

## ***Airing Pain Programme 26: Transforming pain services: joining up pain management and involving the patient***

***The health professionals working to improve pain management, and the importance of getting patients more involved.***

*The relationship between doctor and patient is crucial in managing pain. In this programme we look at how the British Pain Society's newly launched Pain Patient Pathways Project should improve the way health professionals manage chronic pain conditions. We'll hear from a patient about her varied experiences with health professionals and from doctors involved with treating pain about the importance of patients getting involved in the treatment of their own condition.*

**Paul Evans:** Hello. I'm Paul Evans and welcome to **Airing Pain**, the programme brought to you by Pain Concern, the UK charity that provides information and support for those of us living with pain. More information on fundraising efforts, is available on the JustGiving page on our website which is: [painconcern.org.uk](http://painconcern.org.uk).

**Douglas Smallwood:** I think if we can map out what the care that a person with a condition experiencing pain should receive, if we can map that out and get an agreement to it, then we can start to hold clinicians the system manages to account for delivering it.

**Evans:** In this edition of **Airing Pain**, we will be looking at how the British Pain Society's Pain Patient Pathways project, should improve the way health professionals manage chronic pain conditions and, not I hope unconnected with this, we will also look at the importance of that crucial relationship between doctor and patient. What happens when it goes well? And what happens when it breaks down?

Jean Smith has numerous health-related conditions, including, chronic back pain and depression. She was not confident of being able to speak to me by herself, so Jeff Williams, a close friend and support for many years, joined us.

**Jean Smith:** The pain can bring on the depression. So when you recognise the signs, I am not saying I can do a lot about it, but at least I know in a couple of days' time it will ease.

**Evans:** When you said you 'felt the signs of depression coming over you', what does that feel like?

**Smith:** [Sigh] You are cheesed off, you cannot focus on a lot of things, when I am bad I sleep a lot, I do not go to the doctors unless I have got too.

**Jeff Williams:** When you were seeing them, if you went to see the doctor for your pain, what would the doctor tell you?

**Smith:** 'Go and see your psychiatrist.'

**Williams:** And when you went to see your psychiatrist what did...

**Smith:** 'Go and see your GP.' They tend to push you from one to the other when you have got double diagnosis.

**Williams:** So, in other words, they never actually then give you anything...

**Smith:** And I have one doctor...oh she is lovely! She sits there – 'How are you today Jean?' And I feel like saying 'I am not a little 5-year-old, you know I am me. I might suffer with depression and mental health problems, but, you know, I am still compos mentis!'

**Evans:** Now, we cannot comment on individual cases, indeed, you will know that we always give these words of caution, that whilst we 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. But I have to wonder, how many people as in Jean Smith's experience, feel that their health professional does not appreciate their circumstances.

**Smith:** My Social worker has told me that I am not a very good patient, because whenever the doctor asks – or the psychiatrist – 'How are you?' 'I am fine.' He said 'you do not tell people what you are like'. I said 'well, people do not want to hear what you are like, people do not want to hear you moaning'.

**Williams:** Are the doctors very friendly? Do they always greet you in 'oh yes, have not seen you for a while' or you know try to build up a conversation with you, to find out what is the matter?

**Smith:** I did see a locum last winter – and I suffer with asthma and I had to have antibiotics – and this locum said to me ‘you old people are all the same’.

I said ‘What do you mean?’

‘Do not have enough heat in, in the winter, that’s what causes it.’

I went back, in May I think it was, in the spring anyway and who was there but the same locum and he said ‘you have got an infection again’.

So I said ‘well, tell me now then doctor, I said, I do not need heating now, what is causing it now then?’ I said ‘It cannot be a cold house’.

**Evans:** How did you feel when a GP tells you basically, it is your fault?

**Smith:** [sigh] Oh, none of us like being told that. I tried to take it on board and think about it, and work out whether they are right or not, and if they are I try and do something about it.

**Evans:** But you say you do not go to the doctors enough...

**Smith:** Because all they ever do is give you painkillers.... I live on painkillers. I have always maintained that there is help out there for people who are druggies; there is help out there for people who are alcoholics and there is help out there for a lot of other things – smoking; but there is nothing out there that gives you any help or says anything about patients who have been addicted on prescribed drugs. I have asked doctors in the past, ‘Are these addictive?’

‘No.’

I had one tablet off the doctor and I said ‘I am sure I have put on weight since these tablets’.

‘Oh rubbish’ he said.

I said ‘I do not think so’.

That passed, I asked another doctor, he was honest enough to tell me ‘yes, you put three or four stone on when you take this medication’, he said.

**Evans:** Jean Smith has shown how a breakdown in communication with a healthcare professional can lead to a lack of confidence and in her case a feeling of worthlessness. The patient’s opinion and input may have counted for nothing in years gone by, but in the broader scheme of things, a lot of progress is being made.

Now, the British Pain Society is a national organisation. In fact, it is the largest UK voluntary organisation for healthcare professionals working in pain management. So, where does the patient's voice fit into this professional organisation? Well, Douglas Smallwood is Chair of its Patient Liaison Committee and Pain Concern's Christine Johnson spoke to him at their voluntary sector seminar in London.

**Douglas Smallwood:** A number of years ago, the professional membership decided that it wanted to make sure that the voice of the patient was heard within the work of the society, and therefore a decision was made to set up a patient liaison committee. There is currently approximately 10 of us, that is seven people with chronic pain and three healthcare professionals, so it is a committee of both patients and professionals, which I think is *very* helpful.

We meet about six times in a year and our objective is to feed into the work of the professional membership of the society. So, for example, there is a series of special interest groups, dealing with different types of pain that the professionals join and one of our objectives is to make sure that a member of our committee is also present at the meetings of the special interest groups, so the views of patients can be built into their work. Because I chair the committee, I go to meetings of the Council of the British Pain Society and can feed in the patient view there. The one point I would emphasise is that there is no... we are not here to develop the British Pain Society from a professional organisation, to a patient organisation. The Pain Society is a professional organisation and the aim is to make sure that the professionals have the benefit of the experience, the knowledge and the views of patients.

Professional-only organisations do great things, patient organisations do great things. I think that the great potential of an organisation that makes sure the patient voice is there, as well as the professional, is that sitting together, in my opinion, more can be achieved. So, if you are trying to influence government, in my experience, there is nothing more powerful than to have the patient talking to a government minister or the Chief Executive of a PCT about their experience of the service, what they experience, what they need and to what extent the service matches up to that. Nothing more powerful than that.

However, to move politicians and to move managers you need more than emotion and experience: you need logic, you need professional understanding of clinical matters and you need to put the two together. So, in my experience, if you are trying to change what services are provided and how they are provided, to make a compelling case to the decision makers,

you need a mixture of the patient voice, combined with the knowledge, the expertise of the professional.

**Evans:** Douglas Smallwood, Chair of the British Pain Society's Patient Liaison Committee. Now, the theme of its annual Voluntary Sector Seminar was 'Pathways for pain management: giving them life'. This refers to the Pain Patient Pathways project, which evolved from the Chief Medical Officers' report of 2008, highlighting chronic pain as a clinical priority and the need for a consensus on the best practice care pathways. So, in 2011, the British Pain Society, set up a working group to produce pain patient pathway mapping guidelines.

Dr Martin Johnson, is the Royal College of GP's UK Champion in Chronic Pain and he is on the Executive Committee for the Pain Patient Pathways.

**Dr Martin Johnson:** The British Pain Society has never had any pain pathways before. They have published leaflets on various aspects, but they realised to defend pain medicine within the context of UK spending cuts, that they had to develop some national pathways, that anybody in terms of clinicians or commissioners or patients can say that these are the overall general pathways that we can follow.

There are five disease areas that we are looking at in terms of pain. There is going to be a general assessment principle, that means wherever a patient presents with chronic pain, these are going to be the basic things that you should do. Then there is one on neuropathic pain, which will partly incorporate the NICE Guidelines. There's going to be one on musculoskeletal pain, particularly what we call widespread pain which is similar to fibromyalgia. There is going to be quite a complex one on low back pain or spinal pain in general. And, finally, there is going to be one on pelvic pain from both males and females.

One of the things to do as well as publish them, there is going to be a whole implementation strategy. In fact, we have been sat in a meeting this morning with the patient group at the British Pain Society, talking about how we should try and implement some of these pathways going through primary care. So it will be a matter of publishing books, getting guidance within all the GP magazines, on radio shows like this, newsletters coming out from the British Pain Society or the Royal College, getting patients educated on it.

**Christine Johnson:** What are the benefits of having patient input, in developing the pathways? How did that work?

**Dr Johnson:** Right from the word go, when Richard Langford our president of the British Pain Society, set up this pathway group, he decided we should have – rightly so – patient input, so we get their experience of having a painful state. I know talking to some of the patients, it has been difficult sometimes when you start... and they are working as the only patient within a diverse group of healthcare professionals. Sometimes they can feel left out and I think we have had to change the way we have worked so that they are inclusive within those pathways so that we can get their experience. But actually, the most important part is not going to be in the actual development part – it is actually the getting it out there part and making sure they are used, that is where patient power, I hope, rules okay.

**Johnson:** And if a patient feels that their GP is not following their pathway, what can or should they do?

**Dr Johnson:** That is always an interesting question in any pathway. I think the important thing with pathways – and this is the experience with other pathways from other disciplines like respiratory – is that we need to get them locally implemented. So it will be taking the national framework, and saying ‘how do we adopt this locally?’ Which means you can then use the resources that exist within your local area, or make sure that you bid for the resources.

Patients are always individuals and there is going to be instances where the pathway might not be appropriate. This is going to be, I would hope, for 95 per cent of the patients with those particular areas it will be something that they can implement. But in terms of the question you asked me, what we were looking at this morning is ways to empower patients, so, effectively, we give them the information through a variety of sources, through various patient groups. So, if they feel that the information is not getting through to their GP, then they can actually ask their GP ‘is there something more appropriate?’ They will be hosted on the nationally available site Map of Medicine, and I believe patients do have access rights to that.

**Johnson:** And in terms of patient education, how did self-management inform the make-up of the pathways and the development?

**Dr Johnson:** There are several key components that are common to all the pathways. So, for example, medicines management is one of them, but the other major one is self-management. All the work coming out of groups such as Co-creating Health which is the big pilot happening with self-management shows that self-management works. And it particularly works when patients are supported by other members of the team.

And I think it is important for even clinicians to realise that self-management is something that can run alongside other forms of management. So even if you have got a patient that needs a spinal intervention, they still need to self-manage as well. So to the extent we may well have to develop a specific pathway to give more information about self-management. We have got people involved, such as Pete Moore from the Pain Toolkit, which means that patients should hopefully get information about that.

**Johnson:** And back to the education, how do you hope this will change pain education for health professionals?

**Dr Johnson:** That does link in with the implementation strategy. I am hoping that it will give the necessary information, because the pathways are, I hope, a very good balance between both evidence-based medicine and a pragmatic approach where the evidence doesn't exist. So it will give a framework for healthcare professionals to manage chronic pain which is one of the biggest issues that we deal with in medicine.

**Evans:** Dr Martin Johnson talking to Pain Concern's Christine Johnson at the British Pain Society's Patient Liaison Committee Annual Voluntary Seminar.

Here is Douglas Smallwood, Chair of the Patient Liaison Committee once again:

**Smallwood:** My personal experience as a person with a long term condition and some pain, is that I really want the services to be joined up, so that I see the right professional at the right time and in a convenient location and that is not my experience of the service. I think the pathways will assist with all those points.

There was a seminal report two or three years ago – wasn't there? – from the Department of Health chaired by Lord Darzi, and he had defined quality as having three components – quality of care: one was clinical outcomes; one was patient experience and the third was patient safety. So a high quality service achieves those three things.

I think if we can map out what the care that a person with a condition experiencing pain should receive, if we can map that out and get agreement to it, then we can start to hold clinicians, the system, managers to account for delivering it. When that isn't mapped out, it makes it rather more difficult for people to hold to account.

**Evans:** Now, Douglas Smallwood talked about his wish as a patient for a joined-up service.

Mark Ritchie is a GP in Swansea and he has a special interest in pain management.

**Mark Ritchie:** In Swansea we have very recently set up a pain service which is really in its infancy at the moment, but it has been trialed for almost a year now. And what we have done, is we have taken methods of examination on patients and methods on treating patients from pain services all around the country. We then combined that into a service which we are now putting forward. A part of this is what we call a multidisciplinary assessment, but it is more than just a multidisciplinary assessment, it leads onto multidisciplinary management and an overall holistic approach. So, multidisciplinary assessment means we are not only assessing the patient by a doctor on his own, we are using other disciplines. In this particular case we are using a physiotherapist and we are using a nurse trained in pain management and to a lesser or greater extent we use a psychologist as well.

So what do we do? Well, the patient comes before each of us in turn, there might be two of us together if our examinations overlap. They come to each of us in turn, in a roundabout way, so you might have three patients simultaneously, one for each of us, and then rotating. As a doctor or a physician, I first need to confirm my diagnosis or the diagnosis that has been put in front of me. I need to make sure that there aren't any what we call 'red flags' – things that mean this person could need immediate surgery or hospitalisation, or maybe underlying things that could point towards cancer, things like that, so my primary task is a medical one initially.

Once I have got through that little bit, which really is the first five or 10 minutes, we then move onto actually questioning the patient further: ask them how long this has been going on for; looking at the modalities of pain; the types of pain they have been feeling; then examining them and then the whole way through giving them feedback.

So, having done that, they will then move onto the physiotherapist. A physiotherapist is very much a musculoskeletal type assessment, but in this case, it is not just 'can you move your arms and legs?', it is functionally based. So, the physiotherapist will do things like getting them to walk backwards and forwards over a 10-metre strip for instance, just to see how fast they can do this task. Maybe lifting a ball, and placing it on top of a shelf up and down, up and down, to see how they function – are they able to do basic tasks? Because management here, is not necessarily going to be cure, it is going to be managing both their pain and their life, so they can get the best out of both.



Then they will move onto the nurse. The nurse will do a more psychosocial assessment, where they will look at their living situation: their spouse, their relationship with others, things like sex life comes into it and so on. All of this is then noted down as well.

Once that is finished, the three of us get together as a team for a few minutes, to discuss what we have found. And then we bring the patient in as the fourth member of the team. So, the patient is then drawn into that assessment, we discuss what we have found and ask the patient's comments on what we have found and we then develop a plan based on the patient's needs and what we have seen as his needs, as well as what he or she sees as needs. And then from there we can move forward into treatment.

**Evans:** So, having assessed the persons' needs and ability, what happens next?

**Ritchie:** Well, firstly, can I roll back a second before they are even being assessed. We have a triage system when the letters come in first from the different referrers. And at that stage a number of them will go straight back to the general practitioner. Maybe they haven't tried certain basic medications, maybe we have simply had a query from a GP as to where and how to proceed... we have got this far, where do we go?

We don't wipe them out of the service, we merely say could you try this for three months, and then, if not, send them into us. So that is the first part. Once they have actually been through the assessment team – they have been invited along to the assessment team, before they even arrive – we start to include them in this team work. So, we send them a number of questionnaires, we send them a catastrophizing scale, anxiety and depression score and a brief pain inventory. So, we send them these three questionnaires, so that they can actually put down on the paper where they feel they are. One of these scorers has got a little diagram of the human body on it, so they can actually draw on it, and show them where their pain is. So they have already involved at that stage.

Now they have been through this assessment process, where they have again been involved and now we come out of it – so where do we go from here? Some of them simply need advice, and they will get that advice, we will send that advice back to their general practitioner. We might immediately change a drug, if there is something obvious that needs doing and again, back to the GP. Some of them will need that and other things. So, a classic example, a minor change in medication, a referral to podiatry because the person is flat-footed and needs orthotics and a referral onto what we call a pain management programme.

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So not a curative service. If their pain was curable, they probably would not be coming to see us.

**Evans:** Should patients be asking for this service?

**Ritchie:** *Absolutely!* I think if they are at the limit of what their general practitioner is capable of managing, then I certainly think that they should have the right to request an ongoing referral. But I think they also have to balance that with the realisation that their GPs and their doctors are pretty well trained, and they need to move into that service when it is appropriate, not just on day one. So, this really is for people where we have passed the point of natural healing, normal healing, and there is still an ongoing problem.

And those are the patients we need to refer in. But at that stage, the sooner the better, because people who are not yet off work, people who are still working but maybe moving towards a situation where they might end up being off work, those are the patients we need to get sooner, rather than later – that in-between phase, if I can put it that way.

**Smith:** I went to a pain control clinic in Bronllys which was an offshoot from Saint Thomas' in London, and I found it *excellent*.

**Evans:** Well, just to remind you that ***Airing Pain*** featured that residential pain clinic in Bronllys in mid Wales (mentioned there by Jean Smith) last year. And you can download all editions of ***Airing Pain*** – and that particular programme is number five – from our website at [painconcern.org.uk](http://painconcern.org.uk).

**Smith:** You were assigned a physiotherapist each patient and they worked specifically to you and your problems. We agreed to disagree in the end. She wanted me to do certain things and I said 'No'. And I said 'It is my back, not yours'. I said 'I will do what I can'. So we still stayed friends! [laughs]

**Williams:** How were you after the course then?

**Smith:** Good for a while.

**Williams:** Did you have to keep up any exercises?

**Smith:** Well you were supposed to yes, did I?... Living on my own I need that incentive. I find with a lot of things these days, I need that little push, that incentive to do things. If I am in a class or with other people, I do them fine, but on my own I tend not to do them.

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**Evans:** Well is that not the same for most of us? That things like pain management programmes and I have done the expert patient programme... [**Smith:** I done that as well last year.] ...and you are fired up immediately, but the follow-up is the most important thing.

**Smith:** Well, I went to that last year and I found that *very* good. They had a relaxation CD, and we were given a book at the end of the course. And that relaxation CD is one of the best that I have ever heard.

**Evans:** Jean Smith. Later in the year I will be taking part in Arthritis Care's Challenging Pain Programme. That is for people with all sorts of chronic pain conditions not just for those with arthritis. I will report back to you on ***Airing Pain*** how I get on. But It does seem that self-management is a key element to living with chronic pain.

Kevin Geddes, is the Director of Self-management with the Long Term Conditions Alliance in Scotland.

**Kevin Geddes:** Self-management means different things to different people, but in essence it really is strategies and approaches that people take to managing their own condition, either themselves, or in partnership with their families, carers or with health professionals. Different ideas that people have about looking after themselves and getting involved in their own condition, really. Allowing them to get on and really enjoy the things that they want to do in their life [laughs] without focusing too much on the clinical aspects of their condition, really.

A lot of the work that we do is across different sectors: across the voluntary sector; across the NHS; across local authorities. But *really* at the heart of that there is always the experience of the people who live with long term conditions, or care for people in their family that live with long term conditions.

All the ideas and the approaches that we have been involved with so far, have come from people living with long term conditions themselves, who know best how to manage their condition and know best how to react to their body and know best who to ask for support when they need that. So, really, I guess that the message is the we really want people to get more involved and tell us what ideas are missing and what ideas would work best for them.

The key message is that people should get involved in the management of their own condition and really step up a little bit and see what they can do for themselves. It is not about being alone in that process, there is lots and lots of support that people can access: in

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the community, in the voluntary sector, in the health service and from the local authority, that can help them to live better lives. And I guess to help people feel in control of their conditions, so that their condition is not in control of them.

**Evans:** When I phoned you up last week and said that your name had been passed on to me and I should speak to you...

**Smith:** Yes...

**Evans:** I know and from when I arrived this morning, that you were petrified of speaking in front of a microphone, which is why you have brought your very good friend Jeff along with you to help you out...

**Smith:** And work colleague...

**Evans:** And work colleague.

**Smith:** Yes.

**Evans:** But you did say to me on the phone, 'well I need to be putting something back anyway'.

**Smith:** I used to help run a support group. I also worked voluntarily for about 10 years, in the mental health network, in the end [laughs].

**Williams:** Does helping in a support role, or voluntary sector or whatever it is, does that help you?

**Smith:** Yes, I suppose to give something back to the community, to give something back to other people who have been in similar positions. And you think you are the only one. You do not realise that there are other people out there who suffer the same, or even more than what you do.

**Evans:** We are coming to the end of this edition of ***Airing Pain***, so there is just time to remind you, that if you want to put a question to our panel of experts, or just make a comment about these programmes, then please do 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](http://painconcern.org.uk).

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I will leave you with Jean and her friend Jeff Williams to recall what happened when she became involved in teaching young disabled children to swim.

**Smith:** I did not feel any self-worth at the time and there was one incident where there were two swimming teachers there and they could not get this little girl to go in the pool. I sat and I talked to her and we played on the steps in the pool and then she came round the pool with me. It was such an achievement because the teachers had failed. [laughs] It was great. I did it for a few years.

**Williams:** A number of times you said you did not have any self-worth, did the children help with this?

**Smith:** Yes, because children don't judge you, adults do.

**Williams:** How do you know the children took to you, what did the children used to do?

**Smith:** [laughs] Tell me all their secrets!

**Williams:** How did they tell you their secrets?

**Smith:** Their mothers and fathers would come in and I would say 'well I know quite a bit about you!' [laughs] The kids will tell you all their secrets.

**Williams:** How did children used to take you?

**Smith:** They used to come over. Once I went into the pool, they would all come over and we would all toddle off to the Jacuzzi and have our daily con-flab! [laughs]

**Williams:** That made you feel a lot better?

**Smith:** Oh, it was *brilliant!*

## Contributors

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\* Dr Mark Ritchie, GP, Swansea

\* Kevin Geddes, Director of Self Management with the Long Term Conditions Alliance in Scotland

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