Airing Pain Programme 57: Self-management, psychology and "physio-terrorists"

Stiff joints and dark thoughts: treatment of pain and the person.

'Pain medicine isn't good at dealing with the effect of pain on the person', says Jonathan Bannister, head of the multidisciplinary pain team at Ninewells Hospital, Dundee. Paul Evans visits the clinic where Mr Bannister and some of his colleagues talk about how they care for people in pain.

We hear about the difficulties of getting a referral and how pain specialists can help GPs add pain management to their armamentarium, or doctors' toolkit. Physiotherapist Lynn Sheridan describes how she has to win the trust of patients scared of visits to the "physio-terrorist" after encounters with the vigorous methods of traditional physiotherapy. Her more gentle approach focuses on regaining function and helping people do more without flare-ups.

Helping people distinguish between their thoughts and the truth is one of the key aims of Clinical Psychologist, Dr Jonathan Todman. He explains why mental health is very often affected by chronic pain and how pain affects people with mental health problems.

Paul Evans: Welcome to another edition of ***Airing Pain,*** a programme brought to you by Pain Concern, a UK-based charity working to help support and inform people living with pain and healthcare professionals. This edition has been funded by a grant from the Scottish Government.

The Tayside pain service in Scotland is based on three main hospital sites, in Perth, Brechin and Dundee. It was at Ninewells Hospital in Dundee that I met Consultant in Pain Medicine and Anaesthesia Dr Jonathan Bannister, along with some members of his multidisciplinary team.

So who gets referred then?

Jonathan Bannister: We've moved, I think as probably most pain clinics have now, a long way from the old model where referral was very restricted, and we'll take referrals from any medical professionals, or any paramedical professional, so we're happy to take referrals from physiotherapists, psychologists, occupational therapists – anybody can refer into us who's appropriately qualified.

Evans: But at what stage does a patient have to be before that happens?

Bannister: Too late usually, is the honest answer. Pain clinics have always been quite a scarce resource, and even now we hear patients who come and see us who say 'I've been trying to get to the pain clinic to see you for years but my GP says: oh there's no point referring you to the pain clinic because their waiting list is four years long, or two years long, or 18 months long'.

And of course we now conform to the same targets that everybody else does. So we have a 12-week referral to first appointment target, as everybody else does. And we meet that. So we conform to the same target as everybody else does.

The comment I made was that people get to see us too late. One of the problems with chronic pain is that it tends to creep up on people, and a lot of it can be managed outside a hospital service like ours; but a lot of it isn't managed particularly well outside hospital services, because one of the things that one needs to do with patients who have chronic pain is to sit down, listen to them and explain what you believe is going on, so that they can understand what's going on and transfer that understanding into a feeling perhaps of some reassurance that lets them get on with their lives. That's very difficult to do in a seven or eight minute consultation with a GP.

So by the time somebody's been filtered by their GP, or by their operating surgeon, or their physician. They can be maybe 12 or 15 months down the line before they get to us. In an ideal world you'd begin to treat chronic pain effectively using the whole biopsychosocial model structure from the minute the patient began to show that they were going to have pain for a prolonged period, and this wasn't going to be fixable easily or quickly. The Scottish service model of chronic pain treatment will begin to address that, and there is a major redesign going on in Scotland just now to try and improve the way we, as a whole health service, help chronic pain patients, so that may move us to a better situation where chronic pain is treated earlier and more effectively, with a wider variety of approaches earlier in a patients journey.

Evans: How will that work then?

Bannister: The main thing that needs to change is what happens to a patient outside a pain clinic: so in their early phases, in their early parts of the journey with their general practitioner, with their physiotherapist, with pharmacists who might look after medication review, and this sort of thing. And also getting people access to things like self-management training, which is vitally important at a very early stage, so the patient learns to deal with their

pain in the best way that they can so that the pain has less and less impact on the patient. Because what, certainly I find, is that pain comes with two problems: it comes with the problem of the pain, and the sensation of hurt and injury; and probably a bigger problem is the affect that that has on the person.

Now pain medicine, my particular sort of area of the speciality, the biological part of it, is not especially good at dealing with the effect of pain on the patient, and really that's something they need to be trained differently to deal with. Pain management is anything but one size fits all. So we have a very catholic approach and we will do interventions and we do everything right up to and including spinal cord stimulation.

But it's really important for everybody to remember that being a GP is incredibly difficult. It's a really broad level of understanding and knowledge, and I qualified in 1980, and what I had to know to qualify then is really very small compared to what I would have to know as a GP now. They're asked to do a vast number of things; one of the problems is that pain isn't big on their list, for various political reasons.

So in a lot of ways you can't expect a GP to be an expert in pain management, although it's a very interesting conundrum because pain is the most common symptom that a patient will present with, so you'd think that the GP would be particularly interested in pain, but often pain is used simply as an indicator of what the other problem is and the interest lies in the other problem, not the pain.

Probably what we need to achieve with our colleagues in primary care is a better level of understanding of chronic pain and also we need to give our colleagues in primary care a much, much bigger toolkit to help people with. At the moment, for the majority of GPs, all they've got is a prescription pad. And we know that drugs are of limited value in chronic pain, there isn't enough access to things like chronic pain physiotherapy, and by that I mean physiotherapy which is tailored to somebody with a pain problem, rather than tailored to somebody who's just had a knee operation or a shoulder injury, which is very much rehabilitation to cure, which pain physiotherapy is not about: it's rehabilitation to function.

Lynn Sheridan: My name's Lynn Sheridan. I'm the specialist pain physiotherapist for NHS Tayside. Most of the patients that I see have had pain for a long period of time, falling into the chronic pain category. No matter where it is, that's usually led to an element of deconditioning, so they're less active because of their pain, which then leads to more pain. And a lot of my job is trying to educate and advise on how to get that function back again and increase their activity level.

Evans: Many people will think of a physio as a beast.

Sheridan: Yes. [laughter]

Evans: Or a beastess.

Sheridan: A “physio-terrorist” we’re often called. [laughing]

Evans: Is that justified?

Sheridan: Certainly not in the pain world, I would hope not. It’s a barrier I often have to break down because people have seen physiotherapists in the past who have inadvertently caused the pain to increase. As physios we are trained traditionally to deal with more acute pain problems and work on rehab from an injury that will improve over a period of time, so the treatment can be a little more vigorous and progress more quickly, whereas in a chronic pain condition the approach is a lot more gentle and paced and working on improving function, and hopefully not trying to flare the pain up too much. So, I would hope that I don’t fall into that category and that wouldn’t be justified, but it can take a long time for me to persuade the patients with regard to that as well.

Evans: So it’s a mind thing as well as a body thing?

Sheridan: Yes, absolutely, yup I think the mind comes in a lot in the chronic pain side of things. To try to break down the barrier of attitudes of healthcare professionals as well as the patients themselves.

Evans: One of the big issues with people with chronic pain is boom and bust I guess [**Sheridan:** yes]: it’s the pacing business [**Sheridan:** yep]. When somebody’s feeling well, they really want to go for it.

Sheridan: Yes.

Evans: And that’s the boom time, and the bust time comes later.

Sheridan: Absolutely, a lot of my work is trying to change that habit, if you like, and a lot of it is habit, that that’s what we’ve always done. We work through a job and we finish it, when you’ve got pain it’s not always that easy because it can lead to that bust cycle again.

Evans: But it’s more than habit isn’t it? Because it’s the, you know, feeling good when you’ve been feeling lousy [**Sheridan:** yep] is more than habit; you just want to grab it while it’s there.

Sheridan: I was speaking to a patient about this yesterday actually, and she said that she has a big fear around, if she doesn't do all that when she feels good, when will she do it? And that fear of things are going to be bad again, so I'll not have the chance to do that, but a lot of it is about changing that, because by doing everything all at one go, is perhaps then leading to that bust cycle, so it's trying to change that.

Evans: So what did you tell her?

Sheridan: I asked her to keep an activity diary, to see if we can start to establish some patterns so that she can try and identify areas that we could possibly try to change. Doing it all in one go is not easy, and it's not easy, pacing is difficult, I completely recognise that; it's against what most of us would want to do because you have to plan a lot more carefully as well, I suppose. But, yeah, often getting the patients to keep an activity diary, so they can start to establish patterns of what may be contributing to a flare of their pain can help.

Evans: It's actually writing something down, it's like being on a diet, you write down the calories you're taking and [**Sheridan:** absolutely] you suddenly realise that a bag of crisps is putting on five pounds. You don't know what exercise you're doing.

Sheridan: Yes, I think that's it; a lot of people don't recognise the role that stress and things plays as well, you know I'll encourage them not just to write down activity levels, but how they're feeling, what's going on in their life at that point in time, because it's usually a combination of a lot of things that cause a flare. And it's not always a cause and effect straightaway, sometimes it can come on a few days later, so that it can be difficult to recognise, and in that way writing it down over a period of a couple of weeks [they] can start to see if there are some patterns there that you can change.

Evans: And can you spot patterns that perhaps the patients can't?

Sheridan: Yes, I would say we can. [laughing] Probably more so, we're not as in that lifestyle I suppose, and looking at it from the outside you can sometime identify little ways, or give suggestions on how things can be done differently, because we do get in a way of doing things and don't often think of how to change that. So part of my job is helping with that problem solving on how to change tasks to make them easier, to pace them better, so they still get done, and people are perhaps doing more, but just in a different way than usual.

Evans: A discussion I often have at home is my lawn, I mow the lawn, complete, front and back. [**Sheridan:** yes] And I'm ill. [**Sheridan:** yes] My wife says 'why did you do all that? The lawn will be here tomorrow, it'll be here next week.' And my argument is: 'I may as well take the hit now'. [**Sheridan:** OK] What would you say to that?

Sheridan: I would agree with your wife, why do you need to do front and back in the same day? Perhaps doing one one day and one the next, you know I'm not saying to leave it for long periods of time – I know that can get frustrating as well – but it doesn't all need to be done within that one day. And also looking at what else you're doing on that day as well, if you're going to choose to do that task in one day, perhaps just adapting what else you're doing so that's your priority for the day. And other things you might let go to another day, if it's something you really, really have to do. Adding in some relaxation techniques and things to cope with that hit is maybe another way of managing that, looking at the things that help your pain and doing more of that on that day as well.

So, yeah we don't always change everything, but just giving other ideas on how to help and to cope with that flare. And sometimes it is a choice, you know, people have events to go to, weddings and things, and they know that that's going to cause them a hit, and I wouldn't say don't go. It's just planning a little better for that.

Evans: When somebody is referred to you, and they haven't done any exercise for goodness knows how long, are they frightened, or worried that they've been referred to a physiotherapist?

Sheridan: Yes. Absolutely, and they often look terrified to be there, and it takes a lot of persuasion to encourage them to continue with the physiotherapy treatment. And usually at that point in time I will try and concentrate the consultation on finding something to send them away with that they can do, rather than giving them an exercise sheet of things that they struggle with, to try and reduce that fear to some extent.

Evans: Do people go away thinking, 'well all she's done today is got me to bend my wrist, or something like that?'

Sheridan: Yeah, quite frequently people do say, 'is that all that you want me to do?' And I think that's usually a perception of what they've had in the past from physio, which they have said hasn't worked, so we need to try something different and what I'm asking them to do is to add something new into their day that they can manage, and putting them in control of that as well.

So it might be that it is only bending their wrist, but they may spend most of their day avoiding doing that because it's sore, so if they can bend it five times in a day, more than what they were doing, then we can start to build up that strength there, so it's starting at a level that's comfortable.

Evans: What's your perfect outcome?

Sheridan: Improved function is my perfect outcome for a patient. I would never promise to any of my pain patients that I'm going to reduce their pain because that's usually unrealistic.

Sometimes we can, whether that's through an improvement in function, therefore the pain becomes less of an issue to them, or whether some of the exercises do help to reduce some muscle tension that's causing extra pain on top of what they have, but, yeah, any improvement in function, range of movement, these kind of things is a positive.

And for some people just not making them worse – so they're managing their condition in a way that prevents their muscles from weakening and their joints from stiffening, which may cause their pain to get worse in the future. If we can prevent that then that's a positive outcome as well.

Bannister: If it was easy for a GP to get somebody into psychology or self management, or appropriate psychotherapy, or an OT they would probably do that a lot more than reach for a prescription pad. But, at the moment, if the only thing you've got is a hammer, everything looks like a nail, and that hammer is a prescription pad.

Evans: Somebody I was talking with said that they'd been all through years, and years, and years with a GP, and the final solution was a conversation with the community psychiatric nurse, who I'm told was absolutely fantastic, [**Bannister:** yes] and sent this person on an expert patient course. Wouldn't it have been lovely if that had happened much earlier?

Bannister: Yes. Doctors are trained to improve patients' lives, and that's why we're all doing it. Sometimes that means you say to the patient, 'I'm really sorry, I can't do anything more here, I need to get you to see somebody else.'

Sometimes it can be difficult to let a patient go and to admit that you can't do what you thought you might be able to do, and so some of the issues around when patients get referred are to do with how a doctor views their contract, if you will, or their responsibility to the patient, to hang on to them until they've done absolutely everything they can possibly think of, within their remit, or whether to go, 'hmm, this is not going how we want, let me get you to somebody else who may have a bigger armamentarium'. And that's not going to change. You're talking about changing human nature there.

But I think if you offer GPs a large armamentarium of appropriate therapeutic options for chronic pain, then they will inevitably begin to use them. It won't happen overnight, but as they learn that if you send somebody to a self-management training programme, if you send them to the right sort of physio, if you send them to an OT who understands chronic pain,

they're not continuously back in your surgery saying, 'this still really hurts doctor, can I have some more drugs?'

Jonathan Todman: I'm Doctor Jonathan Todman, I'm a clinical health psychologist in NHS Tayside.

Evans: And you work as part of the pain management team in Ninewells Hospital in Dundee?

Todman: I work as part of the clinical health psychology department and we take referrals from anywhere, but a large number of our referrals come from the pain services in Tayside.

Evans: So who refers to you?

Todman: At the moment referrals come from GPs, we get a lot of referrals from the pain clinic, whether that's from the anaesthetists or the physiotherapists, pain nurses, I sometimes get referrals from other psychologists, where issues have moved into health issues from mental health issues. So in principle anyone from the health service can refer to us.

Evans: So you work specifically in the chronic pain field?

Todman: I suppose the work that we do is, anyone with a physical health problem that is affecting their mental health, I suppose, would be one way of defining it. But chronic pain fits very squarely within that.

Evans: Explain how chronic pain fits into that?

Todman: Living with chronic pain, the amount of things that that means to the patients in terms of what they've had to lose as a result, what they have to cope with on a regular basis, those affect their mental health. So as a result of trying to deal with those aspects they often develop things like depression, or anxiety, or I suppose, alternatively, there are people with existing mental health problems, who then get a physical health problem like chronic pain and it complicates matters further, makes it harder to manage that mental health problem.

Evans: If somebody said I had a mental health problem, I feel I would get a mental health problem from being told I had a mental health problem.

Todman: Yeah, I kind of agree, so psychologists sort of deal with this in different ways and my approach is that it's a perfectly understandable response; it's a reaction to an abnormal situation, having to live with that amount of suffering on a daily basis, it would be strange to think that someone would have no effects on how they feel about the world or themselves.

So it's not that they have a diagnosis in addition to the mental health problems, I'm not a psychiatrist, there's no particular reason for me to give anyone a diagnosis, and I don't talk in those terms with patients. But there are similarities as well, so it's useful for me to be able to think it terms of depression or anxiety, those are often responses to stresses – whatever's going on in your life – it's the response to those stresses that tends to be similar. Whether it's pain or whether it's grief or some other factor from childhood or whatever it is, it's the response to that that ends up being quite familiar patterns of behaviour and of thoughts.

Evans: Can you explain that?

Todman: The thoughts that people have are the things that will determine what they feel like they're able to do, they'll determine what they feel they've lost and where it is they're hoping to go. So, I mean in some senses thoughts are important because they have all that power to affect what we're able to do.

And a lot of what we end up working on in psychology is trying to address those thoughts. I suppose one thing that we're trying to do though, is also to try and recognise that those are just thoughts. There will be reasons why that thought comes up, but partly because of the power that thought has it's given an awful lot of credence; it's given its own power because it feels so terrifying sometimes, or the feelings attached to it may make those thoughts more powerful. So sometimes what we might do is, we might try and work with patients on recognising that a thought doesn't need to be the same thing as a truth.

Evans: A thought is a thought and not an action.

Todman: Yeah, it's not an action, it's not the truth, it's not a reality, it's just a thought and we have a hundred thousand of those in a day. And it's worth remembering that this one we had that had all those responses in our body, made us feel awful and all that sort of thing, well that was just another one of those thoughts. It's just one that happened to have all these responses attached to it.

It's a part of these symptoms of depression and anxiety to give particular thoughts particular weight, so thoughts that something awful is going to happen feel more believable when you're feeling anxious than when you're not, perhaps [thoughts] that you're worthless, or you failed are given more believability when you're feeling sad or depressed.

Helping patients understand that that's a part of what's going on, that these thoughts have been given power to effect what we're able to do sometimes helps them reduce that power, whether just by doing the thing anyway, recognising that they are thoughts, or by giving them ways of taking the thoughts on a little bit, checking them out and seeing whether they stand

up to scrutiny. I'm describing sort of two different therapeutic approaches there, and I might do one or other with different patients, but that's a part of the process.

Evans: You mentioned earlier that you see people with chronic pain who have become depressed, if you like, but you also mentioned that you see people with mental health problems who develop chronic pain through that?

Todman: I wouldn't say people develop chronic pain as a result of having mental health problems, but I suppose there's an overlap in these two groups, there are people out there who've for a long time suffered with depression and anxiety, obsessive compulsive disorder or post traumatic stress disorder, all sorts of things that we have diagnoses for, who may have seen other psychologists or psychiatrists in the past. And when they get this new thing happening in their life, they need to find a way of integrating it, of understanding it on top of everything else that's going on. They may have been coping quite well with their life up until the point that they had this physical health problem, but they now have this new problem on top of it, that they have to adjust to.

A lot of what we do is really about that process of adjusting to something, and whether or not someone's had mental health problems in the past, or has them now, this is something that they need to integrate into themselves – find a way of remaining themselves despite having pain.

Evans: So it's people who develop chronic pain and it's just another weight on their shoulders?

Todman: I guess that's a way of thinking of it. I mean the way I often see people with physical health problems in general is that we have to give them similar coping strategies that we have to give people with depression and anxiety, or OCD or whatever. But we need to give them even more of it; they need to be amazing copers in order to cope with all the things that are going on. And it's always a source of amazement to me that people are able to cope so well – I see examples every week of people who have to cope with an unbelievable amount to pain, as well as everything else that's going in their life that the rest of us struggle with, and yet manage to find some meaning in their lives to feel like they're moving forward.

How you tell that is different with different people and their different ways of looking at it – there's a whole psychological therapy now, acceptance and commitment therapy, that has as one of its strands an attempt to move towards the valued areas of your life. And when you see people start to do that in their own way, then the days have meaning to them, they're not

able to do everything they once were, they've come to terms with that, accepted their limitations but aren't willing to say that they're not going to move towards the things that matter to them, they're not going to give their life to the pain, they're going to say, 'how do I still move forward in spite of this pain?'

Evans: I've been looking at the posters in the waiting room of your clinic here in Ninewells Hospital in Dundee, and there are a lot of posters, are they self-help or self-management?

Bannister: They're self-management: the important thing to do is to learn what you can do by yourself, or within yourself with your own resources, to manage your pain better. I have a bit of an issue with the word self-help because there are self-help books by the thousand out there, and as one of my colleagues in another discipline once said, 'self-help books tend to help one person, and that's the author.' That's a very, very, very broad brush and I'm not, and I'm obviously not tarring everybody with that same one, I don't know, it's just that self-help just seems a bit frilly and a little bit...

Evans: It also implies that the patient, the person buying the book is doing something wrong.

Bannister: Exactly, and they're not. In the case of self management for pain, it's not that you're doing something wrong, it's the case that you could do something better, and different. And different and better is a really important approach in pain management and pain self-management in particular.

We work very closely with a group called Pain Association Scotland, and we both contribute to a six-week intensive course where patients go for half a day over six weeks. And also we discuss the progress of the services with Pain Association, and also they have monthly groups that patients go to for top up and support. The number of times that patients' lives are completely turned around by these self-management approaches is remarkable. Equally remarkable is what appears to be a response from a lot of patients who go in thinking, 'this is nonsense, this is all fluffy, how can this possible help', and then by about week three the light bulb goes on and they go, 'this makes so much sense. I had never realised how much sense this makes, and I'd never realised how much I can do this'.

So we have people who, with Pain Association's help, are going back to work. Not everybody, but the vast majority of people experience an improvement in their quality of life as a result of these programmes.

Evans: I can vouch for that. How do you get that message across to people who don't know that?

Bannister: It's difficult. It's part of the process of acceptance of change. We've all come across these circles where you see people who are ready to roll, they're ready to change, there's a contemplative phase where they're thinking of making that change, people who are pre-contemplative, they're just not quite there yet and people who are just not interested.

I think one of our jobs as 'experts' in pain medicine and in treating and managing pain, is helping people around that circle to the point where they can accept that this makes sense. And of course one of the things that is really important for a patient to realise is that doing self-management is part of the whole approach of what we do in pain clinic – it's not a separate or a hand off, or an annex to us. It makes enormous sense integrated into the way we work. And so if a patient is learning self management at the same time as we're optimising their medications or perhaps doing some interventions, it makes the whole system work much more powerfully, much more synergistically.

Evans: That's Dr Jonathan Bannister, who leads the NHS Tayside pain team, at Ninewells Hospital Dundee.

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I'll leave the last words to Lynn Sheridan, Jonathan Todman and Jonathan Bannister.

Bannister: Those patients who take control of their direction of travel do much better than patients who are very passive.

Todman: It's a lovely feeling to feel like you're progressing and you've found something that gets you out of bed in the morning, and gets you going to bed at night thinking that was worth doing, what's next tomorrow. That's the stage I want to get the patients to.

Sheridan: If a patient comes in and says that they have gained some help from what I've given them, or a patient that has done exactly as I've asked and has noticed the benefit of that, it certainly makes me smile very, very brightly.

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