

Airing Pain Programme 43: Patient Involvement and Pain Management

Involving pain patients in health services and learning how to self-manage pain whilst working.

This programme was funded by the Big Lottery Fund's 'Awards For All' programme in Northern Ireland.

*In this edition of **Airing Pain**, Paul Evans travels to Northern Ireland to visit a patients' organisation, the Patient and Client Council. The Council provides patients with an independent voice in the health and social care system by involving those who live with chronic pain in the decision-making process and supporting patients who wish to make a complaint, with the overall aim of improving patient services in Northern Ireland.*

Louise Skelly, Head of Operations at the Council, describes her organisation's work promoting information and advice across the healthcare system and using patients' experiences, suggestions and stories to raise awareness of chronic pain. She highlights some of the advances and improvements that the Council has brought about in recent years.

Paul also speaks to pain patient and member of the Patient and Client Council's pain strategy group, Jay Flood Coleman, who shares his own personal experiences of chronic pain that has been complicated further by a series of health issues.

Board member of the Patient and Client Council, Rena Shepherd, who herself lives with chronic pain, contributes with her first-hand expertise and explains that with little adjustment on the part of employers, employees suffering from long-term pain conditions can still work full-time and be productive, with self-management pain courses proving very beneficial.

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

Louise Skelly: There's nothing as powerful as the patient's story. And what surprises is that people in the system don't always stop and listen to what are the real issues. They talk to their colleagues, they talk to other people, but sometimes they forget to talk to the people who actually use the service.

Evans: Not so very long ago, the idea of a patient being involved in his or her own pain management, or even having an opinion on it, would have been as likely as a flying pig. Doctor, as they say, or said, knows best. Attitudes for the most part have changed, but sometimes a catalogue of errors, be they clinical, administrative, or all to do with some policy change, compound to make a patient's experience of the National Health Service at best – stressful, at worst – catastrophic.

Who then will champion the lone voice? In this edition of *Airing Pain*, I'm looking at one such patients' organisation in Northern Ireland. The Patient and Client Council was set up in 2009 as a powerful and independent voice for people. Its Head of Operations is Louise Skelly.

Skelly: The Patient and Client Council is an independent body which is actually set up to be the independent voice of patients and service users in Health and Social Care, and our independence lies in that voice, and having that evidence base, and what are the issues for people. And we work with the Health and Social Care system to try to bring about improvements in services for people. And we support individuals who wish to make a complaint, we do a lot of work around involving people in decision making, so that's one of the reasons we've got involved with people who have suffered from chronic pain.

Evans: Are there any ways that Northern Ireland differs from mainland UK?

Skelly: One of the big advantages that we have here is that Health and Social Care is integrated, so it should, theoretically, be a seamless service for people – that's debatable. But one of the other things that is a particular gap for patients here is that we don't have a single advice and information service unlike in Scotland where you have NHS 24 and you have – in England – you have NHS Direct, so they have a single advice and information service. That's a big gap here in Northern Ireland: what people tell us repeatedly – they don't have the advice that they need. So we've been working on and we've now got a scoping paper which has been approved by the permanent secretary, and actually this morning I was in a meeting where we're moving forward with the business case for that.

Other things that happen across the 'water' which we don't have here is – there's not the walk-in centres, the 24-hour walk-in centres for direct access. And again, that's an issue, and what we've found is a lot of our patients end up in A&E, totally inappropriately. We have been campaigning for an improvement in GP out-of-hours, and GP access. There's an element of blaming patients for being in A&E, but the reality is they don't have an awful lot else – nowhere else to go to. When they're worried, that's where they end up.

Evans: So would you act as a kind of ombudsman?

Skelly: Well, to an extent, yes. But there is a very discreet role, which is the role of the parliamentary ombudsman. Our role is very much around working in the system, working with individual patients, working with groups of patients who have issues, and in the whole broader involvement agenda. And we provided information and advice. We also *promote* the provision of information and advice across the system. So we have provided a range of services which are around patients and service users. And Northern Ireland's quite different in that we have Health and Social Care under the one umbrella organisation, under the one department.

Evans: It sounds as if there might be a gulf between those who provide and the customers, if you like, the patients.

Skelly: Well, there can be. And one of the things we do is we work with the providers, as well as the patients, to promote the whole involvement agenda. There's nothing as powerful as the patient's story, and what surprises is that people in the system don't always stop and listen to what are the real issues, they talk to their colleagues, they talk to other people, but sometimes they forget to talk to the people who actually use the service. And that is when the real experience comes to the fore that is of so much value for everybody to learn from. And we do a lot of work in that, promoting that right across the system.

Evans: Do you have an example of a patient's story that might influence the profession?

Skelly: We have lots of stories. But one that sticks to mind is recently I was working with a young man who needed to get into genito-urinary medicine services, and he came to us because he had a very poor experience: first of all of finding out about the service, and when he got there, getting into the service, he didn't realise that there was a big queue which ran out and up the street. And the whole experience he found very degrading. And he came to us because he felt this was a big issue. Once he got into the service, and the actual

treatment carried out was actually very good, but the issues were around access, information and simple things like if you needed to come back and you needed to phone in to change your appointment, the phone didn't work. So lots of simple things around how the system wasn't working from a patient's perspective. And as a result, I encouraged him and supported him to meet with the manager of the service, with the people who commissioned the service, and we were able to facilitate him to tell his story.

And when I spoke to the nurse manager who'd been managing the service for many years, I said to her 'Did you ever, you know, ask the patients what it was like to stand in the queue or what it was like, you know, to try to get information about your service?' she said 'We've made a number of changes to the service, but we talk to the other staff', and that was so fundamental to me that they hadn't actually asked all these people who stand in the queue outside the door, for maybe an hour or two every morning. But, you know, the fact that she hadn't stopped to ask *them* what's that like, what's that experience like, and as a result we were able to work with them to bring about a number of very significant changes, not the least of which was a new phone system.

Evans: In terms of pain, you have a pain steering group, what does that do?

Skelly: We have a small group of patients, and there's a doctor on that as well, and some other people who have an interest in this area, local advisors. And what we've been working [on] for the last year – to raise awareness of chronic pain and how that affects people's lives. It became clear to us that there are individuals who, for a variety of conditions, suffer from chronic pain, and some people who have no condition at all that has had a diagnosis, but certainly pain is a big part of their everyday life, and we felt that they had a voice which was unheard in the system. So we have been working with the MLAs [Members of the Legislative Assembly] in the Assembly. We had an event up in the Assembly where patients were able to speak directly to the Minister for Health and the Health Committee. We then held – worked with the Pain Alliance around the Pain Summit.

Evans: That's Louise Skelly, Head of Operations of the Patient and Client Council in Northern Ireland. And you can hear more about the Northern Ireland Pain Summit that she was talking about in ***Airing Pain*** programme number 35, which, like all editions of ***Airing Pain***, is available for download at <http://painconcern.org.uk>. Jay Flood Coleman is a member of Patient and Client Council's pain strategy group.

Jay Flood Coleman: When the Patient and Client Council was initially setting up local advisor committees, I became interested because I always thought that for people who have been through a lot of health experiences, there must be a way of feeding that experience back into the system. I thought I would like to apply to see if there was anything I could contribute on a local basis. And I was interested to see what would happen, and how it would actually filter through to the health boards, if you were to actually try and give information on the ground about what you thought was affecting people locally.

Evans: So you committed as a patient?

Coleman: As a patient, yes. My pain would have started initially with probably my second brain haemorrhage, because I had two brain haemorrhages, and after the second one I had about a year in hospital and rehab unit, 5 years in an electric wheelchair. And I lost my dominant side: I used to be left-handed, and that's the side I lost, and also I lost a quarter of my brain. And I found after that time that I had a series of health issues which affected my pain levels, so what started off as a medium pain quickly seemed to accelerate the more I tried to become independent.

Evans: So you're in the pain strategy group of the PCC [Patient and Client Council]?

Coleman: Yeah, I haven't really thought about it being a pain strategy group as such. Yes, initially what was happening was I was bringing up chronic pain repeatedly as an issue at my local advisory committee, because I thought that it was affecting a lot of people within the population in Northern Ireland, and I thought that it was something that needed to be addressed.

Evans: How does your experience then and your thoughts, how does that help the strategy?

Coleman: It helps if you can share your personal experiences about the difficult road of how you actually handle pain, the 'tunnel vision' that you can get, and the depression that can actually come in from trying to just do it medically, and trying to fathom out what else might be available to help you 'see the light at the end of the tunnel'.

I think, basically, like a lot of people you would go to your local GP to try and see what can be done about the pain levels you are experiencing. And the most important thing for us is to actually be believed, because some of the pains that you are experiencing may not be detectable on an X-ray machine, but they are very vivid within your own experiences. And

then you quickly find that you accelerate within the pain medication, not always knowing exactly what it is you're taking, I think, at times, which is a very dangerous thing. And then after you get to a certain level, you actually realise, as well, from the interchange you're having with your family that you're maybe not even contributing in the same way as you used to, as a member of that family, and that can be quite scary. So, for a lot of people, I think they're trying to find a way out of that experience, to a 'new dawn', if you like, to what they can do about it, rather than what's been done about it in the past.

Evans: How do you mean, trying to find a 'new dawn'?

Coleman: Well, I think for a lot of people it is – they do find that they're in a very dark place, because all they can do is – a lot of people are on what I would call opioids – or they are called opioids – and I find that they have a damaging result to a lot of people. I know quite a few people who are on such a large dosage they should not be out and about sometimes. Some of them are still driving, they shouldn't be out driving. But I think the main thing is that you don't realise what these are doing to your body, you don't realise how your body then adjusts to the medication, and you don't realise what effect they are having, if any, after a long term of many years' medication. And it's then trying to figure out, what *can* you do about that?

Skelly: We are all service users, at the very minimum are all registered with their GP, so we need everybody to get involved and have a say what's – Health and Social care is the one service that we're all going to use at some stage in our lives, and as we get older, the chances are we'll use it more. But some people, even children, are very heavily involved, right from the start, just because of, if you like, whatever hand nature has dealt them. And we want to provide that avenue for people to have a say which is appropriate to them. So yes, we do have those people who have maybe a single issue, and are very passionate about that issue, and we welcome them. But at the other end, we have people – the whole spectrum.

And of course then we also have the complainants. Some of those cases who come to us are very difficult cases, and very harrowing cases, and of – the service works really well for many, many people, but for some people, things go wrong, unfortunately, and we're here also to support those people. Most people don't actually want to complain, but they do need

help when they really have a complaint, and sometimes the cases that we are dealing with are at the very hard end of the scale, and they need that support. Sometimes that support is as simple as helping them to write letters, other times it's attending meetings, there's the whole – and we can be working with them maybe over a period of months to help them to get some issues resolved. Some are resolved quite quickly.

Evans: I suppose a big problem for people – and for health authorities – with complaints is the authority you're complaining against or the person you're complaining against becomes frightened of talking to that person, in case he says something that costs a lot of money. Sometimes people don't want to go down that route, they just want either a 'sorry', or 'please, can you get me a phone number, please, can somebody speak to me at the other end of the line'.

Skelly: Yes, it is an issue: the system can be defensive. And what we are doing is we are working with the providers and the commissioners to change that culture, but that's going to take some time. We do think there has been a change. I think there's now a recognition, for example, that a lot of complainers – actually all they want is for someone to say 'sorry', or quite often what they say 'We want some sort of reassurance that my experience is not going to be the experience of another person or another family'. That's really, really important to complainants. So if we can work with them early on in their process to get that – sometimes that's as good an outcome as they can have.

We've had, for example – recently, we've been working with some women who had an issue with pain relief and maternity services, and they had a very bad experience with one particular hospital here in Northern Ireland in terms of – quite, almost draconian attitude to pain management: 'Oh, you're having a baby, just get on with it' type of thing. And there was an attitude amongst some of the midwives in that particular unit. And what we did was we worked with the Trust and we got some of the ladies involved with training the staff to tell them what their experience was like.

And as a result, there was a new programme put in around pain management in that particular area. But what one of the service users, one of the ladies came back and said 'You know, thank you so much I'm now able to get on with my life!' Because she had such a dramatic time that, you know, she wanted to have another baby, she wanted to go back to work, all of that, but because she couldn't get past this bad experience, being supported to get past it and move on with her life that made such a difference, and she felt somebody had

listened to her and then had provided her with a way to try to make a difference for others, and quite often that's what people want. If they have a bad experience, they want some reassurance that that's not going to be repeated for other patients, and that's very important to them.

Evans: Louise Skelly. Of course, dealing with the NHS is just one part of life with chronic pain. For those still in the workplace, an employer's attitude can make all the difference between sinking and swimming. Rena Shepherd lives with chronic pain, and she's also a board member of the Patient and Client Council in Northern Ireland.

Rena Shepherd: As a board member, I advocate for and represent the patient, ensuring that the patient or the service user's voice is heard by all the commissioners, by the providers of services.

Evans: So you're that link, if you like, between what the patient says and making sure it gets to where...

Shepherd: It gets to where it's heard. It needs to be heard.

Evans: You also have a business background.

Shepherd: I started my life out in Price Waterhouse, and I then moved to the oil industry, I was marketing manager with BP Oil. I then went to work for a publishing company, and of late I worked at an executive level in Royal Mail.

Evans: And that experience must be invaluable dealing with the suits of the NHS.

Shepherd: Yes, absolutely. The experience has been invaluable. The experience has taught me that with a little modification on employers' parts, a lot of people with long-term conditions, not only with chronic pain, but with various other long-term conditions, can actually work full-time and be very, very productive.

Evans: Are you involved in talking to businesses and to employers about this?

Shepherd: Yes, I am currently working with a group to try and get an organisation together that will link employers with healthcare providers, and get employers more inside the head of people with disabilities, and with the providers of healthcare in order that the two can be brought together to work better for the service users. Yes, I have spoken to a number of employers, I will give of my time if employers, for arguments sake, want to set up some self-

management courses. That's the thing that I have found very, very beneficial. Very, very beneficial. And the scientific evidence is out there for people who have completed self-management courses: they see their GP less often, sometimes they can reduce their medication, their sick absence decreases, they become more productive, their self-esteem goes through the roof, and various other benefits that will have a knock-on effect on productivity.

Evans: Have you had any success with employers taking on a self-management group?

Shepherd: The employer that I've had best success with was with Royal Mail. When I was with Royal Mail Group, Royal Mail were very, very accommodating for people with disabilities of any description. Royal Mail also had a Disability Action Centre which they set up, which is an online service for anyone who had a long-term condition themselves, for anyone who was managing an individual with a disability or long-term condition.

Evans: I guess nobody wants to disadvantage somebody with pain. But it's knowing how to do it.

Shepherd: It's knowing how to do it, it's knowing how to do it, and again, as I said earlier on, it's the modifications and the adjustments can be so small, I mean, so much can be gained for such a small adjustment. I think it's about two things: it's about getting people, like myself, to be honest about their condition, and that's very, very difficult. You know, Northern Ireland is a very, very small place. There's always the scary factor, if people do know that you are living with chronic pain that it can make you tired, will they worry about your performance, will they worry about employing you? I think personally I'm in a very lucky position that I've proven myself. I've lived with chronic pain for years, and years, and years, and I've proven I can do the work and manage my pain. But for other people, I think we have to work harder to make people not be so scared of coming forward and talking about their conditions.

Evans: In many situations, it's a 'black and white' thing. If you tell your employer that you have chronic pain, immediately they say 'Right, we will sort this out, we will manage this', whereas in actual fact, it's the person with pain who wants to manage it in his own way.

Shepherd: You tell them what you have, and then *they* will put their solution on it, where in actual fact all you need is to tell them how *you* need to manage. And I think that's just from fear. They're running scared of DDA.

Evans: DDA?

Shepherd: Disability Discrimination Act. A lot of employers are running scared of that. A lot of employers feel that we've got this policy so we must adhere to the policy, strictly to the policy, not realising that most people who are living with a chronic condition of any description are best placed to manage it. And if they can come to the employer, if you can come to your employer with your management plan, and say look 'Can you fit in with this?', you've a much better chance of being allowed to manage it yourself. But more progressive employers will absolutely hand it over to the employee in question. You know, they'll say 'Look, you know what's best, it's your condition, you know how best to manage it, and you know what's best for you'. So I think it's about being brave enough to come forward.

Evans: Rena Shepherd, board member of the Patient and Client Council in Northern Ireland. At this point, I'll just remind you of Pain Concern's usual words of caution that whilst we believe the information and opinions on *Airing Pain* are accurate and sound, based on the best judgements available, you should always consult your health professional on any matter 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. Back to the Patient and Client Council, and its Head of Operations, Louise Skelly.

Skelly: Health and Social Care is such a big system here in Northern Ireland, and there are 77 000 staff; the Patient and Client Council have only 30 staff, so we've got to prioritise, and we've got to think what are the issues that we can actively have an impact on. So each year we work with the patients to tell us what are the priorities with them, and then we make those into our priorities.

And again, because we're small we have to think of ways of punching above our weight, so we have developed a membership scheme which is for people right across Northern Ireland. We would like 1% of the population on our membership scheme, [that] we launched it in 2011. We now have 9000 people, and they are people who are actively interested in what's happening to Health and Social Care, who keep in touch with us via e-mail, via a whole range of ways, and they tell us what are the issues for them, and we use that information to feedback into the whole system. That's a really effective way of how people can get involved here in Northern Ireland.

Evans: So how would a patient become involved in this?

Skelly: The membership scheme is open to everybody. You can register online, you can ring in to the office here. Northern Ireland has a legacy of community and voluntary groups: there's about 7000 community and voluntary groups here in Northern Ireland, which is huge in size. But not everybody, especially people who are carers of people who have maybe long-term diseases and chronic illnesses – they can't always get involved in groups. So the membership scheme, as well as having some groups on it, is a way for the individual to get involved.

Now they can get involved as little or as much – people, when they sign up, they tell us what their area of interest is in. And they can keep in touch through e-mail, they can come to meetings, conferences, workshops, whatever's going on around that particular issue – very much their choice what it is they're interested in. And we find their interest changes depending on what their needs are. We may not hear from them for a while and then suddenly something happens within their family, or whatever that they're interested in, and they get involved in that particular issue. So it's very much led by the people.

Coleman: I've input my experience basically by first trying to make people aware of how extensive I think chronic pain is, within lives, within the community, and how insular I think lives have become because of it. But also how narrow I find the opportunities are for trying to get out of that 'tunnel' experience, and I think that's been thankfully vindicated by other people's experiences in other areas.

Evans: Are you optimistic for the future?

Coleman: I am optimistic. I wouldn't even be here if I wasn't optimistic. I was optimistic when a consultant first told me that I would never walk again, and I had to prove him wrong. And I'm optimistic when people tell me that things will only get worse within the economy. And I'm always optimistic because I think that unless you have optimism, then that affects so many things, not just your health, and we need to have a positive attitude in order to move forward in our lives.

As well as being an optimist, I'm also a realist, and I know that there's only a certain amount of funds – funding that's available. But one of the things that I personally would have a dream about is that, for some aspects of chronic pain –not all – that we would have locally facilitated chronic pain groups, because a lot of people in pain don't want to travel very far because it is painful to travel. So if we could have locally, cheap groups of chronic pain

management, facilitated by people who themselves have been in pain, and I think that would go a long way towards actually helping the system without costing a lot of money, but then of course there has to be a wider education programme going on as well.

Evans: The Patient and Client Council has been running since 2009. What difference have you made?

Skelly: We've provided people with a voice. We've also provided a very good evidence base over the last 3 years in terms of what are the real issues for people. And we're feeding that into the system. For example, we have produced somewhere in the region of about 35 to 40 reports which are a very clear evidence base. Those cover issues from what are people's priorities in terms of things that should be addressed through to issues around urgent care, transport, access to GPs, and all of that. And what we find is that the commissioners and the trust boards when they're developing their plans, they rely very heavily on that information, so that has begun to filter into the system, and bring about changes.

We've made a lot of changes for individuals in terms of their care, but as well as that, with groups of patients, a bit like GUM [genito-urinary medicine]. And for example in cancer where we've been working with chemotherapy patients, who, when they become unwell between episodes of chemotherapy, find themselves in A&E. You know, here's a situation where you are a chemo patient, and you were told 'You're not allowed to go to your granddaughter's christening, because you can't mix with the crowd, stay away from people', and all of that, and all of a sudden you find yourself sitting in an A&E department for 5 or 6 hours with everybody, from flu to whatever around you. It just didn't add up: why is this very ill patient sitting here?

So we worked with the system, we got two beds in the cancer unit for direct access. We got some improvements to the help line in terms of the advice and information they were getting. And now the numbers of cancer patients who go through A&E have dropped about 90% in the last couple of years. That's one area where we have made a fairly significant difference, and there are quite a few examples like that.

Now what we're doing – we're just about to launch a questionnaire which we're going to issue through the membership scheme. It's a fairly big piece of research where we're going to hold focus groups as well with the interested groups, and what we're hoping to do is get many thousands of people through the membership scheme and through the wider

population, who will come forward and tell us what their experience of chronic pain is here in Northern Ireland, what their experience of the services are, but also what their experience is in terms of how that impacts on their lives, because we want to take that information, and then take that back to the commissioner and the Trust and say 'Look, what are you doing about this? How are you going to make a difference for pain?' We would like to see a regional strategy around pain management, and we would like to see an improvement in the services. But until we get a really good evidence base, we think we will be [un]able to do that better. So that's why this questionnaire, and this research project, is so important.

Evans: Louise Skelly. And you can find out more about how to get involved with the Patient and Client Council in Northern Ireland at their website, which is <http://www.patientclientcouncil.hscni.net>. And don't forget that you can 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, e-mail, Facebook, Twitter, or pen-and-paper. All the contact details are at our website, which is <http://painconcern.org.uk>.
Last words from Jay Flood Coleman.

Coleman: I think people have become quite despondent with the health system as a whole, and don't know how to be effective and how to make a valuable contribution. And I think the Patient and Client Council is one of the first small organisations – because in health terms, they're quite small. They are trying to make a real difference, and they are trying to do things at an intelligent, fundamentally realistic level. Rather than just trying to do things for their own reasons. They're trying to make a real difference, and that's why I like to be part of it.

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