

Airing Pain Programme 45: Helping us to help ourselves

Empowering patients from GP's surgery to pain management programme.

Healthcare professionals and people with pain need to work together to manage chronic pain conditions, but how is this achieved in practice? Paul Evans speaks to a GP, physiotherapist and clinical psychologist to find out more. We begin by hearing from, GP and pain specialist, Neville McMullan about his work with Ulster Hospital to improve access to pain management programmes by bringing them out of the hospital and into the community and giving people the skills to manage their own pain. Dr McMullan stresses the importance of getting patients out of a cycle of inactivity and physical deterioration.

This is where physiotherapy comes in as we hear from Ashley Montgomery, a physiotherapist at Ulster Hospital. Montgomery describes how understanding the reality of chronic pain, being believed and getting the balance between rest and activity right can give people the confidence to take the first steps towards self-managing their condition.

Consultant Clinical Psychologist Jenny Maguire explains how acceptance and commitment therapy (ACT) builds upon CBT (cognitive behavioural therapy) to help people adjust to living with pain as a long-term condition.

Paul Evans: I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living in pain. This edition has funded by the Big Lottery Fund's 'Awards for All' programme in Northern Ireland.

Dr Neville McMullan: We've been criticised, whether rightly or wrongly, that 'My previous GP only did this, and only gave me painkillers and only did X, Y and Z or the dose of the painkiller was increased.' That's not necessarily the right way to manage pain appropriately and we need to get the message across to the patient that the way to manage your pain is not always to go up to next dose of painkiller or that stronger painkiller, but it's really to assess their pain fully and then to educate them that there may well be more than just the pain involved in their experience of the pain.

Ashley Montgomery: A lot of people come and they ask, 'What is wrong with me? How long is it going to take to get better and what can you do?' And there's very few people that actually say to us, 'What can I do?'

Evans: In this edition of *Airing Pain* we're looking at how pain cannot be dealt with in isolation; how pain management professionals can be key to helping us help ourselves. And how a pilot scheme in Belfast could make pain management programmes more accessible. We'll start at the doctors' surgery, which is more than likely the starting point for most of us when chronic pain hits. Now a GP with a special interest provides additional services while still working within the community so, for instance, your local health centre may have GPs with special interests in diabetes, epilepsy, headache, cardiology or, if you're really lucky, pain management.

Dr Neville McMullan is one of just two such GPs in Northern Ireland. He works out of Cherry Valley surgery in Belfast, but also with the pain management team in the Ulster Hospital.

McMullan: I've been involved with the Ulster Hospital for the last 3–4 years. I do a weekly clinic there every Wednesday and I was brought in initially to try and improve the very long review times that a lot of these patients were experiencing. They had their initial consultation and then it could've been upwards on 3 years before they had their review with the pain clinic, and that's an unacceptable time limit. So, along with myself and the staff over the last 3 years, within about 9 months we had that down to about a 6-month review.

The problem with chronic pain patients is that there's no cure and I always try and compare it with the diabetes model: there's no cure for diabetes but we have to try and manage them as best we can. So these patients do need to be reviewed and again, we can argue about what the best setting is to review these patients – they don't all need to be done in a hospital setting. But you know, your goal for a number – but not all patients, this doesn't hold true for every single pain patient – would be to give the patient the tools to manage their condition themselves, as best as possible, and can dip in and out of some specialist resources if they need to in the future. But ideally, they would be given the empowerment and the tools to manage their pain rather than just getting more and more cocodamol from their GP.

Evans: What sort of tools would you give them?

McMullan: We actually have a thing called the 'pain tool kit' which is a lovely wee handbook that is written in very simple language that they can use. It talks about very basic concepts of pain management, which they can manage themselves whether it's through pacing and goal-setting and setting themselves realistic achievable targets. It talks about physical activity and how important it is to keep things moving and keep things mobile. It's the old

adage: 'If you don't use, you lose'. We would use physiotherapists quite a lot through the Ulster Hospital to encourage patients to break through this chronic pain cycle where they get into this chronic misuse of the limbs or whatever it may be, and the muscles then waste away and they don't have any support for their spine or whatever the pain may be.

Evans: Dr Neville McMullan, GP with a special interest in pain management. Ashley Montgomery is a physiotherapist at the Ulster Hospital. She works with its pain management programme led by consultant clinical psychologist Jenny McGuire

Jenny McGuire: The pain management programme in the Ulster is an 8-week grid-based programme; it's 3 hours every week over 8 weeks, and it's multidisciplinary so I work into it, Ashley works into it from the physiotherapy end of things, and one of the pain consultants works into it as well from the medical end of things. So it's a multidisciplinary treatment programme based on acceptance and commitment therapy.

Evans: Acceptance and commitment therapy?

McGuire: Acceptance and commitment therapy is one of the newer third wave cognitive therapies so it has sort of built, if you like, on the foundations that were there in traditional CBT, and what we found is that this type of therapy can have better outcomes and work better with long-term conditions.

Evans: Now CBT, cognitive behavioral therapy, these are talking therapies but if we're in pain, we don't need to talk about it, we need it fixed.

McGuire: I think in an ideal world if it was that straightforward, that's exactly what would happen, but I think as you probably know Paul, from your own experience, pain is a very, very complex thing to live with. It's not just the physical component of pain: pain impacts on you emotionally; it impacts on you psychologically; it impacts on the choices that you make in your life; it impacts on the reality of what you can and can't do in your life. So pain is not just a physical experience. So, if you consider all of that, then clinical psychology has a lot to bring when you think about living with a chronic condition like pain, like chronic pain.

Evans: But I've said this many times over, I'm probably boring people to death with this: when you feel low and as you say incredibly depressed and the pain is doing all these other

things, the last thing you want to be told is to see a psychologist because we're not mad; we're perfectly normal people but we're in pain.

McGuire: I think that's one of the things clinical psychology comes up against in chronic pain: sometimes the assumptions that are there about psychology and as soon as psychology is mentioned, I know we've had people in our programmes that have said to us when they're sitting there in the consulting room and the pain consultant says, 'Maybe you should think about having a talk with our clinical psychologist.' The automatic assumption is, 'Is he trying to say this pain is all in my mind? Do they think I'm making this up?' It's almost like their pain experience is invalidated in some way and, actually, that couldn't be further from the truth of what it is. I think there is a recognition now, and if you look at most of the pain services across the UK, there will be clinical psychology attached to them, that this is a long-term condition that is very, very difficult to live with and it spills out into different types of areas in your life: it impacts on your self-esteem; it impacts on relationships; it impacts, as you've said, on your mood, on your functioning. So it makes sense that there would be a clinical psychologist involved in your care as part of a multidisciplinary team.

Evans: Many people as they start their pain journey, they will not be seeing you at the very beginning. In fact, it's very, very late in the pain journey.

McGuire: That's something that we are very aware of and it's something we do talk about as a team. By the time a person gets to a pain clinic – and the gateway to our pain management programme is through the pain clinic so it's not widely accessible – and by the time people sometimes get to the pain clinic, they maybe try different medications for a while or there's other investigations to be done before there is a clear diagnosis of chronic pain or a condition with chronic pain and it's then that the pain management programme is talked about. So it is late in the journey and I think that's something that comes back to maybe resources and where certain healthcare professionals are being placed in the pathway of care for chronic pain. I certainly think in our team, the nursing staff and the doctors are more and more now having that conversation about self-management and about the pain management programme earlier, even though the referral might not happen until other investigations and things like that are done. But I do think overall it needs to be moved earlier in a person's experience of pain.

Evans: Ashley, you're a physiotherapist. Are people sent to see you too late in their pain journey?

Montgomery: I work in a service that is an acute service, so I work in a hospital site: so I would see people very early on in their journey, in other words: people directly from the emergency department, directly from orthopaedics. Then the other side of our service is people who come along with chronic pain conditions and that's via the pain clinic or through the rheumatology service. So I see two types of patient groups: I see the acute presentations and also I see people who are already on the pain journey, who are already experiencing chronic pain over a long period of time, and they're very different groups of patients. And my management of that patient and the care of that patient is very different.

Evans: Tell me if I'm wrong, but I suppose the difference being a physiotherapist with somebody with acute pain is that you're helping them get better, whereas somebody with chronic pain, you're helping them just manage it?

Montgomery: Yeah, if somebody was to come to me from the emergency department after having sprained their ankle, I'm there to help them to get better. Somebody that comes through the pain service that has been round many services probably by that stage and they've been diagnosed with a chronic pain condition, whether it be a rheumatology-based condition or fibromyalgia or chronic low-back pain, it's a very different management of that condition and the journey for that patient is very different accordingly. And my approach would be very different because it's not about curing, it's not that biomedical 'motto' where you're going to make them better, it's more about helping them to understand their pain and introducing self-management strategies and tools to help them on that journey.

Evans: What sort of self-management strategy tools would you introduce?

Montgomery: I think a lot of people come, hopefully you'll agree Jenny, and they ask, 'What is wrong with me? How long is it going to take to get better and what can you do?' And there's very few people that actually say to us, 'What can I do?' I actually introduce it that way: 'Well, this is my understanding of your condition, how your presenting, this is what I can do and this is what I think we should proceed with in terms of self-management.' In self-management, I think there's different aspects to it – certainly people actually understanding what chronic pain is, understanding that it's not in their head, that's a really real experience for them and that their pain is real is very important. I think also, not just that understanding but the fact that somebody can actually understand and believe them that they actually *are* experiencing pain – that's very important in terms of them accepting their own condition. Then there's different aspects in terms of activity: pacing. Physios have got a reputation I

suppose in terms of 'Get people with pain moving; they'll feel better for it.' [Laughs] But I come from a more balanced approach in terms of the balance between rest and activity – it's important with patients that are experiencing chronic pain.

The other thing is, with self-management, it's not just the understanding, but it's actually the patient learning to accept where they're at. It's not a sign of defeat, it's not them giving in, 'Now, OK. I've got this condition.' It's actually the start of a process that helps them live with their pain. That's why we follow the ACT principles because, for them to actually commit to that and start to make changes and to make adjustments, that's the first step. That's really, really important and whether that be in relation to physical activity or whether that be in relation to emotions or feelings or fears, it encompasses both of those.

Evans: ACT is acceptance and commitment therapy, we've talked a little bit about accepting it, but how much of a barrier is that to accept something... .

Montgomery: That you don't want?

Evans: Or that we think that the doctors are there to make us better, accepting something that is making your life worse?

Montgomery: I think it comes back to what acceptance means and I think sometimes acceptance gets confused with resignation, putting up with, and in ACT acceptance is not that. Acceptance is more around how you make room for this change that has come into your life. You don't have to like it, you don't have to want it – if somebody came along with a magic wand and said, 'We can get rid of this', you can absolutely say, 'Yes please, I'll take it.' But it is about making room, I suppose, for some experiences in your life that are unwanted and unasked for. Sometimes those are negative things and sometimes they're positive things and it's about making room for all of those experiences, whether you see them as positive or whether you see them as negative. And it *is* very difficult because when you're in pain, your normal response is to do something to make it stop and if you can't do that by yourself, you seek medical input. And we're in a culture, I suppose, where there's an expectation that the doctors will at some point find something to fix us, to ease it or to make it go away. I think it's a very hard reality, sometimes, with chronic pain particularly when people sometimes have seen so many different doctors and they've tried so many different medications and the pain is still there. Sometimes they're also living with quite bad side effects from the medication that they're on.

I think it can be a real crossroads really with chronic pain to get to a point where you realise that the doctor may not, at this moment in time, the doctor may not be able to do anything more. Different people get to that point at different stages and some people may never get to that point – everybody's journey is different and I suppose where we would work from is with the acceptance end of it. It's about making room for this thing in your life that you didn't ask for and you don't want and it's having quite a lot of impact on your quality of life – on working life, on finances and all that kind of thing – but how can you make room for it and try and live your life alongside it. So as well as accepting and making room for this condition that has come into your life, it's also about reconnecting with your values, with those things that are close to your heart. Very often we find with chronic pain, in your effort to try and manage the pain or to try and reduce the pain or try to have some control over the pain, all of a sudden the things that really matter to you in life are the things that start getting cut out: so you don't see your friends, you become less active, you may be saying no to things that you could do just in case it would be a bad pain day or it might flare things up, so you start actually disconnecting from things that are precious to you. So ACT is about both of those things: it is about making room for something that maybe is difficult to live with, exploring your relationship with your pain, but also reconnecting to those things that actually matter to you, with your values.

Evans: In those conditions, pain is ruling your life, pain is managing your life – it's moving away from that so your life is managing the pain?

Montgomery: That your life is living with the pain; there will be times where the pain feels more dominant. So if you're in the middle of a flare-up, the reality of that is you have very minimal choice if you're in the middle of flare-up pain but if you're maybe at other points, we talk about 'wiggle room'. Your wiggle room might increase on other days compared to the amount you might have on flare-up days, so it's increasing your flexibility and living with the pain so that day-in, day-out, depending on how your pain is, you can still make choices that are in the direction of your values, that are in the direction of what actually really matters to you, rather than it being an 'either or' – 'I either have to do the things that really matter to me or I'm in pain and I can't.' It's not, it's a 'both and...'

Evans: One of the things that must go along with that – you mentioned 'pacing'. 'Boom and bust' is an expression that everybody with chronic pain will have experienced?

McGuire: Yes we often touch on this. We discuss it very openly in the group as well. I very much come from an understanding where people with chronic pain, it literally impacts not just on everyday life in terms of their emotions and the psychology side of it, I suppose, but also physically. In other words, when people withdraw they become less physical in terms of they don't go out walking, they don't socialise – even the simplest things like breathing can be affected by their chronic pain. And posture because they're sitting down more, they're afraid to move. Things like balance – some people become more dependent on walking aids because as they withdraw, as they become more sedentary, and because their pain has dictated that to them, all the time what's happening is they're becoming more de-conditioned.

But some theories would say, 'Right, get people going, get them moving, get the adrenaline going, get the serotonin released, it'll make them feel better, it'll give them confidence, it'll impact on their pain and that will be well and good'. And that is true to some extent, but a lot of people with chronic pain, particularly by the time they've come along to the Pain Management Programme, I think it would be very unprofessional of me to suddenly get people up and moving when they haven't moved in maybe 5–10 years and they're still on a zimmer rollator and I'm expecting them to do step-ups. So I introduce very much the basics; I call them my building blocks and we talk about breathing and about improving their breathing pattern, we talk about posture, we talk about balance, we introduce that, we allow them to self-assess that for themselves. It's not about coming along and doing lots of exercise, but it's introducing these basic tools or these basic aspects of physical activity first of all, and then hopefully that allows people to get more confidence and get the basics right. There's no point in me encouraging people to go for a walk if they find that even going up a few steps is difficult because their balance reactions are down. So it's very much, rather than 'boom or bust', it's very much 'I'd like to get the basics right', building that and allow people to gain confidence in their own ability and then introduce other strategies like the benefits of more physical work like going out walking, like going swimming, because that's where the other aspects of, I suppose whether you call it pain control or the 'pain gate theory' come in, and how moving can impact on your pain experience as well as the psychological talking therapies.

Evans: Well that's easy, that's absolutely settled now, we all know how to do it. The problem is that when somebody with chronic pain feels well, they want to do it all today. How do you break that barrier?

McGuire: We actually spend quite a long session talking about flare-ups and we talk about the impact of a flare-up. That impact can be very emotional and it can be very physical. We strip it right back and oftentimes people with a flare-up can get warning signs and also triggers, so it's actually taking it back and allowing people to become more familiar with those warning signs and start to read them and take action, because, like you said, a lot of people with chronic pain think, 'Oh this is a good day, I *have* to do this, I *have* to get the house cleaned or I *have* to go meet somebody' and then they suffer for it for another 2 weeks. So it's actually talking about getting that balance again. It's actually being more aware of what your body is telling you, but also then putting it into practice so that instead of, yes maybe that day you get a sense of achievement, you feel good for it and maybe someone says to you, 'Well that's great, you got that all done.' But then for 2 weeks you're off kilter and you feel miserable and you're sore and you can't do anything then. It's about giving people the tools to recognise that, but also talking them through in terms of those management strategies and that's in relation to that commitment to actually take onboard what they're telling themselves. Patients are the experts in this; they recognise very familiar patterns, particularly in groups, they're very quick at saying, 'That's me, I can understand that and I do exactly the same.' And they actually come up with very good coping mechanisms and coping strategies and give very good examples. And some of them actually challenge each other in terms of, 'Well, why *did* you do that? You could do it this way or do it that way'. So that's not just from a physio head, that's from a psychological head in terms of being, you know, looking at it and stripping it back and looking at how it impacts you, not just physically but emotionally as well.

Montgomery: I think sometimes it is about very much handing choice back to people that are living with the condition and, as you're saying, if you have a good day then the pressure's on to do everything in that good day and then inadvertently you do too much, your pain flares up and you're out of action for whatever length of time. And sometime it's about handing that back as a pattern and saying, 'How much does that way of doing things fit with your values?' Yes, on that one day you might get all of your ironing done and you get your house cleaned and you get your...whatever tidied out but for the rest of the 2 weeks you're too sore to see your friends, you're too sore to play with your children. So think about how you're managing and what way of managing fits best with what actually matters to you.

Evans: But you see, one of my strategies – you can tell me whether I'm right or wrong – is that I will do what I want to. I will take the hit just for that afternoon climbing a mountain, or something like that.

Montgomery: And is that something that's close to you heart, that getting out and climbing the mountain and actually going, 'Yes I've done that. I know I'll pay for it but it's something that's really precious to me.' Is that a strong value?

Evans: Yes, it is.

Montgomery: And that's, again that's some of the choices that you make and we've had examples in our group where people will sometimes do things – maybe it's an activity, maybe it's something with children – where they know they are going to be very, very sore after it but they will do it because the value and the importance of that in their life overrides what the pain is telling them about the negative consequences of doing it. And it's really important to hold on to stuff like that because the pain will still be there. What you've just talked about there, that's the stuff that makes life worth living.

Evans: How much pain does one need to be in to come to a pain management programme?

Montgomery: We don't put a level on it. As far as we're concerned, your pain is whatever you tell us it is so we very much come from, as Ashley said, you are the expert in your pain. We might have ways of thinking about your relationship with pain or provide a space in the programme to maybe critically evaluate and reflect on that a bit, and we certainly have hints and tips around what you can do to get going again, but you're the expert in your own pain so you take the parts that fit for you, that have meaning for you. It's not prescriptive; it's very much led by people's own pain knowledge and pain experience.

McGuire: Yeah, and it's not about the level of pain or the frequency of pain, it's more how that person is feeling the impact of that pain on their life, so it's not just that unpleasant physical experience, but it's that unpleasant emotional experience they're having alongside that. And when that's starting to impact on their everyday life that's when we feel the pain management programme can be beneficial for the patient, so it's not about how severe it is or how frequent it is, it's more the impact that pain is having on that person's day-to-day life.

Evans: Physiotherapist Ashley Montgomery and consultant clinical psychologist Jenny McGuire at the Ulster Hospital. I'll just remind you that whilst we in Pain Concern believe the information and opinions on **Airing Pain** are accurate and sound, based on the best judgments available, you should always consult *your* health professional on any matter relating to *your* health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf. Don't forget that you can still download all the previous editions of **Airing Pain** or obtain CD copies direct from Pain Concern. If you'd like to put a question to Pain Concern's panel of experts or just make a comment about these programmes then please do so via our blog, message board, email, Facebook, Twitter or pen and paper. All the contact details are at our website which is painconcern.org.uk.

Now, back to what I said earlier about GPs with special interests able to work within the community. Dr Neville McMullan with his special interest in pain management and links with the Ulster Hospital pain team has his own view on bringing pain management services closer to the people who need them.

McMullan: Of the patients I would see regularly in the hospital setting, and certainly the review clinics, they could be managed equally well in a community setting and with multidisciplinary input, which would probably appeal more to the patient rather than having to trek up and find parking at the hospital and the hassle of getting an appointment and so on. So if we could do it in a more local and neutral setting, a neutral venue with appropriate people seeing the patients, then my feeling would be this would be the right way to go.

Evans: What are you talking about? Church halls? Leisure centres? Sport centres?

McMullan: I'd have no problems with any of those! Neutral territory means it doesn't have to be in a healthcare setting. We are certainly keen to push the physical activity side of things for health prevention in lots of other disease areas: where there's cardiovascular or diabetes or obesity, so certainly a leisure centre would be an ideal setting to run clinics from. Why not?

Evans: How is that progressing?

McMullan: There are pain management programmes in place within the Ulster Hospital. There are some pilots that GPs are now able to refer into which are hopefully going to

develop into more permanent programmes, but we'll have to wait and see on that. There are other pain management programmes running in the Belfast Trust as well and they are multidisciplinary in nature too, but they are currently in a hospital setting and not in the community. So there's work to be done; there's definitely scope for those clinics to be built upon or developed. One of my other big, burning issues is to get nearly a public health campaign going about educating – certainly in the musculoskeletal field – of the need for patients to be physically active. We touched upon that earlier, that they need to be engaging in a form of activity to keep their muscles and joints working. But there's a real need to educate healthcare professionals. I think one of the worst things that can happen to any patient is to go along to their GP and their pain isn't taken seriously. I was at a meeting recently with some patients with endometriosis and one of the biggest problems with seeing their GP was that they felt they weren't being believed. And I think that's very important that the patient's word is taken as this is their pain and this is how the pain affects them. I think if they can be listened to and believed and then we can come to some sort of way to manage their pain better, then patients will get a lot more out of that rather than being dismissed with a stronger or an alternative painkiller.

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