

Airing Pain Programme 51: At the community pain management programme

Practical insights and life-changing experiences at a community pain management course

*In the previous edition of **Airing Pain** we explored the pros and cons of taking pain management into the community. This time Paul Evans travels to Powys – the most sparsely populated county in Wales – to see how community pain management works in practice at the programme run by Ystradgynlais Community Hospital.*

Course leader Gethin Kemp explains that the community approach makes pain management techniques available to people who are unable to undertake a residential programme. For people whose lives may have been completely taken over by pain the course offers strategies for coping with the emotional fallout, increasing their activity levels through pacing and getting a good night's sleep.

Participants on the programme, Toni and Nia, explain what they hope to get from it. We hear from them again at the end of the eight-week course when they reflect on the progress they have made – from learning to communicate more effectively to rediscovering a love of painting.

Paul Evans: You're listening to **Airing Pain**, brought to you by Pain Concern, a UK-based charity working to help, support and inform people living with pain, and for healthcare professionals. I'm Paul Evans, and this edition's been funded by an Awards for All grant from the Big Lottery Fund in Wales.

In the last edition of **Airing Pain**, we heard a debate at the Welsh Pain Society's Annual Scientific Meeting. It explored the pros and cons of bringing pain services right into the community where patients live. Of course Wales, just like England, Ireland and Scotland, has vast rural areas where for patients to just travel to a major centre is at best punishing, and at worst impossible. So following up from that debate, I went along to a pain management programme at the Ystradgynlais Community Hospital. Ystradgynlais is a former mining village in the vast rural county of Powys. This is one of 18 community pain management programmes for people with chronic pain and/or fatigue run each year by the pain and fatigue management centre at Bronllys Hospital in mid Wales. Pain Concern featured their three-week residential programme in **Airing Pain** (programme 5). You can download that from Pain Concern's website, which is painconcern.org.uk. So, having let the participants settle down in week one, I joined them at the start of their second of eight weeks, but before meeting with them, I asked physiotherapist Gethin Kemp, one of the programme leaders, how important it is to have these pain and fatigue management courses within the community.

Dr Gethin Kemp: As you are aware, we run the residential pain and fatigue management programme at Bronllys, which is for people to come and stay with us. But there's an awful lot of people who've got lives to get on with, who can't give up that time or can't, for whatever

reason, be away from home for those kind of quite intense courses. This enables people to, I can't say it's on their doorstep, at least access it close by, where they can actually interact and get some level of management strategies under their belt so they can carry on having a good quality of life. But when they can't take the time or are unable to take the time to come on a residential programme, it's also really important for the health professionals to be able to refer into that as well because people are at a loss of what to do because there are psycho-social components, there are stress components, there's all these other components that affect people in chronic pain and in chronic fatigue. And our specialism is to help people with those particular issues: where their mood's affecting them, where their social interactions are affecting them, all those kind of things. And other therapies won't have the time or probably the skill set to be able to manage those in the way that we do.

Evans: Another important thing for people to remember, for those who don't know the geography of Wales as well as you and I do, Powys is the largest geographical county in Wales.

Kemp: [laughs] It certainly is, yes.

Evans: With the smallest population. I can't remember what the statistics are, or the number of sheep to people [Kemp laughs], but it's very, very high. So people have to travel vast distances with very little public transport to receive help.

Kemp: Yes, yes. And of course finances are quite an issue for people because often the people with chronic pain and chronic fatigue have had to give up work or certainly their earning potential for them has been curtailed.

Evans: That's Gethin Kemp, one of the leaders on the community pain and fatigue management programme in Ystradgynlais in mid Wales. One of the participants was Toni Williams.

Toni Williams: I have reflex dystrophy sympathetic syndrome, which I am told is basically like a form of MS (multiple sclerosis). I have pelvic spondylitis. I have tenosynovitis of the right foot, and I have the lower fourth or fifth discs which aren't whole, causing sciatica and quite a lot of back pain as well.

Evans: That's quite a list. How long have you had these conditions?

Williams: Since 1996, this started.

Evans: Now that's 17 years. So 17 years on from that, you're coming to a pain management programme.

Williams: Yeah. I was actually offered this up in Bronllys but you had to stay for five days and then come home over the weekend. With children being small, even though I couldn't do much with them, I was still there. They needed mammy, mammy was there. So when this programme became available that I could go home, I took the chance and I thought, 'Well, why not? I've lived with it long enough. I need someone to teach me how to live with this even longer because it's not going away.'

Evans: That's interesting. You've come to learn how to live with it, not to be cured.

Williams: If there was a cure, if there was a tablet or a procedure or an operation where I could go and be cured of everything and go back to work, and live what's classed as a normal life, then I would because it's other people's perceptions; when you look at me, I don't look as if I've got anything wrong with me.

Evans: People who don't have a chronic pain condition will not really understand how pain impacts on their whole life and that of people around them rather than just having a bad back.

Kemp: I suppose you can liken it to being insistently nagged indefinitely, in a way that's gnawing. And again with the fatigue, never feeling like you've got or can generate the energy to be able to do whatever it is that you want to do. And that kind of gnawing and nagging away is also associated with the loss of what you would like to be able to do and it's just associated with the fear of what that pain means, because in the normal run of things, pain and fatigue, as it happens, are both emergency signals to say that something's wrong.

So we're kind of designed, if you like, to have a fearful response to pain and to react to pain in a very emergency, blue-light-flashing kind of way. And when that happens, of course, everything gets put on hold, life gets put on hold as we try to get rid of pain, as we try to get rid of fatigue. And so people are kind of just trapped in this ongoing cycle. It's taken over their life. It's taken over their mind. There's nothing much more to their existence because it's become their life. I don't mean that in a judgmental way – I just mean that from the point of view that it's kind of taken over.

Williams: It's affected my life in a big way. Everyday tasks; getting out of bed in the morning, to normal everyday things like getting up in the morning with a headache and carrying on with a daily routine in the house – to me that's a huge chore, just even thinking about it.

It affects your mind as well. It plays tricks with your mind. Trying to remember a simple thing like radiator – just trying to remember. You're looking at that thing and you just don't know what it's called. You cannot register in your mind that that is a radiator and you need to get that out. That's so frustrating.

Evans: It's also very embarrassing, isn't it?

Williams: Yes, it is.

Evans: Particularly with names

Williams: Yes it is. You see a neighbour; a neighbour's friend has called. You know who they are, you know their name, and you know where they live. You just don't know how to say it. You just cannot. Your brain doesn't tell you what it is you need to say.

Evans: What do people around you – your friends and family – think of your condition?

Williams: I don't like the pity. They *try* to help, they *try* to understand but nobody can understand what that pain is like, what that feeling is like, how alone sometimes you can feel. They don't understand. They can't understand because they're not living with the pain, they're not living in your body, so that's a hard question.

Evans: In six weeks' time, what would you like to have happened?

Williams: I would like to have a better perception of what I myself am able to do. Today has been about pacing yourself. Something whereas I've thought, 'I'll do it all in one day and then tomorrow I'll rest' – now I realise I've been doing the wrong thing. So every time we come here, we are learning something new, which really, if you sat and thought about it, is just common sense. When you've got that constant pain, the concentration isn't there. All you want to do is finish the job that you've started to the best of your ability and rest. But today we've been told that little and often gives you two or three days of perhaps sitting down and talking to the children, talking to your neighbour, going for a little walk in the garden. That's what I'm hoping for at the end of the six weeks; a better quality of life for myself.

Evans: I'll speak to you again in six weeks.

Williams: Thank you very much.

Kemp: It's important that people feel able to start moving again, and moving in a way that they feel able to move. Quite often people will start doing exercise and actually come out flaring up their symptoms and actually having quite a horrible time with it. So my primary role is helping people to move in a way that's enjoyable, relaxed and actually, believe it or not, pleasurable, so that exercise becomes fun for them again and actually becomes sort of useful. My role is to get some movement going. We'd also be looking at, from an occupational point of view, allowing people to be able to start a process of doing what they want to do. Things like pacing activity, making sure that people can take breaks or swap between activities in the right kind of way so that they're not overdoing it. That also includes how much sense input people are getting, etcetera, because often with more the fatigue-end of things, it's often not the physical aspect, it's the mental stresses and the sounds and the noises and the other aspects so we get people to be able to pace, manage their activities, so they're not going through this big boom and bust. Boom and bust is where, you know, make hay while the sun shines, followed by three or four days of crashing, as it were. When people are booming and busting, they've got a very chaotic life so they can't plan anything. So pacing is a very important part. It's one of the strongest practical strategies.

Evans: And one of the most difficult.

Kemp: Pacing is actually one of *the* most difficult. Partly because 'I've started so I'll finish', that kind of driver that we have is actually very difficult... It's a very different way of running life. It's about leaving jobs partially open, it's about having jobs based on position and particular physical activity rather than completing a set workload, which is how we like to be because it's tidier, if you know what I mean.

Evans: It's task orientated, isn't it?

Kemp: Yes, yes, that's right, yes.

Evans: The buzzword.

Kemp: Then we look at elements of relaxation. If people are in a fight or flight mode all the time, their stress system is running at a high peak, and longer term, which is a *theory* of chronic fatigue – it's not the only theory, by any strength of imagination – but a *theory* is that stress response gets kind of worn down over a period of time, so people's cortisol level

doesn't tie in with activity anymore. So effectively, you feel awake when you don't need to, and when it's time to prep for an activity, you actually haven't got any energy because your body's timing systems aren't geared into that. And it's all a bit depressed as well, that kind of level of how your body gets its arousal or doesn't. It doesn't tie in with how it should because it's gone a bit wonky, basically.

Evans: So that's fatigue. What have we missed out?

Kemp: Elements of getting really good quality of sleep. Sleep's very important, as anybody who's not having it knows. Knowing and understanding sleep, understanding cycles, understanding how to relax, all those kind of issues allow you a better chance of getting good quality of sleep, which is one of the things that really... I think if people were to measure quality of life [laughs], it's almost their quality of sleep, in some respects. Very important aspect, of course, underlying this whole principle; it's imbued with a strong sort of psychological perspective. The way the biology of the brain works, the way the biology of pain works, basically if you like, our pain signals trundle up the spine and they go straight into the areas that are often associated with mood, with threat, and also with emotion. And if we aren't on top of that, to use old terminology, the gateways are open for pain to be coming in. That's quite old terminology but basically if people are in a low mood, the unpleasantness of the pain gets them more. If they're in a threat mode and they're focusing on the pain, the intensity will increase over a period of time. So a lot of what we're looking at is how to – this acceptance business again – how to be alright to have the condition but also many ways of how to work on mood so that you've got some resilience. The terminology is emotional resilience, so that when unpleasant stuff comes along, you've got some ability to bounce back from difficulties.

Nia: I'm Nia.

Evans: And you're on the chronic pain management programme in Ystradgynlais in Powys.

Nia: Yes.

Evans: Could I ask you what condition you have?

Nia: I have chronic back pain.

Evans: And how long have you had that?

Nia: Over four years now.

Evans: How has that affected you?

Nia: It changed my life completely. I used to be very outgoing, doing what any normal youngster was doing, going out clubbing, partying, and doing lots of exercise. As soon as it happened, it all went downhill to the point where I had a six-year-old niece helping me dress because I couldn't put my shoes and socks on anymore, to not being in work, not being able to drive, constantly on medication, which has left me with a constant brain fog. [laughs] I can't remember words half the time. [laughs]

Evans: How old are you?

Nia: Thirty-one.

Evans: That has stopped you in your prime then, really.

Nia: Yes it has. It's affected my relationships with my family, with my partner. I was lucky I only met him two weeks before my back went. I was very lucky he stuck with me but his life has also had to change to my needs, my wants, not so much as doing what he wants to do. A lot of it is working around what I can do, what's physically possible. With future marriage, children, it's all down to what my body can take in the future.

Evans: You're very lucky to have somebody who obviously loves you enough to put up with that.

Nia: [laughs] Yes. I have asked him a few times why he's still here and I have given him the option to walk away, but I'm lucky enough he hasn't walked away and yes, he does want to marry me. [laughs]

Kemp: What happens with a condition is it kind of puts you into a role or you take on a role or a mantle of having a condition and when people want to change, what they find is it's actually quite difficult to change because those around them have changed to reflect where they were. So the communication skills [include] assertiveness training and all those kind of skills that we talk about, and just the ability to understand and self-reflect a bit more. We teach communication skills so people can start to renegotiate their boundaries because certainly if people have been cared for by other people, if you like, there's almost an overdependence of the carer – they feel like they've got to care. So how do you renegotiate that? How do you renegotiate and actually get your independence back?

Nia: He has got to always worry about what I am like, how I'm feeling. If we go somewhere, he will be constantly asking, 'Are you okay? Can we do this?' He will make sure I'm taking my medication on time, and if I need to take more medication, he will push me and say, 'You might need to take more medication at this time.' Because we don't live together, it affects us when we see each other, you know. I still let him lead his life but because I don't go out as much and he still goes out, there's always the depressing fact, will he meet somebody who is *not* ill and leave me for someone who is still able to do everything that you can do with, you know, a 31-year-old. At 31 you should be able to go out and enjoy yourself and I don't often do that now. [Only] on very rare occasions. [laughs]

Evans: That puts enormous pressure on a relationship.

Nia: Sometimes, yes. You know, I always have the guilty feeling of, 'Should we be together? Am I ruining his life by him being with me? Can I provide him with children in the future?' Because he really wants them, I really want them. We don't know if we can have them because I don't know if my body would be able to take it. There's a lot of pressure there, especially for me more than him, because he sometimes doesn't realise what I can and can't do, you know. It's hard work trying to let him know that I can't always do what I want to do.

Evans: Now you're at the start of this pain management programme. What were your expectations before you started?

Nia: I didn't have many expectations. I want to see what I'm capable of doing further down the line. After just one session, I went out for the whole weekend and I've noticed my pain but haven't let it rule me and even after one day, that's helped, one session. I'm hoping

further on that I'll be able to manage my pain mentally and not have to rely on tablets because I want to come off them. So I'm hoping by the end of this, I might be close to being tablet-free, especially with the new year.

Kemp: People are in a mode where their primary experience is suffering. They're in a state of suffering that's ongoing. It affects their mood so they feel depressed. It has knock-on effects. Their life becomes quite chaotic. They have good days where they do lots, followed by crashing – what we call boom and bust – where they crash for a few days. Their mood drops so depression's very common with chronic pain and chronic fatigue. There're some various other bits and pieces as well about what makes this boom and bust: people's drivers, perfectionism, wanting to please others, all those other bits and pieces. Those are the things that stop us being able to take time for ourselves and care for ourselves. So we've got the feeling alright about ourselves, which is the resilience, but actually not having this demon on the shoulder whipping us along and making us do things even when there's nobody else asking us to do them – that's very important from a management perspective.

Evans: Let's go back to my management buzzword: task orientation. How do you get that out of somebody's system? I'm here to do an interview. My neck is now aching. Should I stop?

Kemp: Well, you could've had a chat with me and communicated with me [laughs] that that was likely to happen and we could've actually paced it and actually said, 'Well, every five minutes or so we'll have a shift, change position, get a different sound, location [laughs] or something like that, have a different ambience' and we could've worked it in that way so that you could've shifted. In between shifting, we could've done some relaxed movement, tuning in to all the ways we talked about how to relax. But *physically* relax as well, because mental relaxation's not necessarily the same as muscular relaxation, so actually learning how to muscle-relax, etcetera, that's one of the things we do on the programme too. And just taking time out to tune in to something pleasurable, birdsong, take some deep breaths, etcetera, just enjoy the air, the pleasant weather that we're getting at this time of the year.

Evans: Yes but that's taking away from me the fact that I'm enjoying myself. I'm enjoying talking to you, I'm enjoying the personal contact. I don't want to be thinking, 'Right, let's take time out to meditate now in this conversation' because it's taking away something I'm enjoying.

Kemp: In which case, what you need to have done a lot of work on beforehand is practising that so that becomes an automated response, if you see what I mean, so that your pacing and your grading just become a part of you and you'll naturally shift your position. You'll actually naturally notice your way that you're holding tension and you'll start to make the internal adjustments. But that will be after you'd done the programme and [you are] maybe actually getting quite good at it at that point.

But at the same time, I want to make it very, very clear that pain management programmes cannot be a bolt-on to help people live a crazy lifestyle. We're not going to be making it so that you can have paracetamol for your headache but continue to bang your head against the wall, if you see what I mean. There's an element where habits will have to change.

Evans: That's Gethin Kemp, one of the leaders on the community pain and fatigue management programme held at Ystradgynlais Community Hospital in mid Wales.

As usual, I'll remind you 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 wellbeing. He or she is the only person who knows you and your circumstances, and therefore the appropriate action to take on your behalf. Don't forget that you can still download all the previous editions of **Airing Pain** from painconcern.org.uk, or you can obtain CD copies direct from Pain Concern. The contact details to make a comment about these programmes via our blog, message board, email, Facebook, Twitter or pen and paper are also at the website, and once again, that's painconcern.org.uk. And to learn more about the Bronllys pain management centre, the community *and* residential programmes they run, go to their website, which is managingpain.org.uk. Once again, managingpain.org.uk.

Okay, six weeks on, Toni and Nia. Can I just remind you, Toni, what you said six weeks ago? You said, 'What I'm hoping for is a better quality of life.'

Williams: So far, it has opened my eyes to pain management: how to cope with it daily, different methods, different medication, how to take them. It has changed the way I think about pain relief, pain management and yes, I think it will give me a different quality of life because I have realised that I've missed out on something that I enjoy doing, which is painting.

Evans: Yep, when I walked into the group this morning, you were showing around a watercolour.

Williams: Yes. When we came to the first meeting, we were asked, was there anything that we enjoyed doing that we wanted to do again, whether it be painting, writing, reading, you know, just socialising with friends, and I thought, 'Yeah, I used to paint.' And I did one for my mum, which she loved – she's got it on her wall. And I brought in a photo of the painting I had done to show the group, and one of the gentlemen that's in the group, Steve, he'd always wanted a painting of the sleeping giant.

Evans: The sleeping giant being?

Nia: It's a mountain. [laughs]

Williams: [laughs] And I finished it for him this week and brought it in and he's really happy.

Evans: Well, he was more than happy because I saw that and I heard him. But you've started painting again because of this group?

Williams: Yes. This group hasn't only brought to mind that maybe we are all capable of just a little bit more if we tried. You've got to know your limits. You don't do anything that's going to hurt you because it's pointless coming here if you're going to do exercises or do anything that's going to put you back three weeks. But by pacing myself, which I learned in the group, and an understanding of my illnesses, I have done it. I have really, really enjoyed it, and I'll be doing more.

Evans: Nia, if I could remind you of what *you* said all those weeks ago. First of all, you talked about it having affected the relationships with your family and your partner. Have they changed?

Nia: Not as much as I would've hoped. My partner still thinks it's a bit funny, me coming here. But when I actually sat him down and told him this is what we do, he said, 'Well, you should have told me earlier, and I would've had more understanding of what you actually do in the group.' So by me actually communicating – which I learnt on the programme, how to communicate with my partner and my family – he understands. I'd like a bit more out of him, but that is just me communicating more, so I've learnt communication is important.

Evans: So the communication problem wasn't him not understanding, but you not talking to him.

Nia: Yeah, that's right, yeah, because I don't always want to burden him with my problems. I've learnt through the programme that it's okay to share with him how I'm feeling and just to pass on knowledge of the programme to him so he has a better understanding of what I'm actually going through and what benefits I am having, going in the group. Because he would say, 'Oh you're going to therapy.' And I'd say, 'It's not an AA meeting.' But finally telling him, 'This is what we do, this is what we learn, for me, learning this, we will have a better quality of life when we get married and have a future together.' So he is slowly understanding it but it's a process we both have to go through together, and it's not going to be achieved in eight weeks. It's a process that's going to happen through our lifetime together of us talking about what's going on with my symptoms and how we can best manage it together, not just me managing always on my own.

Evans: Can I just remind me of the words you said to me six weeks ago. You said, 'I'm hoping that I'll be able to manage my pain mentally and not have to rely on tablets. By the end of this pain management programme, I want to be close to being tablet-free.'

Nia: I'm not close to being tablet-free but this programme has taught me that I *can* become tablet-free. But eight weeks was a silly time to limit myself to try and come off all my medication in one swoop. It's going to take a lot longer, but I'm making progress of booking appointments with one of the advisors to be able to manage. It's not going to be done in eight weeks, I've realised that. It is a long process to actually wean yourself off all your tablets, but I'm okay with that. I've learned to accept that nothing can be done over a short space of time.

Evans: Is that part of the programming, if you like, that you'll learn to manage your expectations?

Nia: Yes, yes, we have learnt to manage our expectations and being alright saying, 'No, it's not for me. I need to look after myself more.' The programme has helped a lot with being able to mentally manage your process.

Evans: Toni, would you recommend this programme to other people?

Williams: Yes I would. When it first started, the first day I came, I thought, 'What am I doing here?' But if I hadn't have come here, I wouldn't have met the bunch of people that are here because I've come with knowing nobody but gone with a lot of friends.

Evans: Another thing I noticed is that there's a lot of laughter in here, even some smutty jokes.

Williams: Yeah [laughs], because we've got to know each other very well. We've all got the same symptoms, if not the same illnesses. We're all here for the same reason, and it's good to laugh. So we have got to know each other, and I'm going to miss everybody. It's the last day today and I am going to miss not coming here on a Friday and meeting everybody.

Evans: Do you think that that will be a problem?

Williams: No, because I'm sure we'll all see each other, whether it be in passing, in shopping, in town – we'll all see each other. The teachers, they're all on the end of the phone, so you're not on your own. You're not on your own. It's the last day for us to come here and meet here, but we won't be on our own.

Evans: And you all get invited back in three months' time.

Williams: Yes we do, yes.

Nia: Party. [laughs]

Williams: Can't wait.

Nia: A day trip out.

Williams: Yeah. [laughs]

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