

Airing Pain Programme 6: Pacing and Arthritis

How pacing can help people with pain regain control, plus arthritis myth-busting, the future of pain management in the UK and a Q&A session on pain relief.

Pacing is the thing that makes the most difference to his patients' lives, says David Laird, Consultant in Anaesthesia and Pain Management in County Durham. We hear about how pacing allows people to build up slowly to doing more, and Pete Moore describes getting his life back on track and becoming a patient expert on pain management.

Also in the programme: Dr David Walsh provides information about the different forms of arthritis and the treatments available and Dr Paul Johnson and Nia Taylor set out some of the opportunities and challenges facing pain services over the next few years. In our Q&A session, specialist nurse Ruth Day answers your questions on painkillers.

Issues covered in this programme include: Arthritis, pacing, misconceptions, painkillers, back pain, educating health professionals, paracetamol, codeine, TENS, flare-up, side effects, osteoarthritis, rheumatoid arthritis, joint pain, pain service cuts, policy and economics.

Paul Evans: Hello and welcome to **Airing Pain**, a programme 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 Funds Awards for All programme and the Voluntary Action Fund Community Chest, this has enabled us to make these programmes.

I'm Paul Evans, and in today's programme:

Martin Johnson: It's been estimated that £120 billion is spent, from UK PLC, on chronic low back pain. And yet still pain is not a priority, why?

David Walsh: It's commonly thought that arthritis is a condition of old people, that's not true.

Nia Taylor: A lot of doctors, unfortunately, think that they can look after someone with pain themselves, and if it's a complex and long term pain problem, actually that's no longer appropriate.

Evans: We'll be addressing all these issues later on in the programme. But each fortnight on *Airing Pain* we look at the topics that affect us. The coping mechanisms, medical interventions and therapies that might help us regain control of our lives. And one subject that's been mentioned over and over again is pacing. It's a simple concept, but if you're like me, it takes practice to achieve. So today we're going to look at it in greater depth. Here's Dr David Laird, who's a consultant in pain medicine in Durham.

David Laird: For general day to day work on a long term basis, pacing is what patients have told me makes the biggest difference, most consistently. And pacing involves changing activity, if you're walking you stop and rest, if you're standing you change your posture, if sitting you move before you become too stiff. But the key to pacing is actually making the changes before the pain, and the muscles spasm that comes with that pain becomes apparent. And that means that it has to be done on a queue, it has to be done when the ads change on the TV, when the music changes on the radio, or when a buzzer goes off in the pocket saying ten minutes, or twenty minutes is up, rather than wait until the back starts to ache or a task is necessarily finished.

Some of my patients have said that they do things such as divide the ironing into two baskets or three baskets, so they can do one basket and finish a task and then stop and change. And I think one of the main reasons why people who are in pain have difficulty pacing is that on a good day we want to do things and the result of that is that we push and over-push and then we pay the cost. And the next two days, three days, we're wiped out, we're frustrated and everything builds up again.

And I've talked to people who are athletes and how they train is not by doing a ten-mile run one day a week and nothing for the next six days to recover and then another ten-mile run. They do a little and they do it often. And by doing that they build up their stamina, they build up their strength, because muscles start working together and they have a sense of achievement.

But that takes discipline, it takes the ability to have a long term view, that in three months I'm going to slowly climb this ladder, where I start at the bottom doing a little and often, but each week I do a little more and often. There's a Tanzanian proverb that says 'little by little, a little becomes a lot' and that is so relevant and it's more consistent. It can give us hope. And patients have taught me that has enabled them to achieve, to be more consistent.

And, yes, there are days when, for that special occasion, you do too much. For the shopping trip, or with somebody who you haven't seen for a long time, or for a wedding, or for an

extraordinary occasion, where you know that you're going to push yourself and you'll mark off in the diary the next two days because they're going to be diminished in what you can do and how you're feeling and what you're thinking, in your muscle pain.

A lot of people seem to be aware of what pacing is, when you talk to them, but it's not emphasised. And when I teach medical students, they have never heard of it, and whenever I do teaching with nurses and GPs people acknowledge it but I think we have to do more than acknowledge it, it's a skill.

Evans: You're listening to *Airing Pain* presented this week by me, Paul Evans, and brought to you by Pain Concern, a UK charity providing information and support for people who live with pain.

Now, one of our aims on *Airing Pain* is to find answers to questions you've raised with us, so do take advantage of this opportunity to connect with our experts via our message board, email and not forgetting pen and paper. I'll give you the address later in the programme.

But 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.

With that in mind, our first questioner writes, 'I live with constant pain and have been prescribed paracetamol, but it doesn't work and tramadol makes me feel like a zombie. I've tried to explain this to my doctors, but they don't give me anything positive. What can I do?' Well answering your questions is Ruth Day, she's a pain nurse at Torbay District General Hospital.

Ruth Day: Some of the stronger painkillers, or analgesics as doctors sometimes call them, can have that effect of making you feel a bit like a zombie. But the idea of combining paracetamol with another painkiller is really quite an effective way of managing pain. I think what it might be worth doing is going back to your doctor and seeing if there is something that's a little less strong than the tramadol.

I don't know if you've tried codeine in the past, but codeine and paracetamol combined together is a very useful combination and you can get the codeine in different strengths. So some people have more codeine than others and it's often the codeine that might make you feel a bit zombieish – a bit like the tramadol might do as well.

The other thing that you might try, if you're able to, is that you can combine paracetamol with an anti-inflammatory drug, something like Neurofen, I suppose, is one of the most common ones. Some people aren't able to take anti-inflammatory drugs, but again that's a very nice and useful combination of drugs, to have the paracetamol and the anti-inflammatory together. So I think maybe armed with that information you'd feel a bit more confident about going back to your GP and asking about that problem. I hope you manage to sort it out.

Evans: Thanks for that, and here's another question relating to the suitability of paracetamol. 'My mother is eighty-eight years old, living with two hip replacements since 1983. She now has osteoarthritis in the spine and knees. For the past two years she's been taking concentrated cherry juice, which has left her pain free, however, recently she's had a flare up and her GP has suggested paracetamol, which at first seemed to work. Now she's still in pain, even with the paracetamol, so she's wondering what to take without bad side effects.'

Day: Well first of all I'm delighted that your mother has found that the cherry juice has been helpful for her pain and I'm sorry to hear that's she's had this flare up. Paracetamol is helpful and I think even though your mum feels that it's not controlling her pain completely, I think it's worth carrying on and taking that. I understand her worries about taking other painkillers, because they do, all drugs and medications have side effects and sometimes those can be really troublesome.

What I think your mum might think about is whether she might use some things other than tablets to help with her pain, and I wondered whether she found things like a heat pad might be useful. Often people find that quite comforting, particularly with back pain. And you can get these pads which you can plug in and they run off the electricity and they're fairly flexible so you could have it on your back and you could also bend it so it goes across your knee to provide some pain relief for her knees as well.

So that might be quite useful. And also thinking about heat things, lots of people find a warm bath or a shower gives some relief, so that might be something too that your mother might be able to build into her day.

I think it's really important that she keeps moving and moves her joints as much as she possibly can. That movement of the joints keeps the fluid in the joints working, so that they're a little bit less painful, or crunchy sometimes it feels when you move them. So that would be a good thing to encourage her to keep up and about and moving. And maybe she might find

some massage, or rubbing in some creams, may well help as well and that helps both with keeping the joint moving and also the warmth that you get from massaging something.

You might also want to look at using a TENS machine. They're not suitable for everybody but you would be able to find out about that, so it might be exploring that. And again, it's not putting any medicines in, so there aren't major side effects with using that.

I think if those more straightforward things don't help it's worth asking your GP to see if there are some other tablets, which perhaps aren't quite as strong and may just help and work with the paracetamol to enable your mum to get a bit more comfortable. So I hope some of those things will be helpful.

Evans: Yes, I hope so too. And thanks to Ruth Day, who has been answering your questions today.

And we'll stay with the subject of arthritis because according to Arthritis Research UK a staggering ten million adults consult their GPs each year with arthritis related conditions. David Walsh is Associate Professor in Rheumatology at the University of Nottingham. He's also director of the Arthritis Research UK Pain Centre.

David Walsh: Arthritis is an overriding term used to describe a whole series of conditions that affect the joints, ranging from the commonest form of arthritis – osteoarthritis – which I tend to think of as a kind of repair response in the joints, through to conditions such as rheumatoid arthritis, which are inflammatory conditions which erode and damage the joints. Osteoarthritis probably affects everybody at some stage in their life. Conditions such as rheumatoid arthritis are much less common but are very important because they cause a lot of problems. So, maybe two percent of the population in the UK may have rheumatoid arthritis. And then there are some other forms of arthritis which are much rarer than that.

One of the factors that's common across all forms of arthritis is that they cause pain. It's commonly thought that arthritis is a condition of old people, that's not true. It is true to the extent that any condition that currently doesn't have a cure is going to be more common in older people, because we collect things as we go through life, but arthritis can affect people for the first time at any age. So children can have arthritis and old people can have arthritis.

I get frustrated because often I hear people talking about osteoarthritis and back pain as being 'degenerative conditions'. 'Degeneration' to me means 'wear and tear', like a car. The more miles you do in a car the more bits wear out, until you can't replace them anymore and you get rid of it. There's a big difference between things like back pain and a car – a back is

not wearing out, what's happening is that it's constantly repairing itself and the changes that we see on the x-rays are a consequence of that repair process.

So, in fact, people are not wearing their bones out, people with back pain don't have thinner bones, they've actually got more bone, you see extra bits of bone. So these conditions, they're not degenerative in the sense of a car wearing out. And I think that's important because it changes the way that you look at it. For your body to repair itself as well as it can do it needs to be used, which is the exact opposite of wear and tear. The more you use a car, the more it wears out, by keeping using your body it repairs itself better. And secondly if it was wear and tear, then the older you got the worse it would get, but in fact that's not what we find.

Evans: So what treatments are available? David Walsh again:

Walsh: Pain is the commonest symptom that people describe. And yet a lot of treatments for arthritis have focused, rather than on pain, on other things such as whether the arthritis is damaging the joints. So there is some fantastic treatments for rheumatoid arthritis, which have been developed over the past few years, which have major impact on the damage that happens to the joints. But I am slightly concerned that they've distracted a little bit from the main problem that people present with in the clinic, which is their pain. And unfortunately I don't think the treatments for pain have advanced at the same pace as the treatments for the inflammation.

Pain is complex – it's not a single entity. Somebody with arthritis doesn't just have a pain, the pain that you get in your knee when you're lying down in bed at night that's stopping you going to sleep is not the same pain that you have when you're standing up and trying to walk on it. There are different pains and these different pains are from different mechanisms and the different treatments we have target those different mechanisms.

And yet we have a very incomplete understanding as to how we should use those treatments for the individual's pain. But also, there are a lot of parts in the pain pathway which we are currently not able to target with tablets. There are new treatments coming through that will help target those. So over the next five to ten years I would anticipate there being a much broader spectrum of medications available for arthritis than there is at the moment. That again means that we'll need to be much clearer about who will get benefit from which treatment and how you can select and use them to the best effect.

So that's just the tablets, but the same principles I think apply to all the other approaches that we have for arthritis pain, including exercise type treatments, weight reduction for knee osteoarthritis, psychological approaches – there are several different psychological approaches. And again, who will benefit from those treatments and how we can target those treatments to get the best benefit out of them is an important question for the future.

Evans: In the last edition of *Airing Pain* we visited the Powys Chronic Fatigue and Pain Management Centre – and don't forget that you can still download that, and all the previous editions of *Airing Pain* from www.painconcern.org.uk and you can obtain copies from Pain Concern itself – we spoke to patients, or should I say 'graduates', who were just completing the three-week residential programme and the overriding story was one of success to the point of elation. Criticism, however, was levelled not at the pain management programme itself, but at how long it had taken them to be referred there, lack of GP knowledge about their pain conditions and the role of primary and community pain management.

Now I'm very aware that this was just a straw poll of opinion but:

Martin Johnson: A survey from Action on Pain said that 93% of patients don't know that pain clinics exist, that's very frightening from a chronic pain population.

Evans: Martin Johnson's Chairman of the Royal College of General Practitioners Pain Management Group. He's actively involved in the politics and future of pain management. And *Airing Pain* met up with him and other speakers in this programme a few weeks ago, at the 2010 voluntary sector seminar for the British Pain Society.

Johnson: Statistics abound about chronic pain management and the sort of problems that occurs. It's been estimated, for example, that £120 billion is spent from UK PLC on chronic low back pain, and yet still pain is not a priority. Why? There's lots of theories, pain is not a disease in its own right, it's just a symptom, that's the one that's always quoted. Or the other thing that's always quoted is the fact that people don't die of pain, but now we know from the research from Torrance and Blair Smith that people do die of pain: they die quicker when they have chronic pain, their brain changes. Their brain shrinks by up to 20% when they've had chronic pain for up to three months, from the work from Irene Tracey. We need to be able to link this into GPs, into GP training, to make it a higher priority.

Evans: So how could this be achieved and what would it mean for the patients? Martin Johnson again:

Johnson: What that would mean would be over a three-year period that pain will be one of the major priorities for the Royal College of General Practitioners: they will appoint a national clinical champion that will cover all four UK countries and that will increase education; it will get representatives from the Department of Health; it will increase the knowledge database and also increase guideline production.

The other contentious question at the moment is how will pain services be delivered within the new environment. I think nobody knows – I don't think it will matter too much at the GP commissioning level as long as we get the infrastructure right and give them the right guidelines and the right tools to use. GP commissioning groups will be quite happy to adopt anything that's given to them because they're going to be desperate for models given to them. So I don't think we need to worry too much about the GP consortiums, apart from the possibility of variability of care and possibly increasing the possibility of postcode lottery.

Evans: Now, one of Martin Johnson's worries is that a development by Sheffield PCT, or primary care trust, could have wider implications:

Johnson: Sheffield PCT have decided, due to finance, to make most procedures within pain clinics, procedures of limited clinical value, which means things like acupuncture, it means facet joint injections, it means epidurals; in fact, nearly everything apart from pain management programmes, talking to patients and giving drugs out, have now been put on the limited list. This is a very worrying development and something that the British Pain Society is going to be tackling head on.

Evans: That was Martin Johnson, Chair of the Royal College of General Practitioners Pain Management Group.

Nia Taylor is Chair of the Patient Liaison Committee for the British Pain Society:

Nia Taylor: The thing about pain management services at the moment is that they're so patchy, so inconsistent. So you will get some really brilliant ones and some non-existent pain services, somewhere it's just one GP in a whole area, or one anaesthetist working as a main doctor in a hospital.

And the other thing about pain services that is such a problem is that people don't know that they exist and where they are and how they can get themselves referred to a pain service. So a lot of doctors, unfortunately, think that they can look after someone with pain themselves and if it's a complex and long term pain problem actually that's no longer appropriate. The GP should be asking for somebody, a team, preferably, a multi disciplinary

team of people, to look after that person and give them advice and information that they need and treatment that they need.

It's a big worry really, that the sort of community pain services that we would like to see happening, it's going to be even more difficult in the current economic climate and with the cuts and with GP commissioning to see that happen. But the idea should be, I believe, that, where these services work well, they can actually be very cost effective, because you're avoiding people having to go into hospital and see a consultant and that's really expensive.

So the way I see it working, is that people should be able to go to a community pain service before they go to the hospital or maybe instead of. And I would like to see people being able to self-refer to one of those community pain services, maybe that won't happen, maybe that's too much to hope for, that would be they would just have a number and phone up and say, I would like to come and see you. The alternative is that their GP refers them, but obviously then the GP has got to know that it's there. That's how I see it, the community pain service is sitting between the GP and the hospital services, either replacing them or acting alongside them I suppose.

Evans: So how could the community-based approach work in practice? Well, Val Conway is a consultant chronic pain nurse, Clinical Lead for Chronic Pain Community Services in East Kent, where they've been working with such a model.

Val Conway: The model that we have developed in primary care is very different to the model that is delivered in acute hospitals. We don't feel that it's particularly helpful to deliver a hospital model in the community services: the models are very different and there is a place for both models to run alongside each other in a seamless fashion.

The revolutionary part of our model, which we started at the beginning of the year, was to introduce a single point of access. This means that when a patient is referred to pain services in East Kent by their GP, their letter is triaged, either by myself or my colleagues, or by one of the hospital pain consultants. And depending on what information is given in that letter as to where that patient then receives their pain management. If a patient sees their GP and they had an epidural last year, or facet joint injections, which were particularly successful, then when we triage that letter, the patient will be seen in the hospital pain clinic. If the letter shows that the patient needs more of a long term support, medicines management type approach, then they will be given an appointment in primary care, community services. This has meant that patients have a minimal wait and they are seen by the right person at the right time.

Evans: Consultant chronic pain nurse Val Conway. And the term 'triage' simply refers to the initial assessment of the patient's condition to determine the next appropriate stage in its management.

You're listening to *Airing Pain* presented by me, Paul Evans. And we're discussing the future and development of community pain management programmes. Here's the patient's view:

'My darkest day was in 1994 when it was the 31st of December and it's my birthday and some friends came round and said, 'Pete come out, it's your birthday, it's New Year's night'. And I said 'I just can't come out, the pain is so horrific today'. And I'd had my full quota of medication that day and I just couldn't stay upright. So there I was on my birthday Year's night, laying on the floor looking at the TV and I actually contemplated topping myself.

I thought to myself, 'is this what my life has come to now, you know, that I can't even do the simple things I do on my birthday?'

Evans: Well Pete Moore got through the lowest day of his life and went on to a pain management programme at Saint Thomas Hospital in London. He's now an instructor for the Expert Patient Programme in England.

Pete Moore: I think first you have to define what a pain management programme is – is it something run by a healthcare professional, or is it something like the Expert Patient Programme where it's delivered by people with health conditions themselves? But there's another type of course now called 'co-created health', where the courses are actually delivered by a healthcare professional, alongside a layperson.

So there's lots of innovative work actually going on now within the community, where people can actually get the help and support that they need to actually become active self managers. And I use the word 'active' because a lot of people, when they go down the doctor shopping route, or the therapy shopping, where they're expecting the doctor, or the healthcare professional to give them something, or do something to them so that it controls their pain.

And I think, especially with the Expert Patient Programme, or the Arthritis Care programme, because they're delivered in the community, by people with the health conditions or the pain themselves they can actually become more effective. And I always remember a physio actually giving me a call once – and someone had been on one of our courses, the Expert Patient Programme, the persistent pain programme, and was actually going on to an NHS

pain management programme – and he rung me up and said ‘send me more like that’, because they had learned some simple skills which enabled them to support them along the way on the PMP programme.

Pain management isn't difficult, but what a lot of people do is do complicate it. The actual concept of it is quite simple really. With pain management you don't let the pain be your guide. So say, for example, you sit and then you wait for your pain to start and then you say ‘I'd better get up and move now’, well, pain management is the opposite to that – it's actually getting up and moving before your pain starts. I mean it's not rocket science – it's pretty much like a Noddy guide really.

And I'm also looking at the future now, because I think where people have to go to somewhere to attend a course, what about those people that may not be into groups, they're not group people. Perhaps they hated school and they think, ‘I've got to go back and sit in a group again. I don't want to do that.’ So it's about offering them other alternatives, so pain management on a one-to-one basis, it may be costly, but it could be effective.

What about where they attend a pain management programme online? Young people these days, are they going to pick up a book and learn pain management? I pretty much doubt it. What they are more likely to do is look on the internet for pain management skills. But what about going one step further, putting pain management onto iPods.

As I said, the pain management message is a very simple message, it's how we switch on that persons pain management light, to actually engage with that concept, to actually learn how to pace themselves. They find that stretching exercising isn't fearful, but in actual fact it can be fun.

Evans: That's Pete Moore, of the Expert Patient Programme in England. And his new information and self-management handbook for patients with persistent pain was launched this month. It's freely available on the Pain Toolkit website, along with other useful information about managing your pain. And that's at paintoolkit.org. We'll be taking a closer look at the Expert Patient Programme in a future edition of *Airing Pain*.

And finally, if you'd like to put a question to our panel of experts, or just make a comment about the programme, then please do so via our blog, message board, email, Facebook or Twitter. The address to write to, as promised earlier, is Pain Concern, Unit 1-3, 62-66 Newcraighall Road, Fort Kinnaird, Edinburgh, EH15 3HS, and all this information is on our website at painconcern.org.uk. The website is a one stop resource, to get further information

about the programme, including a glossary of the main 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.

In the next edition we'll be looking at issues arising from MSP Margo MacDonald's Assisted Suicide Bill in the Scottish Parliament. But for now I'll leave you with some words of simple wisdom from Dr David Laird:

Laird: I sometimes ask patients, if I wanted to run ten miles and I tried it at the weekend and was really rather exhausted and it's now Thursday, what advice would you give me? And patients have no difficulty telling me what to do: to do less and to do it more often. So everybody I've encountered has got that little voice inside their head that's very good at giving advice, but I think we can turn that around and we can even use the little voice to write a letter to the imaginary person and then we can read our own advice for ourselves. And that's better, I think, than it coming from a doctor.

But if you find it helps, tell your doctor it helps, because then maybe they'll pass it on, they'll learn from you and then they can help others. And that is very empowering for you – knowing that you have helped others.

Contributors

- Dr Martin Johnson
- Ruth Day, Pain Nurse, Torbay: (Q&A)
- Nia Taylor
- Val Conway
- Dr David Laird, Consultant in Anaesthesia and Pain Management
- Dr David Walsh
- Pete Moore, Creator of the Pain Toolkit

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