions, which cause pain for long periods of time, have psychological impact, and sometimes we can't necessarily cure the underlying problem. But we can often help people to live with that problem and yet to be able to pursue those things that they value in their life.

Kelleway: That's Professor David Walsh, Associate Professor in Rheumatology at the University of Nottingham and Director of the Arthritis Research UK Pain Centre.

Walsh: One approach to helping people to manage their pain is what we call multidisciplinary pain management programmes. These are often used in situations where individual treatments to try and suppress or eliminate pain have not been entirely successful, when the pain's still interfering with people's lives.

Multidisciplinary pain management programmes work on the principle that, well, we could send people to see a psychologist and we could send people to see a physiotherapist and we could send them to see an occupational therapist and at the end of all that, in fact, what people's experience usually is, is one of confusion. That everybody seems to be using different language to explain what's going on. Sometimes it seems contradictory – it doesn't seem to fit together.

And, therefore, people have developed programmes whereby all the different types of approaches which are out there can be brought together under one treatment. And these programmes are often run in groups of people, partly because actually people often get more out of talking to other people with similar problems than they can do out of health professionals who have never had the problem themselves. Now, everybody is different. Nobody's problems are exactly the same. But working within groups is often, I think, more effective than just talking one-to-one with a professional.

So pain management programmes are commonly used and recommended for chronic pain for which there isn't a simple cure. These programs don't aim to eliminate the pain. They accept that the pain is going to still be there at the end of the programme, but if the pain doesn't dominate the person's life in the way that it was before, then that's a useful outcome.

Jones: One of the things which I find most awkward is just using a knife and fork when you're eating. When I was at university, I just used to eat pizzas all the time, because you can just pick it up with your hands. But it's embarrassing, in a way, because just this week, I was in a restaurant with a friend, and my left wrist was in agony, essentially, so I couldn't use it at all, so I'm there trying to hack through my food just using a fork with my right hand. It's just frustrating that simple things like having your dinner causes pain. I don't think anyone can fully understand until they've experienced it themselves.

Kelleway: And I'm sure what Kiera Jones says is true. But here on ***Airing Pain***, I and others bringing you future editions have experienced this sort of pain. And I'm hoping that our mutual understanding and shared experiences, along with those of the health

professionals, will help all of us, sufferers, carers, and health professionals, gain a better understanding of each other's challenges.

But let me remind you that what we cannot do on ***Airing Pain*** is offer a diagnosis or recommend a specific treatment, therapy or drug. We will, however, help you find your own way through the labyrinth of information and misinformation that is available on the internet and elsewhere.

Ian Semmons: Some are worn down by going through the various parts of the NHS and going nowhere and they don't know where to turn. Others will search the internet for anything and there's a danger there because people are looking for what we call the 'Holy Grail'. That they're going to find a cure for their pain and you generally have to accept that a cure for chronic pain just isn't there. Managing your pain better, certainly, but the cure might not be there.

Kelleway: Ian Semmons is Chairman of the charity Action on Pain. If you've just joined us, I'm Lionel Kelleway, bringing you the first in a fortnightly programme of ***Airing Pain***, produced by Pain Concern, supporting people who live with and care for those in pain.

Here's the patron of Pain Concern once again, Claire Rayner.

Rayner: It all started with osteoarthritis. I began to get wear and tear of my joints when I was still quite young. Oh, I suppose in my fifties. And it was not much fun. I did what most people would start with – I'd take a couple of paracetamol and try and ignore it. Ultimately, I was given artificial joints. I've had, over the years, five knee joints. Now, as well as knee joints, I've got shoulder joints. I'm very lucky that one has worked magnificently. But most of the time, I honestly think, you deal with pain by… you have to be rational about it. Is there anything you can do to get rid of it? Yes – do it! Is there anything you could do to get rid of it completely? No. Okay. Bad luck – live with it! And that's what you have to do.

You learn as I learn not to think about it, not to focus on it. When I find I have a pain that bothers me more in one knee, I will start flicking my fingers, even as I'm watching

television, because that makes me shift my focus of attention from the achy bit to a bit that isn't aching. And that works quite well. I don't do it — if I do it in the cinema, people might notice, but even there, if something hurts, I might flex my toes, because that shifts my physical attention to another part of my body.

Kelleway: That's good, personal advice from Claire Rayner, who amongst all her campaigning and writing is President of the Patients' Association and a former member of the Royal Commission on Long Term Care of the Elderly.

Many of us are under the impression that pain and old age come together, but pain is not an inevitable part of aging. Professor Nick Allcock is an associate professor at the School of Nursing in Nottingham.

Prof Nick Allcock: When you're suffering from chronic pain, if you have a belief or an attitude that the pain is inevitable – that it's because of your old age, there's nothing that can be done about it – you're worried that talking about your pain to others might lead to others getting fed up with you or fed up with hearing about your pains and your moans and therefore you don't say anything. It can often lead to things like social isolation because it's very difficult when you are suffering from a chronic pain that's quite dominant in your life. It's difficult often to talk to others about it. It can be something that other people don't always want to hear you talking about, so something that is dominating your life and making your life quite difficult because you can't sleep, you can't exercise, you can't do the things you want to do, and yet, you can't talk to other people about it – it leaves people feeling quite isolated.

Therefore, it's important to realise, I think, that pain is not inevitable in older age, that just because you're older doesn't mean that this is something you've got to put up with, that you do need to be talking to your general practitioner; you need to be talking to your carers and your family about this. We need to make sure that older people feel they have as much right to access the services that are available, and the specialist pain services that are available, as anybody else. Just because you're old doesn't mean that you should put up with it.

Rayner: Absolutely, yes! My treatment has been artificial joints. This one is no longer treatable, my right shoulder, in the sense that I do not want to be exposed to further surgery, so my care is based on analgesia – painkilling, and pain avoiding. I don't reach for things I shouldn't. I learn how to use it wisely, this arm. It's all right for the writing, but I've learned not to try and lift myself up with it. I've learned not to stretch with it. Tricky 'cause it's my right arm, but there you go. And I shake hands when I meet people. I put up my left hand to say: 'Hello, it's lovely to see you.' They're a bit startled at first. I say: 'Sorry, the other one's a bum.' [laughs] And there you go. Just be cheerful about it.

Just be cheerful about it. I'm deaf as a post. When I meet people I say, 'You'll have to speak up love, I'm a bit mutton.' You know the term 'Mutt and Jeff'? Good old cockney, you know, Mutt and Jeff, I'm a bit mutton. [Laughs]
You've got to be brave and upfront. Do remember that once you're an old grown up person, you don't have to be polite and good anymore – you are allowed to be selfish, if that's what you think it is. I don't think it's selfish, I think it's common sense to look after yourself. But you're allowed to ask for what you want – you're allowed to say, 'Please help me.' There's no loss of face in that, I do it all the time.

Kelleway: Claire Rayner.

One of the many casualties of living with constant pain is a good night's sleep. Trying to find that decent sleep can turn your bedroom into a torture chamber. Dr Nicole Tang is a research fellow at the Institute of Psychiatry working on sleep and pain research.

Dr Nicole Tang: When people are not sleeping and they have chronic pain, that can be like a double form of torture. You're not sleeping, you're not feeling comfortable in your body and you're alone in the middle of the night, thinking about the upsetting things in the past. That can be quite traumatic, because if you talk to pain patients or insomnia patients, they feel that they are stuck in a vicious circle and they don't know how to get out. In therapy, mainly what we do is just to pull them out a little bit, see what they're facing and what are the options for them in terms of treatment and then gently lead them to a way that will help them to maintain their sleep.

Usually the strategies that we suggest to them are very counterintuitive. Let's say if you want to have better sleep, actually, the best way is to not lie in bed for so long trying to get to sleep. When you're dying to get to sleep, perhaps the best way to help you to sleep is to regulate your sleep so that your sleep could be consolidated. You will be craving for sleep at the right time so that you can control the timing of sleep and you don't have to wait for hours in bed, tossing and turning and yet, sleep doesn't come.

Kelleway: Don't forget that in today's edition of ***Airing Pain***, I'm just giving you a taster of what will be explored in much greater depth in future programs. Sleep is certainly one of the issues we'll be covering, as is the subject of how to pace oneself. Dr David Laird is a consultant in pain medicine in Durham.

Laird: When we're suffering from pain, on the good days, we try to carry on as if the pain wasn't there - for our grandchildren, for ourselves, for our friends and family, sometimes for work. The result of that is that sometimes we push and over-push and then we pay the cost. On the next two days, three days, we're wiped out, we're frustrated, and everything builds up again. I've talked to people who are athletes, and how they train is not by doing a ten-mile run one day a week and nothing for the next six days to recover, and then another ten-mile run. They do a little and they do it often. There's a Tanzanian proverb that says: 'Little by little, a little becomes a lot.' That is so relevant.

Yes, there are days when, for that special occasion, you do too much for the shopping trip or with somebody who you haven't seen for a long time or for a wedding or for an extraordinary occasion where you know that you're going to push yourself. You'll mark off in the diary the next two days because they're going to be diminished in what you can do, in how you're feeling, in what you're thinking, in your muscle pain. But for general day-to-day work, on a long-term basis, pacing is what patients have told me makes the biggest difference most consistently. It's their accomplishment and they feel much more in control. I really want to pass that on to you, because that's a major lesson that I have learned.

Kelleway: That was David Laird.

It's my hope that you found this first edition of ***Airing Pain*** useful. You can get fuller information on what's coming up in future programs from the Pain Concern website at: www.painconcern.org.uk.

Don't forget that Pain Concern is a charity that can help you. We have a sister magazine to this program, called ***Pain Matters***, and we'd like you to be part of our community, be it on our Facebook and Twitter pages, email, or good old-fashioned pen and paper. If you have a question that we can put to an expert on your behalf, then we would love to hear from you.

And finally, let's end this first edition of ***Airing Pain*** with a few words of encouragement from Pete Moore, of the Expert Patients Programme in England and Pain Concern's patron, Claire Rayner.

Moore: People with pain, we become so hardened with life, you know, think everything's against us, but the best suggestion I can give people with pain is: 'Don't give up.' There are answers out there. You're on a journey. It can be an exciting journey. Things will happen to you beyond your wildest dreams. Get yourself on a course. Get yourself on a self-management programme or a pain management programme, whatever works for you. But work closely with your healthcare professional. You'll find that things will happen to you. If you feel that you've lost your family, they'll return. If you feel that you've lost your job, you'll get another job. But if you think life's going to come to a screeching stop because of your pain then you need to think again.

Rayner: One of the best things you can do is get in touch with a specific group – they're all there. Use them. And then just get on with living your life! And if you've been dealt a bum hand, well, you can turn it into something good.

Contributors

* Dr Beverly Collett – Introduction to Pain
* Dr Sherrill Snelgrove – Chronic Lower Back Pain
* Kiera Jones – Personal Story
* Dr David Laird – Pacing
* Dr Steve Allen – Pain Clinics
* Claire Rayner, Patron of Pain Concern – Nursing and Pain/Patron's Voice
* Professor Blair Smith – 'What is Pain?'
* Professor Richard Langford – The British Pain Society
* Professor David Walsh – Arthritis Related Pain
* Ian Semmons (Chair, Action on Pain) – Action on Pain
* Professor Nick Allcock – Pain in Older People
* Dr Nicole Tang – Sleep and Pain
* Pete Moore – Living with Pain

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