Airing Pain Programme 7: Exercise and improving mobility

Getting back into exercise and improving mobility. Plus, funding for pain services, and how can we best describe pain to a health professional?

Airing Pain *visits the Frenchay Hospital Pain Clinic in Bristol where we hear from staff and patients. Paul Evans sits in on a consultation with physiotherapist Pete Gladwell and hears the advice given to one patient about how to increase her mobility and exercise without causing flare up. We learn about how to talk to your health professional and the different ways of assessing pain. Also covered is how well funded pain care is by the health services, and the patients at Frenchay tell us their stories of living with and managing pain.*

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 of us who live with pain.

Pain Concern was awarded first prize in the 2009 NAPP Awards in Chronic Pain and, with additional funding from the Big Lottery Funds Awards For All 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…

Rose Marriot: Many of the patients that stopped by to talk, all of them were in pain, 90 per cent of them were not aware of pain clinics, probably the same amount didn't know how to describe their pain to their doctors and they weren't asked.

Evans: Rose Marriot is a nursing sister at Frenchay Hospital Pain Clinic in Bristol. Her straw poll taken at a public road show event, revealed a shocking level of ignorance and what people understand about their pain conditions, their awareness of pain clinics and how to describe their pain.

Rose Marriot: So, they will go to the GP and say 'I've got a bad back' and the GP says 'Ok then, you will take paracetamol and whatever for that bad back'. But what the patient hasn't done is told them that they've got leg pain as well as the back pain and there will be different types of pains, so one pain may be addressed, the other one may be missed. I asked them about their pain, asked them to describe it and told them to go and tell their GP what they have told me. And I also, on a few occasions asked them when they saw their GP to ask if they could be referred to the pain clinic.

Evans: In this edition of ***Airing Pain*** I'll be trying to address these areas of ignorance – ignorance which I'm not ashamed to own up to myself, even though I've had chronic pain for some 20 odd years.

Firstly, and I found this incredibly difficult, how do we describe our pain to a health professional, or to anybody else for that matter?

Marriot: I'd want you to tell me the nature of the pain, for example, is it burning? Is it searing? Is it sharp? Where is it? And it's important to be able to describe where your pain is and the quality of the pain because that helps in the doctor being able to make a decision of how to treat the pain. For example, different types of drugs work on different types of pain – you know, is it there all the time? Does it come and go? Is it sharp? Is it burning? Is it aching? People have very different ways of explaining or describing their pain. Sometimes it's good to be able to help people to suggest ways of describing their pain.

Evans: Rose Marriott, who is a nursing sister at the Pain Clinic at Frenchay Hospital here in Bristol.

Patients who attend this clinic, all have chronic pain and they've usually been referred by their GP unless it's by a consultant in a different area of the hospital. Dr Cathy Stannard is one of the pain consultants here.

This is quite a big and busy pain clinic. We have six consultants working here and a large team of health professionals from different backgrounds working: we have a clinical nurse specialist; we have a team of pain psychologists; we have several pain rehabilitation physiotherapists; occupational therapists who work on the pain management programme and a specialist pain pharmacist who comes and works with us here in the clinic.

We also closely work alongside other disciplines, who come and consult here, including colleagues from neurosurgery and a team of child health specialists for young people with pain and also an addiction medicine psychiatrist for people who have a history with substance misuse and also have pain.

We see a lot of what we would describe as the usual pain conditions: neuropathic pain, diabetic neuropathy, post-herpetic neuralgia. This is a very busy regional, neurosurgical unit and we also have a large orthopaedic spinal service. And so the vast majority of our patients will have back pain and really they will be quite complex patients with complex post-surgical problems. We would see a lot of patients who've had one, two or often many more spinal surgical interventions and still have persisting symptoms and often we have to manage patients in conjunction with their surgeon.

So a lot of what we do is investigating and finding out if there's new pathology, scanning and making surgical decisions alongside pain management decisions. So that's a big chunk and that's to do with the type of hospital that Frenchay is.

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Margaret Howdle: I had a crushed vertebra in my spine. I had two operations in a week. I've got two titanium rods in my back and then I had a little space in the spinal cord so I had to have a little cage which had to come right round. You had to do it from the front. And then I had that fitted in.

Pete Gladwell: And you've tried a vertebroplasty – or had tried it – and that hadn't been helpful.

Howdle: Not really.

Evans: That's Mrs Margaret Howdle, who's kindly agreed to me sitting in on her consultation with Pete Gladwell. He's the physiotherapist here at the pain clinic at Frenchay hospital and we'll be following their progress throughout the programme.

Incidentally, the vertebroplasty that they mentioned: it's a procedure where an acrylic bone cement is injected around the damage or crumbling vertebrae in the spine and that repairs it and hopefully relieves the pain.

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

This is a good time to remind you that whilst we believe information and opinions on ***Airing Pain*** are accurate, based on the best judgements available, you should always consult your health professional on any matters relating to your health and well-being. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Now, we've had a lot of questions relating to mobility, exercise and the role of the physiotherapist in pain management and we're hoping that our eavesdropping on Mrs Howdle's consultation with Pete Gladwell will go a long way to answering some of your questions.

Gladwell: We see people with persistent pain problems who often have a lot of impact of that pain on the rest of their lives. And the most obvious area for most of my patients is that

affects their mobility, it causes all sorts of problems, it slows them down. And as a result of that they can lose some physical condition and that makes the problem even harder to manage then.

Partly I can help them by trying to find a balance of movement and rest that works for them as an individual. A number of my patients I'll find will tend to push themselves with activities until they can't do any more, until the pain has reached the pitch that they can't carry on at that stage. But sometimes the recovery time then can be quite slow and then of course whilst they're recovering, if it is a slow process of recovery, they can't move around as much. And if it's two or three days of recovery – or even longer sometimes – then physically they've lost some of their ground at that stage.

Howdle: Is that what some people will describe as ‘boom and bust'?

Gladwell: I know it as boom and bust. It’s known in the trade as activity cycling as well, with that increase of activity and then decrease in activity.

Howdle: So, how do you stop people 'booming and busting'?

Gladwell: Partly it's to find out whether they feel it's a feature for them in their lives? Is it part of how their pain behaves? And if they recognise it, probably they're half way to stopping it already. And then it's trying to find some way for them to work out how much to do on a given day, so they don't overdo it, and then have the repercussions for two or three days afterwards.

Gladwell: Ok. It's nice to see you again, but what would you like to cover this afternoon? I don't know if there is anything in particular?

Howdle: Well, I am having a bit of difficulty in walking Pete. Now, can I get up and show you what I mean. I seem to be as though I am stiff and when I'm walking it is so I can't get one foot before the other. Do you see what I mean?

Gladwell: Yes, I can see that. You're having difficulty lifting each leg as you go.

Howdle: It's all of a sudden happened and I've been doing my exercises.

Gladwell: Overall, it sounds like things are a struggle at the moment.

Howdle: They are, I'm afraid. And I would like something to improve it.

Gladwell: My job's made slightly easier here because all of my patients have met up with one of the pain consultants, so I've already got information about what their diagnosis is, about how long they've had a problem for, what treatments they've tried, what they're currently trying.

So I'll be thinking about a slightly different agenda here – about asking first of all how I might be able to help. I'm always interested to know what my patients would like from me, so that's a little bit of agenda setting, if you like. And then to catch up with what they are doing physically and what the pattern of that physical activity in the week is. So I'd be looking to see whether there's any signs of boom and bust in their patterns, whether they're currently exercising… or often the people I see have tried exercising, it's been problematic, so a lot of my time is spent on unpicking 'what went wrong?' And how can it be done differently.

Gladwell: You're keeping going with exercising even though it's difficult?

Howdle: Uh huh.

Gladwell: So, you've got the acupuncture to try later on?

Howdle: Yes, it usually works.

Gladwell: So the main problem you're having at the moment with walking is being able to lift your feet? Part of that is about your posture with the changes with the surgery. It makes it harder for you to shift your balance. Part of it is about being able to balance on one leg.

Howdle: Dr Stannard said it's the muscles.

Gladwell: Hmmm, I'll just get you to stand on one leg for a moment. Keep yourself safe. Use the table if you need it. How does it feel to stand?

Howdle: Oh, I'm a bit hesitant.

Gladwell: Do you know why? Do you know what makes it feel difficult to do?

Howdle: I don't know really.

Gladwell: You're using your hands a lot to do the work, aren't you?

Howdle: Peter I don't think I can do it with one hand, I think you'll be all beating me up if you do!

Gladwell: Ok, have a sit down when you're ready. That's given me that bit of extra information.

Howdle: I wobble a bit.

Gladwell: Yes, I was wondering about that.

Howdle: I do wobble a bit.

Gladwell: One of the challenges, if you've got a long term pain problem and you're trying to work out an exercise programme, is about how much to do and how much to move, because by definition, most of the people I work with, are finding it painful to move.

So exercise may not be a comfortable process for them, but yet if they don't move around and don't exercise, they can get weaker and stiffer and often as the result, the pain can actually get worse by doing less. So it's about trying to find a balance within that and part of my job is unpicking the efforts that people have made with exercise in the past.

I'm trying to work out a level that they are happy to work at and we often use something that's called a ‘baseline’ for that. And that might be about somebody working out that they can do three repetitions of an exercise today. And they might, if they've got that right, be able to do three tomorrow and three the next day. But after a week or two they might be able to build up to four. And that's a really basic part of exercise and rehabilitation, but it's often overlooked and it's often thought that the health expert ought to know what a patient's baseline is, but my feeling is that the patients are better at working out their own levels and their own baselines.

I would be asking the patient how much do they feel confident to manage on a daily basis. And I think, a lot of people will want to push themselves. There's a sense, that pushing yourself is the right thing to do. So, if I ask somebody how many of an exercise they can do, they may say 'Well, I can do 10.' And if I ask the question, ‘do you think you will be doing 10 tomorrow?’ Some people say: 'hmm, I'm not sure if I can manage 10 tomorrow'. So my next question then would be: 'How many do you think you can do today and still feel reasonably confident of doing the same tomorrow?’ And that's getting close to what their baseline might be.

Evans: Of course the really difficult thing is that somebody who has been fit and active, you tell them 'walk 50 yards today or 10 yards today', when they really want to run a mile.

Gladwell: That's a big area, isn't there? And that's getting into the psychology of pain management and rehabilitation really. And I suppose, everybody knows that you've got to start somewhere. But the challenge for that person is to hold back when they know they could do more today, but it's actually about looking after tomorrow and tomorrow's mobility by doing less today.

We use a range of exercises here. We have a range of stretching exercises that cover the arms, the trunk and the legs and we encourage people to do those in a slow and relaxed manner, so they're getting control of movement. And we have a set of strengthening exercises as well that cover right the way through the body. So it's a general exercise programme that many people will be familiar with, because at the moment there is no evidence that a specific exercise programme is any better for most of us with most chronic pain problems than a general exercise programme.

But some people do really well with some forms of exercise and that's an individual matter. So if somebody really enjoys swimming and they do well with it, that's going to be an important area for them to work on. Other people really enjoy walking and that's an area that they can manage well, other people branch out into tai chi or they make a start with a gentle yoga class. It's about that individual finding something they think they will enjoy. So for someone who wants to get back to better walking the dog, for example, then walking's a perfect exercise for them, but they may do well to fit in a bit of strengthening and stretching work to improve their walking as well. Whereas if somebody actually wants to improve their balance, they may want to be looking at tai chi, they may be interested in other forms of movement that just challenge their balance gently, but in a safe way.

I'm fairly broad in what I think people should be thinking about with exercise. I think that's important, because there are so many forms available these days, and so many ways in which people could explore movement. It's nice to have that scope really.

I'm wondering about a couple of relatively easy exercises to help you with your muscles and your balance together, but you would start off in a standing position, holding on. I'll give you a quick demonstration and the first thing is just to shift your weigh from leg to leg and then in the same position, so that you're safe holding on, shift your weight slowly onto your toes and slowly backwards. And you're getting two sets of muscles working there that are really important when you're trying to shift your weight and to stand on one leg.

Howdle: And will that help the muscles in my back?

Gladwell: It will. They're, you're always working those muscles as you're doing that, shifting your weight, leg to leg. How does that feel to do?

Howdle: It's quite, it is easy.

Gladwell: Good. And do it to music?

Howdle: Yes.

Gladwell: And then very gently forwards over your toes and leaning back a little, so you're not going up on your toes but just much more taking your weight forwards and then back.

Howdle: Do I lose… lift my toes?

Gladwell: You don't need to for this. It's just much more about transferring weight forwards and backwards. And as you're doing that you're using your trunk muscles and leg muscles together to coordinate and that might help you a little bit out when you're trying to stand on one leg and lift to walk because all those muscles that stabilise your trunk and your legs will be toned up.

Howdle: Yeah.

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Stannard: It's interesting because I guess if you talk to patients in the waiting room, the perfect outcome would of course be that they would leave the service without having pain. If you examine the data for the effectiveness of pain interventions, that's probably not going to happen. And I think most patients will have pain in the longer term, they may be supported, they may have periods where they have less pain, but they are going to have pain that's persistent in the longer term and that reflects almost, I guess, the decision to refer the patient here in the first place.

Dr Cathy Stannard, Consultant at Frenchay Hospital here in Bristol.

Now, at the start of this edition of ***Airing Pain***, we asked why such a high percentage of people with chronic pain were unaware of specialist pain clinics like this one? Could that be because the health professionals in primary and secondary care treat clinics like this as the end of the line for people in pain. A last chance saloon, if you like.

Stannard: I think it's seen unhelpfully as being a last chance saloon. Particularly, actually by secondary care specialists, who will maybe operate or carry out other interventions and then feel that when they're a bit of attempting to control the patient's symptoms hasn't worked, it is now pain clinic or bust. I think that's maybe not a very helpful framework.

Talking to colleagues in primary care, they would very much feel that we would provide a useful input in helping patients understand and manage their symptoms, optimising therapy, maybe offering other interventions, but then preparing them to go back into primary care and move on with managing their pain. So, we are not really a last chance, we're I think an important focus in helping draw strands together to support optimal management in the longer term.

If you look at the likelihood of a patient having persistent symptoms, usually most definitions of chronic pain for research purposes would be a time-based definition, for example, a patient who's had pain for 3 months or 6 months. But, actually, the research suggests that's the likelihood of symptoms persisting is not just based on the intensity of symptoms and not based on the duration of symptoms, but all sorts of things, like the degree to which the pain interrupts, the meaning of the pain to the patient and so on. So in a way some pains are chronic from a very early stage and I think if one can identify and recognise those groups, one can then give strategies for supporting self-management in the longer term.

And I think in a more direct impact of us seeing patients late is we'll often see patients – and it's a great frustration – who will have got to the point where there're about to lose their jobs, their benefits are threatened. They will have no salary and no income and actually this is the start of doing a piece of work which should improve their quality of life and maybe get them back into the workplace, but we come in at the time when it's all almost – not too late, it's never too late – but it would be hopeful for that patient if they didn't have the uncertainty of financial difficulties and so on, before they came here.

Evans: So, is this a funding issue? Surely money gained by the exchequer by keeping somebody with chronic pain in regular work could far outweigh the cost of treatment?

Stannard: Absolutely, and I think this is big picture stuff and I think this is where strategically, nationally, the pain community are trying to make policymakers understand that the economic burden of pain is heavy and complex. And I absolutely agree that to return somebody to taxpayer status very, very quickly recoups any spend I guess on providing healthcare support for that.

But we have to be realistic in the environment we work with. And in our own service we are subject, as are all other services across the local area, to having to make efficiency savings and the need to reduce spend by reducing the number of patients that come to secondary care. It's going to have an impact on us and on patients. And I guess the challenge is to make the impact on patients of that type of service reconfiguration, minimal, and to support interventions, if you like, in primary care, which can give the patient the same sort of support in moving on with things as we would give here. And that should be possible to do but it's about thinking about things in a different way.

But I do very much agree that there needs to be, across social care, Department for Work and Pensions, all the sorts of impacts of somebody having, living with chronic pain on them and their carers and their family and their work... the financial equation is very complicated. And I think we are a little bit hampered. We suspect strongly that bringing somebody to a pain service and helping them function optimally with their symptoms would have those sorts of benefits in terms of getting people back to work or doing what they want to do, but we don't have those financial, if you like, cost effectiveness data, I think because, because it's quite a complex thing to work out.

So we can say that we think it's a good idea but I think there's a need to collect those data, there is a start being made on collecting those types of data on the cost effectiveness of pain services, but we don't have those data yet.

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Ronn Watt: I've had pain for the last 25 years. You can't allow it, for it to win, you've got to win, not the pain.

Evans: Ron Watt is a patient at the Pain Clinic at Bristol's Frenchay Hospital.

Watt: Pains are twofold: one of them is where I've had pain in all my joints and all of the muscles in the body. That is tied in with long standing chest disease which I have had, actually, since childhood.

Evans: Twenty-five years is a long time to have pain. How has it impacted on your life?

Watt: Oh, I think a great deal. You'll have to ask my wife that.

Mrs Watt: I think depression as a result of not being able to do things because it hurts to do it, not having an answer, not having a treatment for this. It's something you've just got to learn to live with and that's very hard, especially when you've worked within the NHS, as he did, and nobody can come up with any answers. So, it impacts on our lives, we tend not to go places, because he can't, because he's in too much pain. I tend to do a lot of the things on my own, like gardening and housework because a) his chest disease is such that he cannot do these things, but also the pain prevents him from doing it.

Evans: Those are the practical things that you can't do, how does it impact on you mentally?

Mrs Watt: I get very angry and he knows that. And I also was a nurse, so therefore I should know better. But I'm sorry, when you are at home, you've given everything to the outside world and when you are at home, suddenly everything is annoying and I get quite cross about it and he knows I do, unfortunately. It's very difficult to hide. When you've banked on going somewhere or you've been invited somewhere and you can't go, because he's just not fit to go.

Evans: How's it impacted on you mentally?

Watt: Anger. I get it at myself, because I cannot do what I want to do, not at the outside world. I think it's very, very easy to ask yourself 'Why me?' And of course I always say 'Why not? What makes you so special?'

Evans: Are there any positives?

Watt: Oh yes! Gosh, I'm alive, what more do you want?

Mrs Watt: No, there are positives, on the good days we do everything together and therefore we go out.

Watt: Yes, I have a wife. She is my best friend. Of course there are positives. We have a nice house, we've got a nice car, nice family. Loads of positives! And that's what you always have to look for, you've got to look for those, because it's very, very easy to think 'Oh dear, why me?' And you know, the glass is always half empty – it is not it's half full. It's always gonna be like that.

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Howdle: So you want me to try to it with one hand?

Gladwell: Well, when you're ready, but I'm not quite sure you're ready yet.

Howdle: No, I'm a bit wobbly.

Gladwell: Hmm, you are and if you practise and the exercise gets too wobbly, you don't actually get better at doing the exercise.

Howdle: No.

Gladwell: That's one of the things about balance exercises. That when you're trying to build up your coordination, if you push yourself too much and try to wean off support too much with your hands, the exercise just gets wobbly.

Howdle: I have been going upstairs more, you know. I think, 'well, I'll just go upstairs twice', then I go up and down, but coming down, that is still a bit difficult.

Gladwell: Do you go down facing forwards or facing the stairs?

Howdle: Yes, I go down facing forwards. Should I try doing it backwards?

Gladwell: Do you know about that version?

Howdle: No.

Gladwell: For some people, they will find it easier, it's a very individual thing really.

Howdle: The only thing about that, I would be frightened of not putting my foot on the stairs.

Gladwell: Yes, that's the trick. That, if that's an issue, you're better facing forwards.

I can offer a range of things, but there are certain things that I can't do. So, in terms of managing boom and bust, as we've talked about, that's one of my areas. I can help people with exercise; I can help people with goal-setting; I can help them to manage any disruption to their sleep because of pain; I can help them to learn basic relaxation techniques that help

with muscle spasm and help with sleep; I can offer advice about mobility aids; I can't get rid of the pain for the vast majority of my patients and, of course, that's what everyone wants.

Howdle: Pete if this is where I am, it's difficult. I would have to have you to help me, because I don't think I dare do it. I can get you to there.

Gladwell: Ok. Could I ask you for a favour, could you turn the chair around a little bit? Sometimes with exercise it's about adapting it and making it work in a way that works for you at your current level. So that's… now, I'll just get you as you were with one hand on the table and this should, if you turn towards me, give you a space to step forwards and back in, but well supported. Do you get a sense of how this might help?

Howdle: Yes, I do because I can feel it. I can feel it in my back.

Gladwell: Well, good luck with those and we will catch up, it'll probably be in the New Year.

Howdle: Yes, right. Thank you, Pete.

Evans: My thanks to Mrs Margaret Howdle for letting me sit in on her consultation with Pete Gladwell. I hope that some of the questions you've put to us, considering exercise, physiotherapy and pain clinics have been answered in this programme from Frenchay Hospital in Bristol. And we'll be visiting other pain clinics around the UK in future programmes. But in the meantime if you want to put a question to our panel of experts, or just make a comment about the programme, then please do via our blog, message board, email, Facebook or Twitter.

In the next programme, we'll be looking at work issue for those of us in pain. Is work good for us? And for those of us who are unemployed, how do we get back into the workplace when our condition might not make us the most attractive prospect to a new employer.

But, until then…

Gladwell: Anybody listening to this will know that long term pain throws a spanner in the works – it creates chaos. And when somebody starts to get things ticking over again, that's a good part of my job.

Marriot: One of the things that does give me a lot of pleasure is the end of an acupuncture course. We've had quite a lot of patients that have considerably improved with their pain and it's enabled them to move on and go back to work, do the things that we want them to be able to do after it. But I think the best thing about the job is being there for people – letting them know that we understand that they are in pain and are there to try and help them. A perfect outcome I think here would be someone who has pain which is tolerable, which interrupts what they want to do to a minimal degree, and that we would support patients in

understanding and managing their pain, so that they could achieve the goals that they want to achieve.

Howdle: Well I've got to say that everybody at the pain clinic has been most helpful – from Dr Stannard, to my acupuncture and to Pete, even the girls on the desk – they have been so helpful. And it's lovely to see a kind word and a smile. It makes all the difference.

Watt: It's very, very easy to think 'Oh dear, why me?' And you know, the glass is always half empty – it is not it's half full. It's always gonna be like that.

Contributors

- Dr Cathy Stannard, Pain Specialist
- Dr Pete Gladwell, Physiotherapist
- Rose Marriot, Pain Nurse
- Ron Watt and Mrs Watt, Patient and wife
- Mrs Margaret Howdle, Patient

Contact

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

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

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

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