

Airing Pain Programme 5: Learning to live with pain

Pain management programmes can 'remove the barriers' that prevent people with pain from living a normal life, says Dr Owen Hughes of the Pain and Fatigue Management Centre in Bronllys, Wales.

Presenter Lionel Kelleway returns to the Bronllys Residential Pain Management Programme where he himself was a patient to talk with staff and patients about what happens on the programmes and also shares his own experience. Mary Rhys Williams describes her work as an occupational therapist helping patients to adjust their lifestyles and consultant Mark Turtle explains what makes a patient suitable for a pain management programme. We also hear from Sheila Day, whose partner has chronic pain, about the challenges faced by the loved ones of people with pain.

Lionel Kelleway: Hello and welcome to **Airing Pain**, brought to you by Pain Concern, a UK charity that provides information and support for those who live with pain. Pain Concern was awarded first prize in the 2009 NAP awards in chronic pain, and with additional funding from the Big Lottery Fund's 'Awards For All' programme and the Voluntary Action Fund Community Chest, this has enabled us to make these programmes.

Berni Bustin: The difficulty with having a chronic condition is that it completely undermines people's confidence, their sense of self-esteem, their sense that they can actually take an action in their life that makes a difference.

Rhian Evans: Last year actually I had a mental breakdown and I got as bad as I could get.

Mary Rhys Williams: Particularly with family and friends, it's often either, 'Well, I don't understand what's going on with you, why don't you get better?' or 'I'll just look after you'.

Sheila Day: You're actually not quite sure how to cope with it. What are you meant to do? Are you meant to keep saying, 'Are you alright, what can I do?' If I did then you would have said, 'no, there's nothing you can do' and you would have got more cross and I would have got more frustrated: 'This is not my fault.'

Kelleway: Our aim on **Airing Pain** is to be led by you on the topics and issues we explore. I'm Lionel Kelleway and over the last few months we've made numerous references to multi-disciplinary pain management. Well, in response to your comments, today's programme is coming from Bronllys Pain and Fatigue Management Centre in rural mid-Wales. It runs

three-week residential management programmes to help people with pain and/or fatigue learn skills for managing their condition. And it's something of a personal journey for me, because in January 2008, I was a resident here and now I'm a graduate of the Bronllys pain management programme.

Evans: It's been something I've been needing for 15 years.

Tracy Thomas: I've come one person; I'm leaving a completely different person.

Kelleway: Owen Hughes is a consultant counselling psychologist and head of the Fatigue and Pain Management Programme here at Bronllys. Tell us a little bit about the programme: what do you do here Owen?

Owen Hughes: Well, what we do is we work with people who have chronic pain or chronic fatigue problems. They come for three weeks on a residential programme and learn how to manage their pain or fatigue, so that it interferes less with their quality of life. What we don't do is cure people of their underlying condition because, as far as we know, both of those conditions are currently incurable. But what we do do is try to remove some of the barriers to people living a normal life. Chronic pain and chronic fatigue may not kill you, but they can certainly end your life as you know it. So it's about understanding what's happened to people in their lives, what's changed and understanding what they actually want their lives to be about now. So it's about looking to the future.

Kelleway: I suppose it's a bit of an indulgence, but I would like to introduce you all to my best friend and loving partner Sheila who, along with me over the last 10 or 11 years has had to live with me and my pain. Can you remember what I was like before I had chronic pain?

Day: Quite easy going [laughs]... You had your moments of not being easy, but on the whole you were quite a jolly sort of person, getting on with normal day-to-day things.

Kelleway: And what about after, when I had the operation?

Day: That was totally different: really down, tearful, lots and lots of hours of not speaking, suddenly disappearing out of the house, not saying where you were going – not that you ever went far, it was mainly around our meadows – but just not communicating whatsoever.

Kelleway: Was I difficult to live with?

Day: Quite. But because I loved you, I stayed with you [laughs].

Kelleway: What were the worst times? I know I used to get angry, I used to snap, I used to get extremely cross and throw things...

Day: All of those – not so much the throwing things – but the snapping used to upset me more than anything, because I probably hadn't done anything wrong, but because obviously the pain was very bad for you, you had to take it out on somebody and I happened to be the nearest thing.

Kelleway: One of the things that people often say, who live with people in pain, is that they feel frustrated because they can't help with the pain and that is a problem for them rather the person suffering from pain. Did you feel that?

Day: Oh yes, definitely. And I suppose a little bit selfishly, you tend to stop asking a lot of the time, 'have you got a pain?' because obviously you have. So, you just don't say anything, which might seem a little bit unkind really. It's just frustrating not being able to do anything to take it away, even if only for a short time.

Kelleway: 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. Before we continue please bear in mind that whilst we believe the information and opinions on ***Airing Pain*** are accurate, based on the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you and your circumstances, and therefore the appropriate action to take on your behalf.

Hughes: Mood has an impact on people's experience of pain. So if people are feeling depressed or they're feeling anxious, guilty, angry... all of those things can increase people's experience of pain and make the pain *seem* worse. And we know that there are actual physical changes that happen in people's nervous systems when they're experiencing those sorts of moods. So this programme is about helping people to feel more confident about their lives so that they don't feel so anxious, so they don't feel so depressed and they can see a future.

One of the ways we do that is by showing people that they can be more physically active and that they can be more socially active as well – so they *can* go back to work, if they wish to do so; they *can* spend more quality time with their families, play with their grandchildren and enjoy life – go down to the pub and spend an evening with their friends, if that's what they wish to do.

Kelleway: One of the important principles here, as I remember from my attendance here three years ago, is that pain doesn't equal harm.

Hughes: Indeed, hurt doesn't equal harm. In acute scenarios where people stub their toe or get a paper cut etc. then yes, the pain is associated with a harm. But, the sort of pain that we're dealing with here is the type that has lasted beyond the normal healing process. For most of us, the vast majority of conditions that human beings get, the human body will have healed itself within three months. The people we see here have usually had their pain problems for an average of eight years, so they've gone well beyond the time when their body has carried out the normal healing process and what they're now into is they have a pain which is a product largely of their central nervous system, as opposed to any ongoing damage.

Rhys Williams: How are you cutting the lawn? Are you still cutting it all in one go or are you taking a few breaks?

Kelleway: No, the last time I said I was going to cut it all in one go I got slapped by one Mary Rhys Williams.

Rhys Williams: Yes, I remember Lionel as a patient and that was what the problem was.

Kelleway: Well, all you've got to do is rearrange the weather, because the weather in Carmarthenshire means that if you don't cut it all in one day, it rains the day before and it rains the day after.

Rhys Williams: I don't care, you can do it the day after that.

Kelleway: For most people, I suppose, the perception of occupational therapy involves raffia, basket making and plasticine, so what has that got to do with the management of pain and chronic fatigue here at Bronllys? Well, here with me is Mary Rhys Williams, who is the senior occupational therapist here. Does it involve plasticine, basket work and raffia, Mary?

Rhys Williams: Not on the programme specifically, but if that would be one of your interests, then some of the things that we actually talk about on the programme would enable you to get some pleasure out of doing that without paying big prices. So actually occupational therapy is very much here as it is anywhere else in terms of helping people to enjoy what they do, but also to do it so that, at the end of it, there is a satisfactory outcome for them, without them actually saying, 'I wish I hadn't done that'.

Kelleway: Do the people who come here onto the programme actually do nothing before they come here then?

Rhys Williams: It's variable. We have some people who, perhaps you would say, totally overdo, so they've arrived here almost at the point of exhaustion, because they're so determined to get things done that they do it whatever price they pay. There are other people, who perhaps have had what you may call 'unhelpful advice', or perhaps advice for managing things in the acute phase, so they've got to the stage where they're not very active at all. And it's quite easy to get into that pattern of doing less and less, because you feel anxious, you feel worried, 'what might happen if I do this and I can't deal with it' etc. etc.

So the message that we try to give here is that any kind of increase in symptom doesn't mean that you've harmed yourself, it just means you've used a bit that perhaps hasn't been used for a while. But, the longer you don't use something, then obviously when you come to use it, the longer the effect of that from doing it. So, a lot of what occupational therapy here is about is breaking into what we look at as the 'over or under activity cycle', or the 'Boom and Bust cycle', in terms of 'I have to get everything done today, in case I don't get anything done tomorrow', but actually quite often then you wouldn't get very much done tomorrow, because you've pushed the boat out today.

I mean, we have a laugh here about, 'do you realise you can stand up to watch television?' And people think I'm being quite funny and what I'm actually saying is that when we go to watch television, we always sit down. Therefore, if the film is three hours long, that's as long as you sit and nobody actually thinks about the idea that, 'well actually, I could stand up behind the chair and still see the film. I can do a bit of ironing and still see the film'.

Kelleway: Mark Turtle is a consultant in pain management and anaesthetist at West Wales General Hospital, where he works for the health authority. Mark, your role here at Bronllys is largely in the assessment of people who are referred here. So what makes the pain sufferer that you assess suitable to come to Bronllys.

Mark Turtle: In my opinion, the person should have examined carefully the option of following the medical model. The medical model initially would be the model which every health care professional, in the whole world, applies. So, if an individual has a symptom, the first thought of any health professional should be that there may be a treatable condition which is causing the symptom, which can be managed and cured.

Kelleway: But one of the very early things I learned from my attendance here at Bronllys as a participant is that most of the people here felt failed by the National Health Service, by their GP and they saw this, the attendance at Bronllys, as the last chance cafe.

Turtle: Well as far as the last chance, in some ways I would accept that because either these people will have experienced other facilities within the health service or they've come straight here, in which case I hope as a part of our assessment process we will agree that the things that they've missed out weren't pertinent to them, in which case we're happy that that doesn't need to be revisited. And whilst conventionally the health service will offer what it has got to offer, and if it hasn't got a cure for the condition, then it tells the person just to get on with it, here we actually help them get on with it.

Kelleway: You and I go back quite a long way, you've been my pain consultant for a number of years, we served together on the Welsh Pain Advisory Board. Let's talk about me for a minute.

Turtle: Alright, yeah.

Kelleway: What made me suitable to come here to Bronllys?

Turtle: Well I think the fact that, as you say, we've known each other for some while and yet you've still got your problem demonstrates that I wasn't able to provide you with a solution. I can only provide what I've got to provide. We'd gone through my toolbox.

Kelleway: I have to say that some of them worked very well, but it was the side effects that stopped me taking the drugs that you prescribed.

Turtle: Yes and it's a balance isn't it? Every drug is a potential poison and it's getting the delivery at the right dose at the right time to an optimal level, at which point you have to decide whether the risks and side effects are more or less than the beneficial effects. In your case clearly you had some beneficial effects, but you had some problems as well and the problems dominated the benefits. So one way or another we still worked through the toolbox and got to the bottom of the toolbox and rather than telling you to clear off we've found, I hope, some way of helping you cope with your predicament.

Hughes: When people get referred to the centre the first thing we do is we invite them to attend an information day, so people can come and find out exactly what it is we do here at Bronllys and that's a four hour session which is held during the day. And at the end of that people then make a decision for themselves, whether they wish to continue and come for an assessment, where we look at their individual problems in more detail, or whether actually that they're still looking for a medical cure for their problems, in which case the program that we have here is not necessarily suitable for them.

Kelleway: You're funded by the Powys local health board, but participants come from outside Wales as well?

Hughes: Indeed, yes people can be referred from anywhere in the whole of the UK, or indeed beyond, as long as their local NHS board or trust agrees to the funding of it.

Kelleway: What does it cost?

Hughes: It costs between four and five thousand pounds.

Kelleway: That's quite a commitment in terms of the National Health budget.

Hughes: It is indeed.

Kelleway: And presumably in return you have to give some assessment of the success or failure of the participants that come here. How do you do that?

Hughes: Well one of the things that we do right the way through the process is ask people to complete a set of psychometric evaluations. So we look at actually how people are functioning when they're first referred, when they start the programme, when they finish the programme and up to a year later as well. And what we have also done is follow people up five years after they've completed the programme here, to see whether they've maintained the gains that they have made, and I'm very glad to be able to say that people are still maintaining the benefits of coming here five years later, which is something which very few medical interventions for chronic pain can claim.

Kelleway: I remember in the early days I saw myself very much as a victim of pain. Did you feel like a victim of my pain as well?

Day: Yes, to a certain extent. I used to get so frustrated at times and I'd think, 'this is not my fault', you know, and get very angry. But I'd perhaps go somewhere upstairs and just sit and be quiet for a while and think, 'he can't help it'. I did on one occasion have cause to go to the doctors and she did ask me how things were and I did break down and cry.

You feel helpless, you don't know what to do, you're actually not quite sure how to cope with it – what are you meant to do? Are you meant to keep saying, 'Are you alright, what can I do?' I think that if I did you'd have said, 'no there's nothing you can do' and you'd have got cross, and more cross, then I would get more frustrated. So I just used to go away and have a few quiet moments to myself and sort of think, 'well, never mind, I know he can't help it, I'll just try and stay as calm as I can'.

Rhys Williams: I think there's an element of misunderstanding by the people around them, so particularly with family and friends it's often either, 'Well, I don't understand what's wrong with you, why don't you get better?' or 'I'll just look after you'. And, you know, neither of those are actually suitable. There needs to be something in the middle and I think if nothing else this programme dwells on the themes of helping patients or actually giving patients permission to say, 'what is it I need and how can I go forth and get that?' if you like. So people with long term conditions find it really, really difficult to say, 'no, I won't help you' and they also find it really, really difficult to say, 'will you help me?'

Kelleway: This is *Airing Pain* at the Bronllys Pain and Fatigue Management Centre in Powys, with me, Lionel Kelleway.

If you'd like to make a comment about the programme or put a question to our panel of experts, then please do so via our blog, message board, email, Facebook, twitter, or if you prefer a good old fashioned pen and paper then the address to write to is Pain Concern, 1 Civic Square, Tranent, EH33 1LH. All of this information is on our website at www.painconcern.org.uk. It's a one-stop resource to get further information about this programme, including a glossary of the medical terms used and to download this and all previous editions of *Airing Pain*, along with a host of information on how to manage your pain.

Bustin: It completely undermines people's confidence, their sense of self-esteem, their sense that they can actually take an action in their life that makes a difference.

Kelleway: Berni Bustin is one of two psychologists here at Bronllys. So, I mean there's quite an emphasis Berni on psychological help that you can give pain and fatigue patients. So, why the emphasis?

Bustin: When you have a condition that doesn't seem to be justifiable by any sort of medical investigation, or the intensity of the pain often isn't justified, or often there's no cause identified, people often get this sense that, 'it's all in my head, nobody believes me'. And it's quite possible on occasion that they are disbelieved. Our culture is not very kind to people that are seen as not pulling their weight perhaps. And that in itself creates real psychological difficulties for people. To be suffering phenomenally with this condition, not be believed by the only people you think that can help you and then to be finally told, 'well, I'm sorry, you're just going to have to get on with it on your own' – why wouldn't you be depressed and anxious about that? It seems a perfectly natural cause.

Kelleway: How can you help then, me as an individual, change my relationships and the way I feel away from here?

Bustin: That would depend on a session that you and I have together Lionel. It really is as unique and individual as that though. I don't know what you want out of your life and until we'd spent some time together... it may be that you don't know what you want out of your life at this point either. And you don't perhaps have a vision of where you want to go, how you would like things to be, because actually if you have got a chronic condition it can knock your feet out from under you with even thinking you've got the capacity to bother to think about that. Because every day can be just such a struggle getting from the getting up to the going to bed, that to actually step back and think, 'well there's a life out here to be lived'. Most people with a chronic condition don't even take that breath and have a look. Actually it's that nose to the grindstone every day with coping and surviving. So what they get when they come here is that opportunity to put the brakes on, stop, step back and breathe and have a look, and think, 'Oh yeah, there is a life to be lived after all.'

Kelleway: Tracy Thomas is a long term chronic pain patient and she joins us on the last day of the one hundred and ninety second pain management programme here at Bronllys. How long have you been a chronic pain patient?

Thomas: It started five and a bit years ago. I pulled a muscle in my neck doing yoga and then for the next two and a half years it kind of happened more and more commonly – the simplest thing I'd do and my neck would go into spasm. And then two and a half years ago I pulled my neck, or rather it went into spasm and the pain moved into my back and I've been in constant pain since.

Kelleway: Do you think the people that were first treating you, your GP and that, understand that pain can take your life away?

Thomas: No, I don't think they do. I don't think when you go to your GP – I've seen a lot of different GPs along the way and I have found sympathetic ones but I've also come across some very unsympathetic ones. I remember one GP just telling me, 'some people just have more muscle pain than others' and I wanted to smack him.

Kelleway: Because one of the early things that they tell you here on the pain management programme is that this is not a cure – you do know that you're going to go away with your pain. How do you feel about that?

Thomas: Part of what they teach you here is acceptance and they've done a very good job of it because I have accepted it and I don't feel upset about that, I feel positive. I feel I can go

away and I can use all the tools that they've given me to cope and deal with the pain and that I can now look forward and have a great life, with pain, but it doesn't necessarily have to control my life and that I can control the pain and it's going to be good.

Kelleway: Rhian Evans is a long term chronic fatigue patient. How's it been Rhian?

Evans: It's been something I've been needing for fifteen years and it's eye-opening because it was all very obvious things really, if you really put your mind to it, but putting it all together is brilliant.

Kelleway: Some participants that I have kept in contact with and those that I spent time with here three years ago saw this very much as the last chance cafe.

Evans: Indeed.

Kelleway: If you fail here then there's nothing left for you. Did you feel like that?

Evans: Absolutely. Last year actually I had a mental breakdown, and I got as bad as I could get. I found alternative help – going to an alternative healer that practices Reiki and that helped me no end. So I had a lot to bring with me to this and this was just like completing the book, as it were, you know like a recipe book.

Turtle: So Lionel you've spent the three weeks on the pain management programme, as you say three years ago. How would you say it changed your approach to the management of pain?

Kelleway: Well, it changed me immediately because I was here with seven other people who were in pain and that was a liberating experience to know there were people who were also suffering. But what the course gave me was the freedom to be in pain, do you understand what I mean? I saw the course, the programme, as a facilitator to understand that it was alright to be in pain. One of the things I always remember you saying in one of your marvellous lectures was, 'You're alright. It doesn't matter who you are or what you feel; you're alright.' So that's what I went away with, but it took me a long time afterwards to – I hate the term unpack – but to unpack what I took away from here, but I took a lot.

And I don't know that, three years later, that I consciously use any of it, but if I think about it it's very much a part of my life and the words said by many of the people here often make me smile. And it's part of what treats my pain, I suppose, every day. It still hurts like hell. It hasn't gone away, but I have a much better life with my pain now after being at Bronllys. Thank you.

Turtle: You're welcome. And what would your nearest and dearest say has been the outcome of coming on the programme?

Kelleway: Well, she can actually tell you herself.

Day: I know it was meant to be 'learn to love your pain' and I do think that you perhaps have learnt to accept it a little better. You're certainly a lot brighter, you're more or less back to your old self – there's a lot of people that recently have seen you that haven't seen you for about a year or so have suddenly said, 'It's just like having the old Lionel back again.' And you're so much easier to get on with now. We don't have the snapping, or only occasionally, but not just out of the blue, you don't get snappy. And you're just back to, sort of, as you were – a lot, lot better.

Evans: It was remarkable the way they videoed us on the first day, and then videoed us yesterday, just to see the difference in walking, standing from sitting and then walking up and down stairs. The difference was just remarkable in three weeks.

Kelleway: You now know it's alright to be you, it's alright to have chronic fatigue...

Evans: Yeah, learning more about me was the awareness and actually looking inside yourself, the meditation-type things and psychology. That was mind blowing if anything and I had quite an emotional week last week.

Kelleway: And for anybody else suffering like you, would you recommend Bronllys?

Evans: Oh without a doubt. In fact I'd recommend the teachings that they have here in schools to be quite honest – life skills these are.

Kelleway: It's the end of a fascinating day here at the Bronllys Pain Management and Fatigue Centre and I've brought together once again Owen Hughes and Mark Turtle. I've had a chat to all your participants today when they were down here for coffee this morning and there was this palpable feeling of elation. Everybody was on such a high today – not just because today is release day, but because they all, to a man and woman, felt so grateful for what you've done for them today. But the practicality of being home again is something quite, quite different – what do they do and how do you prepare them for it?

Turtle: Well, in the final week of the programme we spend an awful lot of time addressing those concerns and also perhaps getting the crystal ball out and talking about what might happen when they get home and how they might deal with that. And it's certainly one of the things that we're very aware of, that when people do leave here we always say that we are here for them, we're at the end of a phone and everyone's more than welcome to come back

and see us for sessions. And we also run these two top up days throughout the first year, because we are very aware that the situation that they find themselves in here is very different to their situations at home. And so understanding how other people might react – whether that be the family, their GP, their work colleagues, their friends – these things need to be prepared for.

Hughes: One of the things we've got to remember about the programme here, which is not exactly unique, but it's unusual, is that it is a residential programme. The subjects who come on the course here do knit together very closely, and of course they are cocooned, they're protected against the threats of outside life. So this going out into the wilds, as it were, is a problem which is specific for a residential programme. Of course, residential programmes have other advantages as well, so it's like everything in life, there's two sides to it.

I think you'll find that over a period of time the vast majority of people will have a degree of elation at this stage. The trick, if you like, is to maintain that because there is a natural fall off. But I think that if we were able to develop some system whereby we could maintain that momentum, then we would have a larger percentage of people who gained substantially in a sustainable fashion.

Kelleway: We've just said goodbye to the one hundred and ninety second completion of the programme here. What do you want them to take away from you?

Bustin: The confidence that they have the capability and capacity to take on whatever changes they need to live the kind of life that they want.

Evans: It's been something I've been needing for fifteen years.

Turtle: You can achieve anything you want to in life, despite having chronic pain, but it may be that you actually need to find a different way of going about it.

Thomas: I've come one person, I'm leaving a completely different person – it's absolutely amazing.

Contributors

- Berni Bustin, Clinical Psychologist
- Rhian Evans, patient
- Mary Rhys Williams, Advanced Occupational Therapist
- Sheila Day, family member
- Tracy Thomas, patient
- Dr Owen Hughes, Consultant Counselling Psychologist
- Dr Mark Turtle, Consultant Anaesthetist and Pain Management Specialist

Contact

Pain Concern, Unit 1-3, 62-66 Newcraighall Road,
Edinburgh, EH15 3HS

Telephone: 0131 669 5951 Email: info@painconcern.org.uk

[Helpline](tel:03001230789): 0300 123 0789

Open from 10am-4pm on weekdays.

Email: helpline@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