

## **Airing Pain Programme 28: Self-management: pacing and communication**

### ***Learning to manage pain with Arthritis Care's self-management programme.***

*In the previous edition of **Airing Pain** we featured the work of the charity, Arthritis Care, and, following up from that programme, Paul Evans looks into their self-management programme, the Challenging Pain Workshop, which is available to people with any kind of chronic pain, not just arthritis. We listen in to the course's volunteer tutors and participants as they discuss learning to pace activities and improving communication skills. We also hear from Rachel Gondwe about how volunteers gain from sharing their experiences of pain and about a trial run by Arthritis Care in partnership with a health authority to measure the effectiveness of self-management programmes.*

**Paul Evans:** Hello, I'm Paul Evans, and welcome to **Airing Pain**, a programme brought to you by Pain Concern, the UK charity that provides information and support for those of us who live with pain. This edition's made possible by Pain Concern's supporters and friends, and more information on fundraising efforts is available on our JustGiving page at [painconcern.org.uk](http://painconcern.org.uk).

**Herbie Roley:** If you can just change your thoughts – the way that you react to life, the way you say things – I *can* cope if I plan and pace myself. I can and will, therefore, be accomplishing something and I'll feel more positive. I *will* try an activity. And even if it's just a small success, give it a big tick because nothing, nothing on God's earth succeeds like success.

**Evans:** Now in the previous edition of **Airing Pain**, I featured the work of the charity Arthritis Care, and following up from that programme, I decided to look into their self-management 'Challenging Pain' workshop. It's for people with any persistent pain condition, not just for those with arthritis. Now self-management is key to you, rather than the pain, controlling your life. Rachel Gondwe is the training services coordinator for Arthritis Care:

**Rachel Gondwe:** Challenging Arthritis was the first self-management programme that was adopted in the United Kingdom, and it was delivered by Arthritis Care. It was a programme that was developed in America, in Stanford University, and we brought the programme to England. It was very successful, and the government recognized that, and they initiated

then, the expert-patient programme to be developed within the NHS (National Health Service) and the Department of Health as a means of self-management for people living with long-term conditions. In the end, there were several organisations that started to run the generic programme, which Challenging Arthritis ran as 'Challenging Your Condition', otherwise known as the 'Expert-Patient Programme', the chronic disease self-management programme.

And so all of those self-management providers, in the end, got together to write a quality assurance programme for the whole network of people delivering the programme and that became known as 'Stepping Stones to Success'. And later on, that grew and became a quality assurance framework to help any organization that wanted to start running these programmes. They would develop a framework that would enable these new organizations to start running the planning, the design, the management and the evaluation side of it, and that was called 'Stepping Stones to Quality'.

**Evans:** We're talking about programmes to help people with chronic pain conditions manage their conditions better?

**Gondwe:** Obviously, Challenging Arthritis is for people with arthritis, and the other programme, Challenging Your Condition, is for people with any long-term condition. But as a result of running these courses for a number of years, we felt that more and more people were asking specifically about pain, pain being a main problem that people faced as a symptom. So as a result, we felt that we needed to actually develop a new product, a new programme, specifically to help people living with chronic pain. So again it's a generic programme for people with any kind of pain, not just people with arthritis, although when you look at our statistics, most people do have arthritis as one of their co-morbidities. They might have other conditions as well, but arthritis, especially osteoarthritis, is one of the main conditions. So Challenging Pain is a self-management programme for people living with chronic pain, but it's run over two weeks – two and a half hours a week for two weeks.

**Evans:** Rachel Gondwe. So a few weeks ago, I took part in one of the Challenging Pain workshops in Cardiff. There were 17 of us including myself, and whilst most had arthritis conditions, we had all experienced difficulties and issues familiar to anyone with persistent pain. The workshop leaders were Jill Davies and Herbie Roley.

**Davies:** I'm Jill. I work for Arthritis Care as a voluntary services supervisor, and that's my colleague Herbie. [To workshop participant] Yeah, so what effect does pain have on your everyday life?

**Workshop Participant:** Temperament.

**Roley:** Temperament, alright.

**Davies:** There's actually spelling today, isn't there Herbie, my wee lad?

**Workshop Participant:** It's the pain, not me. [room laughs]

**Davies:** Thinking and concentration, yea. We start to dwell on our own problems. It's quite easy to do a turn-in on yourself and feel sorry for ourselves. Emotions, yeah – changes your mood. You might be saying, why me? Why is this happening to me? What have I done to deserve this? Eating – it can affect your eating. You might not eat enough, or too much, as in my case – comfort eat. Can't get off to sleep, but if you do get to sleep, [it's] disturbed sleep because you wake up and you're in pain and you turn over and, if you're like me, you've got to take a trot off to the bathroom as well and you're well and truly awake by then. And waking too early. And relationships – yeah, absolutely – with your family, your friends and your health professionals. You're not the same person, really.

**Kirstine MacDowall:** Whenever we run courses the two main problems reported by people, whatever their condition – because we get people with all conditions – not just arthritis, are pain and fatigue. We always say to people, what about your condition causes you most problems in your day-to-day life? And that's the number one answer – it's pain, very closely followed by fatigue.

**Evans:** Kirsten MacDowall's another volunteer tutor with Arthritis Care. Now what everybody with chronic pain really wants is for the pain to be taken away. So is this what the Challenging Pain workshop's all about?

**MacDowall:** I wish we could. I mean that's what everybody wants – some magical medication or tip that will take the pain away. No, it's more about learning how to manage your pain and how to minimize it, so yes, ideally you'll have a reduction in your pain, but no, we don't have the secret of making it go away completely. But I think it depends on your level of pain, you know – if your pain is one out of ten and somebody said, 'I can take it down to 0.9', you'd say, 'can't be bothered'. But if your pain is nine, and somebody said, 'I can help you get it down to 8.5', you'd be interested.

**Evans:** So where do you start with people?

**MacDowall:** I have to say, we start with where they are, you know. We get a complete mix on the courses. We get people from, you know, 17 or 18 right up to the 90s; all ethnicities – just completely different people, so we have to start with where they are. And they have a

mix of conditions. It's hard for me to think of a condition that I haven't at one point had somebody with. So we start with where they are.

**Evans:** Have you been on a course as a participant yourself?

**MacDowall:** Yes.

**Evans:** Tell me about why you enrolled in the first place.

**MacDowell:** I enrolled in the first place because I'm not anti-medication and I think with acute conditions, medication's great, but I think with long-term conditions, sometimes you get to a point where the medication is causing as many problems as it's solving. It's dealing with problems you have, but it's creating new problems. So I wanted to not be solely reliant on medication. I wanted to explore other avenues, especially as I was constantly being urged, you know, by the medical professionals, to keep medication, because of the side effects, to an absolute minimum.

**Roley:** Now normally, without even thinking about it, we breathe in and out over 21000 times a day. So I'm going to try and tell you how to do it, [laughs] when you've been doing it very successfully all these years. When we're in pain, our breathing tends to be inefficient. So we're going to look at just how we can reap the benefits if we learn to improve the quality of our breathing. Conscious breathing, which is what I'm really going to talk about, can help us to un-tense our muscles. That in itself can help us get off to sleep at night, and it can help us to release a lot of the tension that comes with pain. So right, shoulders are dropped – I've got rid of the tension. I'm going to breathe in now so I shan't be talking for a minute or two.

[deep breathing]

**Gondwe:** All of our regional and national offices offer the programme. They're all run by people living with arthritis or chronic pain so they're all people that have that real-life experience. And they're often the positive role models – that's what engages people a lot on the course, to see that there's people out there living with the same conditions, the same kind of symptoms, but getting on with their lives and being able to move forward, and that is a real boost for the participants.

And often, just getting together with other people in the room that are also suffering from the same kind of conditions and symptoms – that also helps people remove some of that isolation that they feel, that they're the only one, on their own and that nobody else understands what I'm going through. And then suddenly you're in a room of people that *do*

*understand*. And people get so much out of this face-to-face intervention. It's incredibly valuable.

You do talk to some of the tutors, you know, people that are living as well with arthritis and pain – how it changes their life to be able to see the change in others. They'll have gone through the programme themselves; they'll have been participants on the course originally and they've got that confidence. They want to give something back and they've come on to be trained as a tutor, as a volunteer, and then they're then giving back to other people and so they get benefits out of seeing others change through the programme. It's a really effective *growth*, so that's what self-management is all about.

**Roley:** When we have a long-term painful condition, we tend to do two common things. One: we avoid doing the things which *we think* will make our pain feel worse. Two: we do more on days when we feel better – on our good days – and then less on those bad, painful days.

During this session, we're going to look at setting goals, working towards them, and taking control. If we avoid doing things which we think will make our pain feel worse, and we do more on good days and less on bad days, we're losing control – we [are], are[n't] we? We're being dictated to. The whole aim of goal-setting is to take that control back for ourselves, because remember, we can only change what we can control.

The first thing is, we need to set our plan towards something that we really want to do. If it doesn't involve inspiring activities, then we're probably not going to succeed. But it's *got* to be achievable. Can it be broken down, you ask yourself, into small, realistic steps? It's important actually to know just how achieving your goal is going to help you in your general life and living. Is it going to give you health benefits, increased confidence? Well if you succeed, success breeds success. That's why it's so important that it's achievable. It's why it's so important that there are small, realistic steps along the way that you can reach out and grasp and say, yes, I am on the way, I am succeeding. Because once you get that feeling of succeeding, it will take you from one step to the next. Jill, what's your goal going to be?

**Davies:** Well, you know, in the last couple of years, I've had problems with my feet and I've had operations on my feet. I live on a hill, quite [a] steep hill and, before I had my feet done, I could walk up and down that hill with a dog, get a bit of a pull as well – not too bad at all. But now, I wouldn't even entertain it at the moment. So to be realistic, I'm only going to go halfway down; take the dog with me [to] this nice spread of grass where he can have a little run around, and then walk back. So that's what I'm going to do next week, and I'm going to do it...three times.

**Roley:** Good. And your level of confidence in success on a scale of one to ten?

**Davies:** Eight.

**Roley:** Eight, that's good. What I'm going to do, I'm trying to lose weight at the moment – my doctor's told me I've got to. And I'm going to not eat any potatoes, or pasta, or rice. Sugar's out, Canderel [artificial sweetener] is in. And by healthy eating, cutting down my portions of meat a little bit, I'm going to try to lose another, let's say, two pounds in the week. That's my aim, just two pounds. My level of confidence is high at the moment because I've just lost ten pounds. I reckon I've got an eighty or ninety percent chance of getting that.

That is what we mean by a goal-setting plan. What is my plan going to do? It's going to lower my weight; it's therefore hopefully going to lower my blood pressure, and it's going to make me able to move a little bit more freely. And if it can do all those things, I'll get the benefits of the extra exercise as we go on. So, if you'd like to write down your own goal-setting plan, we're going to ask you to carry out this plan during the next week and come back and tell us, some of you next week, how well you got on with it.

[To Evans] We try to encourage people to make changes for the better, to use their lives in a way which is perhaps going to help them look outwards more than inwards. Because with a chronic pain condition, it's so easy to turn in on yourself, rather than to look out and move forward.

**Evans:** There were 17 participants today, including me. What do you hope they will get out of it?

**Roley:** We can't expect that everybody here today will take hold of everything that we've talked about and go and start practising it immediately. What we do hope is that each person here will take a different aspect of the course to heart, find that it suits them and bring that into their lives and hopefully, that will cause them to find a level of improvement in their daily coping with pain.

**Evans:** What surprises me is that you're encouraging people or teaching people very, very simple things – breathing, relaxation, taking time for themselves... Why should they have to come to a workshop like this to learn that?

**Roley:** Life is very busy these days. When I wrote a letter years ago, it would take a week to get there, a week to get back and I wouldn't have to answer it for a week after that. Now, with an email, I'm answering it ten minutes after I wrote the first letter. And all that causes

stress to build up and people tend to forget themselves and forget that *they* need care as well as looking after people outside.

It's also a fact that people need to be *aware* of these techniques. It's easy to overlook them. How many people, for example, think of actually planning their day? A simple plan of a day makes life run so much more smoothly *and* looks after all the joints. I was talking to one of these people today just about that, about how, by planning, she could in fact improve her way of life. Things like doing part of a job, moving on to another job, building a rest into the day – it sounds simple. It's logical, but how many of us actually do it without a little bit of a hint from outside?

**Evans:** We've spent three hours here on day one, you've sent them away for a week now, and we'll meet here again next Monday. How do you think they're going to take [on] what you've said today in the next week?

**Roley:** I think [with] the fact that they've taken away a plan to make life better, I think the first thing we will notice is that they will bring it back and many of them will be eager to tell us how well they've performed [in] the tasks. It may well be that they come back having tried some of the other techniques that we've mentioned as well. But I think they will come back with their work plans and many of them will have succeeded and be delighted with themselves.

**Evans:** Thank you very much indeed. We'll see you next week.

**Roley:** Okay, look forward to it. Thank you.

**Evans:** Herbie Roley. So with week one of Arthritis Care's Challenging Pain workshop over, let me just give our usual words of caution, that whilst we believe the information and opinions on ***Airing Pain*** are accurate, sound, and 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.

Now with that in mind, Challenging Pain is of course about *self*-management. So what role does your health professional now have? Rachel Gondwe:

**Gondwe:** We don't want doctors to think or consultants to think about self-management as an extra, but we want to see it as an integral part of somebody's care pathway. And we're working with the Avon Orthopaedic Centre, close to Bristol. We're working with Challenging Pain and we're looking at pre and post-treatment of people [who have] had total hip

replacements. The study will have the control component of people that go through the normal pathway, and then our research component, [in which] random participants will be taking part in Challenging Pain *before* their surgery, and then once they have completed their surgery – about 6 to 9 weeks post-surgery – they are going to be offered a refresher programme, just a one-day programme, where those patients will be able to recap what they learnt on a Challenging Pain course.

We're also running this closely with the physiotherapy department, so the addition to Challenging Pain is that they will get an exercise, a full exercise component to it. We mention exercise, obviously, and the benefits of exercise within Challenging Pain, but we don't have the physiotherapy element that the physio department can offer us, so that's being included in this trial as well. So that's looking at the role of self-management in managing people undergoing total hip replacements. And that's ongoing at the moment and we just are waiting to see the results of that but it's quite an interesting study and we really hope – we know – that the benefits will be great for those participants, and hopefully this will then become part of a routine care for someone awaiting a total hip replacement.

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**Davies:** Nice to see you again. Hope you all had a good week. So during this session today, we're going to have some feedback [on] our goal-setting of last week. That's what we're going to start off with.

**Roley:** I'll go first myself. My aim was to lose two pounds. I can now say, a *mere* two pounds, because I lost four.

**Group:** Wow, well done!

**Roley:** And I haven't even opened a biscuit box since last week [group laughs]. So, really, I'm very pleased with myself. And the steps that I took – things like using a smaller plate, cutting right down on the carbohydrates, increasing the amount of vegetables and fruit that I ate have all worked brilliantly. So I'm real, real pleased with myself. I really am. Jill?

**Davies:** Well my goal is to get back as fit as I was pre-foot operation which would have lasted over 2 years. And because I live on a hill and it's quite steep, I decided that [I'd try] to get fit [by] going up and down the hill, but only halfway to start off with, because it's a big hill. And I said I'd do it three times, and I did do it three times, but the third time, I *really* had to make myself do it.



So this is where goal-setting comes in, because if I hadn't said I was going to do three, I wouldn't have done it. The dog is delighted! So yea, by just setting goals, this is how you get yourself to achieve things. And achieving things makes you feel good, which has a knock-on effect on how you respond to your pain and your other symptoms.

**Roley:** Is there anybody else who'd like to tell us what they've done?

**Evans:** My long-term goal is to increase my fitness levels without booming and busting. And the benefits of lower blood pressure, depression – well, less depression – a reduced pain and a feel-good feeling. I actually set myself a task this week. I wrote down self-control, don't push yourself, leave the house every day, which I wasn't doing before, and take breaks at work. I've left the house every day for a short walk around the block, but I haven't taken breaks at work. In fact, I've just seen this now and it's reminded me I haven't taken breaks at work. So I've failed in that. I really need to push myself more.

**Davies:** So you want it prominent, like on the fridge door or something, to keep reminding you?

**Evans:** Yes. And self-control obviously, that's gone out the window as well, because I haven't taken breaks at work.

**Roley:** Breaks are very important when you're doing things, and they can make a difference, as you say, between success and failure.

**Davies:** We're going to talk about better communication skills because those are very important, especially when you've got a chronic condition and you need to convey to people how you feel and what you need.

**Roley:** Now, it's very important that we communicate our needs to our family, to our friends. And it's very important that they do know how to support us. We may need to tell them how they can help us with our pain management, because friends are for that, aren't they, family is for that. It's for support; it's for help. And if they can help you, a real friend, or a member of the family, certainly will. Now during the next activity, we're going to explore how learning to communicate can help with coping with pain.

**Toyin Onasanya:** Communication is so difficult, and I must say that it's not easy to communicate to the other person. Sometimes you *know* what you're trying to say, but it can be sometimes hard to do that.

**Evans:** This is Toyin Onasanya. She's Arthritis Care's South England training administrator.

**Onasanya:** You know, you go into your GP and you're thinking, 'oh I've got these symptoms', [but] your GP's thinking, 'oh, they're just symptoms of headache and nothing more'. So you need to understand your condition; you need to have been on a self-management workshop [such] as this, where we break it down for you and try to explain certain things. So that when you go in there, you're more assertive and can say: 'See, I've been on Arthritis Care's Challenging Pain management workshop. I have learnt about my pain, and I see this is the way my pain goes. This is what makes my pain better; this is what makes my pain worse. I have also done stress and I find that my stress pours very high.'

A lady there says, before attending the workshop, she was never assertive. She just goes to her GP and she finds out at the end of the day [that] she comes out not getting anything. So she goes in and whatever her GP says, she just comes out like, 'okay, that's it'. She's resorted to the fact that there is just nothing she can do. There is no way. She's got maybe arthritis as a... you know, people want to find out if they've got that condition, but they need to be able to say more before they can be sent to me. And so she said, 'oh, I thank you so much for the training workshop, because I was able to go into my GP and be assertive and I got results.'

**Evans:** Now, as we've heard, the Challenging Pain workshops run over two half-day sessions. So can something as short and sharp as that really have any long-term benefit? Well, in its pre-release days, Arthritis Care carried out a study with the Eric Angel Pain Clinic at Derriford Hospital in Devon. Rachel Gondwe again:

**Gondwe:** We ran about 18 different workshops, and we did pre and post-course questionnaires and we did focus group discussions as well to find out how effective the course was and did it meet what people were looking for. I mean, the study was amazing and it really proved that the two-week programme was *just* as effective as the six-week programme. We've got less drop-out rates. It reduced people's pain and it had a long-lasting effect because we did the study 6 and 12 months later as well. We did a follow-up 6 and 12 months later and it was still as effective 12 months on at reducing pain, increasing people's self-confidence or self-efficacy to manage their condition themselves. It did show that there [were] reduced GP visits and it also decreased people's health distress – their anxiety around their health.

**MacDowall:** As a tutor, I've actually had people weep with relief, because they're just so happy to be with someone who understands what they're talking about.

**Evans:** But what do you get out of teaching the course?

**MacDowall:** Seeing its effect, which varies from person to person, but sometimes you can see quite dramatic changes in people and that's lovely. The man who cried because he was so relieved to meet other people in the same situation and who said he'd thought that everyone else with a condition was coping brilliantly and it was just him who wasn't. And that that was because there was something wrong with him, [that] it was some character flaw in him. And he actually just really cried because he was so relieved at the thought that, you know what, everyone else is not coping that brilliantly.

One lady was sort of bent over and couldn't straighten up. Then she said, 'look at me, I'm straight! For the first time in years.' Or sometimes it's just confidence – people having the confidence to be a bit more active or to do a bit more. We ask people to rate their pain, so that's lovely, if you can see it's gone down. Even if it's gone down slightly, every little, as they say, helps.

**Evans:** Kirsten MacDowall. Now there's so much more to the Challenging Pain workshop than I've been able to cover in just half an hour, so you'll have to go on one yourself to find out what it can do for you. All the information's at Arthritis Care's website, which is [arthritiscare.org.uk](http://arthritiscare.org.uk). So that's all from this edition of *Airing Pain*. Don't forget that you can put a question to our panel of experts, or just make a comment about these programmes via our blog, message board, email, Facebook, Twitter, and of course, pen and paper. All the contact details are at the Pain Concern website, which is [painconcern.org.uk](http://painconcern.org.uk), and from there you can download all editions of *Airing Pain*.

I'll leave the last words to Katherine Williams. She was one of my fellow participants on the Challenging Pain workshop:

**Williams:** I'm finding the course very helpful because suffering in a lot of pain, you feel like you're the only one. Meeting lots of people here at the course has made me realise I'm not [as] isolated as I am. And they're touching on feelings and emotions that you're having. You are very proud and you don't discuss these emotions that you're having and they have such a huge impact on your life. All these negative, bad feelings that you're having that leads to depression and not being able to cope, that you don't really admit to somebody that you know so well. And I found it really helpful, saying it myself to other people and listening to other people, so I found the course very, very useful.

**Evans:** How did you find out about the course?

**Williams:** I care for my daughter [who] has disabilities and obviously, if my health goes down, where's she going to go? It's going to cost the government loads of money to keep my

daughter somewhere, and I think it was the *Caring Times* they send you, and there was an advertisement in there for a course called All About Me, which helps you with depression and anxiety and stress and all things like that. So when I signed up because I thought this could be for me, they recommended this course in Cardiff for me with pain management.

**Evans:** Have you heard about pain management programmes before?

**Williams:** No, never. Never heard of them.

**Evans:** Why not?

**Williams:** Because when you're in pain, you keep it to yourself. You don't share it with anybody, that's just a pride thing, really, I think? And you just feel that's your life – that's what you're dealt with – keep it to yourself and you have to cope with it. But it reaches a certain stage in your life where you think, I can't do this anymore.

**Evans:** Would you actively look for more pain management programmes now?

**Williams:** Definitely, yes.

## Contributors

- Jill Davies and Herbie Roley, Challenging Pain workshop leaders
- Rachel Gondwe, training services coordinator with Arthritis Care
- Kirstine MacDowall, volunteer tutor at Arthritis Care
- Toyin Onasanya, Arthritis Care's South England training administrator
- Katherine Williams, Challenging Pain workshop participant

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