Airing Pain Programme 16: Power over mind and body

Getting mind and body working together on a pain management programme, and loosening up with hydrotherapy.

Pain management programmes teach people with pain the strategies they need to live as full a life as possible. Paul Evans talks to patients and professionals at Astley Ainslie Hospital in Edinburgh to hear their uplifting approaches to pain management. The programme focuses on the way that mind and body work together, with psychologists playing as important a role as physiotherapists. It looks at how tackling negative thoughts and patterns of behaviour are as crucial as dealing with the physical aspects of pain.

We also get an insight into the amazing benefits of hydrotherapy for those in pain, helping people to take the first step towards getting back into exercise.

Paul Evans: Hello and welcome to ***Airing Pain***, a program bought to you by Pain Concern, a U.K. charity that provides information and support for those who live with pain.

Pain concern was awarded first prize in the 2009 Napp awards in chronic pain and with additional funding from the Big Lottery Funds Awards For All programs and the Voluntary Action Funds community chest, this has enabled us to make these programs.

David Gillanders: No matter how much pain you are in, no matter how difficult the things are for you, no matter how depressing and sad this has made you feel, you are not broken. It's simply that the strategy you are using to try to live your life with these conditions, is not a workable strategy.

Derek: She tells you as it is – it's real. And she tells you that disease is not curable but she picks you up and builds you back up again in terms of getting a new life style and confidence to do things that to me she is great. She's my hero actually.

Paul Evans: [Laughs] More on those acts of heroism hope later in the program. I am Paul Evans and in the series of ***Airing Pain*** we have been highlighting different approaches to pain management throughout the UK. Now the Astley Ainslie Hospital in Edinburgh provides a range of services for those in chronic pain conditions and John McLennan is the Lead

Physiotherapist for the Lothian Chronic Pain Service there. I asked him how he assesses somebody who walks through his door for the first time.

John McLennan: Firstly, we will spend a lot of time talking with the patient and them explaining to us the impact of their pain on their day to day life, on their quality of life, the impact it has on what they can do or can't do from a 24-hour perspective, but also from things they can no longer do like sport or go dancing or go out and meet friends.

But we will also look for some objective measure of what patients can or can't do and a colleague Vicky Harding put together a battery of measures that we use here. So we get patients to do four things: we get them to walk for five minutes – we see how far they can walk for five minutes; we get them to do some stairs for a minute; we get them to do a reach test and a couple of other measures that we use. At the same time that we are doing that, we also look for what's called 'pain behaviour'. So they may hold their breath, they may grimace, they may rub the painful part and there is a way in which we can assess in a standardised way the level of pain behaviour that the patient exhibits, while they are doing these tasks.

And finally, we also ask patients to rate their pain before and after they do these tasks and usually the pain will increase because they have been physically active. And that gives us an idea of how doing things impacts on patients' pain. Because one of the things we will teach patients is how to pace their activities, so how to do things without increasing their pain.

Evans: How closely do you work with the psychologists?

McLennan: Very closely indeed. Most patients have a joint assessment. They will meet with a physiotherapist and a psychologist. At the moment we are going through a process of change looking at different ways of doing that. But up until now, that has been a joint assessment, so we've had the patient, the psychologist and the physiotherapist all in the room at the same time. At the end of the assessment, we will agree a treatment plan with the patient, which may or may not involve the psychologists. If it does, so if the patient is going to see both the physiotherapist and the psychologist individually, then there will be quite close liaison between the two professions in terms of the patient's progress.

Leanne Nicholas: My name is Dr Leanne Nicholas and I am a chartered clinical psychologist and I work half my time here in the Lothian Chronic Pain Service. We're very much based on a biopsychosocial model. That means that we look at the biological aspects of the pain and how it has affected someone – what medications etc. they have tried and whether surgery etc. has been offered in the past. We then look at the some of the

psychological aspects of the pain: how that pain has affected the way they are feeling within themselves and how the pain has affected their activity levels. Changes in patterns or could be changes in the occupations, functioning in work and social functioning. People often find with chronic pain they can't participate as much in hobbies and interests that they used to enjoy. We also look a little bit at what life was like prior to the pain to get a whole sense of a person.

Biopsychosocial would say that our minds and our bodies are not two separate things and that they interact with each other. If I ask someone to give me an example that can help them see those links, they would maybe say, 'Well, if I wake up in the morning and I am really sore, I know it's going to be a bad day. And so I have a thought in my mind that this is going to be a pretty rubbish day, then I might feel a bit more down and then the way I am going to approach the day with all the activities I had planned might therefore change.' So you can see how those three areas, the physical areas, the way we are thinking and feeling can impact on the way someone will react in terms of behaviour.

Sometimes that can then get into unhelpful patterns where you can be linked into vicious cycle. And those are the types of things we look for in the assessment, because that's where we can maybe introduce some coping strategies that can help to break those links. Often by the time they come to our service they're feeling as if they are stuck with their pain. So we are looking at areas where we can introduce new strategies or strategies that people have tried before and maybe didn't work then but might work now with a bit of support.

Paul Evans: Can you give me an example of how people might feel stuck?

Nicholas: One example would be with the activity patterns. Sometimes people feel that they got into a battle with their pain and they try to push in to their pain. By keeping up all their activities that they want to get done in a day, but that can result into feeling sore and exhausted and it can make people feel quite down on themselves when they have not managed to achieve the things they wanted to achieve. So, this kind of pattern of doing too much and then suffering for it and having to take time out to rest can be really demoralising over time. So that's one of the patterns we look for and to help people begin to work out what their limits are and what they can manage and do those activities in a paced way, so that they can gradually work up to the level they like to get back to without pushing into the pain and flaring the pain system up.

McLennan: We also run a pain management program here which is a 12-week program and that is delivered by psychologists and physiotherapists. The nurse is involved as well as is

the assistant psychologist. So again there is a very close working relationship between all of us as a team.

Evans: What happens on the pain management program?

McLennan: It's an opportunity for patients to practise putting into practise the ideas that other people have found helpful. So one of the things is they start an exercise program. Many patients are not involved in any kind of exercise program aimed at helping maintain fitness because people are frightened of hurting themselves or less able than they used to be.

Some people are fearful of making things worse, so we have an exercise program which is aimed at not exacerbating people's fear of movement and activity. So the program starts at a very low level, but it can go quite far. Once we got the program going, we will then start to look at individualising it. So if someone has got a knee problem, then we will look at what we should be doing for their knee problem. If they've got a back problem or a neck problem we will give them individual tailored exercises. And it can go to a level where you are looking at cardiovascular exercise.

So it can start to help people either speed up, because they have slowed down, or take on cardiovascular work, if that's appropriate. We will also look at education. People have unhelpful beliefs, if you like, about what's wrong with them, so we will teach them about pain, about pain mechanisms, about pain anatomy posture, that sort of thing. We will teach them how to pace their activities. The exercise program is designed around the idea of pacing your activities, so you are not making your pain worse, so we will then extend that and teach people how to go about their day to day activities without making their pain worse. We will also teach them how to manage their thoughts. Quite often people's thoughts are perhaps unhelpful, so the psychologist will help people develop a way of assessing their thoughts and managing their thoughts in a way that is less unhelpful.

Evans: John McLennan: lead physiotherapist for the Lothian Chronic Pain Service and before him, you heard Dr Leanne Nicholas Clinical Psychologist at the Astley Ainslie Hospital in Edinburgh. And you can read the patients view of attending the hospital pain management program at Pain Concerns website, that's painconcern.org.uk. Just look for 'Pain management: a new lease of life' under the 'Articles about pain' heading.

Now, Dr David Gillanders is a clinical psychologist who shares his time between the University of Edinburgh and the Lothian Chronic Pain Service. For his clinical work he uses a

model called ‘acceptance and commitment therapy’ (ACT). Now, to me the word ‘acceptance’ has a ring of resignation about it, is that really what it’s about?

Dr David Gillanders: People have sometimes been told by well-meaning health professionals, ‘Oh the trouble is you don’t accept what’s happened in your life.’ When we talk about ‘acceptance’ from an acceptance and commitment therapy point of view, that’s not the kind of definition of acceptance that we mean, what we really mean is an active choice to let go of struggling with whatever the current circumstances that someone is having to deal with. So, often, in terms of clinical work I do, I would very rarely use the word ‘acceptance’, instead I would use the word ‘willingness’. Are you willing to have your medical condition as it is and to let go of struggling, let go of needing to change it or needing to remove it before you take needed steps towards things in your life that matter to you?

What we would do in the typical assessment process – assessment engagement process —– would be to provide a safe relationship with the person who is able to talk about the ways in which their condition whatever it is has affected them, some of the impact it has had upon their life.

We then further ask them to explore, what are the things you have been doing to try and deal with this condition, and we would want to get them to generate pretty much an exhaustive list of all the things they have been doing to try and deal with this condition and we then ask them the really difficult question – and we do this with heart and sensitivity – we ask them to take each of the things they have just described about what they have been doing to deal with this condition and we say, ‘how well has it been working in terms of you living the kind of life you would like to live? Is it effective for me or not?’

If the answer is ‘yes’, we say ‘great’, keep doing those things. If the answer is ‘no’, then maybe something has to change. Maybe something different is possible.

Evans: So if I come to you and I say, ‘Listen, I want to walk up Snowdon, I want to walk from John O’Groats to Land’s End I want to do all those things. Every time I try to do it, I just blow myself out.’ There is something wrong with my thought pattern?

Gillanders: Well, first of all I wouldn’t suggest that there is something wrong with your thought pattern. We would, first of all recognise – I noticed the way that you talked about those things and how your eyes light up when you speak about the value that’s in there for you: the value of being outdoors in nature, the value of doing something active… perhaps there might be other values in there for you, for example, perhaps there is someone I always do these kind of walks with and it’s connecting with that person that really matters to me.

So we might make it that we help you to connect with, what is it about those particular activities that you really care about. And if it is the case that those activities really aren't possible to you, we might try and figure out with you what are some other ways that we can get that value into your life that might not necessarily be walking up Snowdon but might be, for example, doing some other activity with that friend you usually do that with or there might be, for example, some other way of accessing nature or whatever it is the particular value is about there.

More specifically what we also do is we'd say, 'Ok, well what have you been doing to try to get back to that part of your values?' And in general when we do that piece of work with someone we are able to help them get more in touch with the idea that the strategy they have been working on has been once I get rid of my condition, then I will start to do the things that matter to me. Not always but that's generally a strategy people are operating under and what we ask is, is it working? If it isn't working then maybe the strategy needs to be changed.

Now one of the important implications of that, is that very often we are giving a message to people that, no matter how much pain you are in, no matter how difficult things are for you, no matter how depressing and saddening this has made you feel, you are not broken. It's simply the strategy you are using to try to live your life with these conditions is not a workable strategy.

Now there are certain values whereby if we break it down to smaller steps and use very a behavioural type of pacing strategy that is designed to carefully and slowly and gradually build up someone's functional capacity, someone's tolerance for activity, that for some people climbing the mountain might well be an achievable goal for them in the long term, if it's done in a slow careful graduated way. For some people that might not be the case that that's the case for them and what we would want to is try and help them to come up with more specific, concrete achievable steps, but linked in this general direction of their values of what that it is they care about, so that there is always a sense that they have a direction that they are headed in.

Evans: That's the acceptance, where does commitment come in?

Gillanders: So if you are the person who has struggled with chronic pain for a long time and you have fears that 'if I do activity, it's going to injure me, it's going to hurt more', then you set yourself a goal which is, 'I am going to take a short walk in the countryside', because that's linked to this goal of maybe one day I might be able to climb Snowdon'. But in the here and now it's linked to this value of being one with nature of getting fresh air, etc.

As you begin, even on that first few steps of the walk, your mind is likely to be giving you stuff like 'this is going to hurt, this is difficult, I better just go back to the car or I better go home, or why did Dr Gillanders suggest this in the first place, etc., etc.' So when your mind is giving you all these kind of, in some ways, bullying, critical attacks. Well, the stance that you have towards that stuff is really critical, really important and it's very unlikely that you are kind of able to get rid of those thoughts, to conquer them or defeat them. So you want then to try and encourage a willingness and acceptance to have these thoughts as they are, as thoughts, as difficult thoughts but none the less simply thoughts and to in that moment commit to the behaviour that will lead you in the direction that you most want to go. So the idea behind acceptance and commitment therapy – I use this all the time with people I work with – is, actually, it's very simple, but it's not easy.

Evans: Dr David Gillanders. So what's the evidence that acceptance and commitment therapy has real value for those with chronic conditions? Nuno Ferreira is one of his doctoral students at the University of Edinburgh. He has been researching its efficacy on people with irritable bowel syndrome.

Nuno Fereira: Irritable bowel syndrome is the most common functional gastrointestinal disorder so we have developed a few questionnaires to look into this particular concept of acceptance. And the results that are coming back are basically if they have a more accepting stance, if they continue to engage in activities that are more important for them, they are more likely to have better outcomes, whether its quality of life, depression, anxiety or even in terms of symptom severity, which is quite curious, because, in a way, acceptance and commitment therapy or the model itself, it's not prone to reduce symptoms to reduce the experience of symptoms.

What we have done is we have taken a model that has been used successfully before with other types of conditions, which is to do very small group interventions, a very short group intervention. In this case, we used a one-day workshop, where people were invited to come in. We would walk them through the model, through the several steps of the model and then we follow that with a work book that we have prepared, so that people can take what they have got from the workshop and then, with the help of the workbook, try to engage in those steps in a period of, say, two months.

We also got in touch with the patients who participated in the workshops two months and six months after to see how they were doing and the results that came out, basically, you know, improvement across the board in terms of everything: in terms of symptoms severity, quality

of life, less engagement with things like avoidant behaviours and more engagement with valued activities. So behaviourally there was this shift as how people approach their illness.

And even things like the frequency with which they had certain cognitions about their illness – even that changed. In a way we were hypothesising this was because this became less relevant to their lives. So they took a step back and said, 'Ok I am having these thoughts, these thoughts are a part of my illness experience and I can have this illness experience while at the same time have a valued life.' So we see the shift in behaviour: instead of 'I need to get rid of my illness experience in order to have a valued life.' We have more 'I can have it, and a valued life.'

Evans: That's Nuno Fereira of Edinburgh University.

You are listening to ***Airing Pain*** with me, Paul Evans, and I just like to remind you that while we 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 health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate actions to take on your behalf.

Now I am returning to Astley Ainslie Hospital in Edinburgh. Not to the consulting rooms this time but to join Margaret Kerr, she is the Hydrotherapy Pool Coordinator for the Lothian branch of the charity Back Care.

Margaret Kerr: Hydrotherapy is the exercises that have been taught by our physiotherapist in a higher than normal temperature pool. It is not a quick fix for people but it is a tool to encourage them to start exercising their muscles and when these muscles are toned up a wee bit better, it hopefully… they would move on to some other form of exercise. We don't only take people with back pain – we take people with any kind of pain. Whether it is fibromyalgia, arthritis, we had people with knee replacements, hip replacements – I don't turn people away.

Evans: I suppose the theory is that in water that's taking all the pressure of ...

Kerr: That's right and it means that for a lot of people it frees them up and if they maybe had muscles at spasm, automatically, going into warm water what happens to your muscles is they relax. If you go in to a pool that's too cold, your muscles are not going to relax and most leisure pools are too cold to people with chronic pain.

Evans: What sort of temperatures are we talking about in your hydrotherapy pool?

Kerr: I would say, it's the temperature not far off having a really quite a warm bath. The other thing with the hydrotherapy pool is the empathy people have with other people using it. I would always see that you are not going in to that pool and start moaning about all your pain. We all know when we are not just quite right and sometimes somebody else will say, 'Oh, have you tried such and such? I go to this sort of exercise. I find Tai chi helps. I find Pilates helps…' It's a very good tool for us to start with people to find out what's right for them. Whether they carry on using the pool [or not], that's fine. If they use it for two months, three months, six months, for years, it doesn't matter if they find it's helpful.

Evans: How do people get to use it, do they book it through you?

Kerr: They book it through me normally. I book them in with a taster session first of all of three half hour slots on a Tuesday night with our physio. If somebody needs more than that, that's not a problem because some people are just not confident enough to carry on without the physio being on hand and that's ok. We have two physios at present, one is on maternity leave unfortunately, but we have Lorraine as well and she is a pain management orientated physio, which to my mind they look at things differently.

Kerr: Do you want to go through and see the pool?

Evans: Yes, please.

Kerr: This is Lorraine, our physio, and in the pool is Derek, Catherine, Joy and Asha.

Lorraine: My name is Lorraine Rahimian and I am a physiotherapist.

Evans: And you are actually standing in the pool. The first thing I notice is that it is very hot.

Lorraine: It is very hot… very hot.

Evans: Why is that?

Lorraine: Because we need the heat to help this hot water, warm water so it's to help soothe the aches and pains for the patients who come to do exercises in the water.

Evans: So how are you helping them?

Lorraine: Well, I think the valuable thinks is it's the community, people are all here with similar problems, as in chronic pain, and so they come and do exercises in the water, which they would find difficult to do on land because the buoyancy of the water is an assistance for them.

Evans: So the water is taking the strain away?

Lorraine: It takes the weight.

Evans: I see the gentlemen here...

Lorraine: That's Derek…

Evans: You've got a rubber ring on your foot underneath the water and you are just raising your leg up and down.

Derek: When I first came here I couldn't even lift it four inches but with Lorraine's assistance we have managed to slowly get this joint more mobile and it's been absolutely wonderful.

Evans: Which joint is that?

Derek: It's my left hip. I have got a peculiar disease called 'Paget's'. It's actually seized this joint, so what Lorraine has done is given me some exercises to get the joint pliable so that I can walk again. She has been my hero actually.

Evans: Why is that?

Derek: Well it first started in terms of going for a pain management course. She tells you as it is – it's real and she tells you that the disease is not curable. But she picks you up and she builds you back up again in terms of getting a new life style and confidence to do things. To me she is great. And now great that this week I got the sign-off from my doctor that I can actually go back to work in two weeks for two days a week and that's after three years I've been in treatment and rehabilitation.

Everyone here thinks I have done brilliantly because people have taken six or more years to do what I have done. But it's Lorraine and Joan as well – they are a great team and really caring and they thoroughly understand. It's very personal, because each particular case is personal. And they know how to get you motivated. It's also about self-help and they actually get you to say, 'well look – go here, go here'. To me it's great.

Evans: So, hydrotherapy isn't just about your hip joint?

Derek: No. No... It's the whole group effort, understanding, getting little tips and then suddenly from that tip, suddenly you get a spark and then suddenly you get a blaze. These guys don't say 'no', they say 'You can do it.'

Evans: Whatever you're giving him, Lorraine, you ought to bottle it!

Derek: No, they're good.

Lorraine: This is Joy. Joy has back pain.

Joy: Hello.

Evans: And how is the hydrotherapy helping you, Joy?

Joy: Well it loosens. I can do exercises here that I find difficult to do on land.

Evans: So what sort of exercises do you do?

Joy: Rotation, just general strengthening against the resistance of the water.

Evans: So how long have you been coming?

Joy: Couple of months, but my back is a long standing programme and I have managed to work all my life, but at odd times things have gone wrong and I have come and had hydrotherapy.

Evans: How do you start working on someone like Joy?

Lorraine: I think, the first thing is, we start at a very low level and pace up. So we introduce pain management techniques really into the advice we give. Joy, would you agree?

Joy: Yes... yes.

Lorraine: We try to do things in stages and chunks.

Joy: And Lorraine always has another tip to help with daily living.

Evans: What sort of tips have you found helpful?

Joy: The bar in a pub, the Bentley, it's along at the bottom. So I open the cupboard of the kitchen and put my foot there and it eases the sciatica [laughter]. You talk about the bar at the pub, didn't you?

Lorraine: I think a lot of the patients benefit from doing balance work in the water, so it's not particularly specific to joints and spine…you know…it's the whole person.

Joy: Well, I know that tomorrow I will be very good and I will be able to walk a long way and walking suits me.

Lorraine: Try and have a holistic approach, I must say.

Joy: And the chat is good fun as well, isn't it?

Evans: And that's the end of this edition of ***Airing Pain***. You can download this and all the previous editions from our website at painconcern.org.uk but I will leave you with Nuno Fereira and some thoughts on acceptance and commitment therapy from his hopefully soon to be published research and workbook.

Fereira: At the end we have a poem that sort of encapsulates what the whole model is about.

'I might have flaws, live anxiously and sometimes get irritated,

But I do not forget that my life is the world's biggest enterprise

And it's up to me, not to let it go bankrupt.

To be happy is to recognise that it's worth living,

Besides all challenges incomprehensions or periods of crisis.

It is not to let ourselves be the victim of problems,

And to become the author of our own story.

It's to cross deserts outrageously,

But still be able to find your own oasis in the deepest of your soul.

It's to be thankful each morning for the miracle of life.

To be happy is not to be afraid of your own feelings,

It's to know how to speak about yourself.

It's to have the courage to hear and know.

It is to have the security to hear your critic, even an unfair one.

And if I have rocks in my way,

I shall keep them all.

One day I will build a castle.'

Contributors

- John McLennan – initial assessment of patient
- Leanne Nicholas – clinical psychologist's approach, thought strategies
- David Gillanders – Acceptance and Commitment Therapy (ACT)
- Nuno Fereira – ACT and its effects
- Margaret Kerr – hydrotherapy and how it works
- Lorraine Rahimian and patients – hydrotherapy in practice

Contact

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

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

To make a suggestion for a topic to be covered in ***Airing Pain***, email suggestions@painconcern.org.uk

Follow us:
facebook.com/painconcern
twitter.com/PainConcern
youtube.com/painconcern