

Airing Pain Programme 77: Realising the painful truth

Putting patients first, and teenage life with pain.

How can healthcare systems adapt to meet the needs of people in pain? Airing Pain returns to Northern Ireland to find out how the findings of the Painful Truth report into chronic pain will be put into practice.

The Painful Truth had a big impact on decision makers – chronic pain is now recognised as a condition in its own right, healthcare professionals receive pain education and people in pain have a bigger voice in developing their services – but with resources tight and pressure on services, putting the report's recommendations into practice won't be easy.

We hear some of the stories behind the statistics. Zara and Aimee, teenagers living with pain, talk about how they cope with the 'invisible' illness of pain and rising above the challenges they face in their social lives and school work. Margaret Peacock and Carrie describe their difficulties in getting help from the medical profession.

Paul Evans: 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 and for healthcare professionals.

I'm Paul Evans, and this edition has been aided with a grant from the Pain Alliance Northern Ireland. Now, the Alliance brings together all those members of, let's call it 'the pain family', together with members of the Northern Ireland Assembly, to raise awareness of the burden of long term pain in Northern Ireland and to press for improvement in services.

Three years ago they held the first Northern Ireland Pain Summit, to raise awareness of the extent of the problem of people living with chronic pain, the cost to the economy and to highlight to those decision makers key opportunities to develop prevention strategies and services for people with chronic pain. You can download edition 35 of **Airing Pain** to hear what was discussed and decided in 2012 from Pain Concern's website, which is painconcern.org.uk.

So let's spin forward to 2015 and the second Northern Ireland Pain Summit, which was held once again in Belfast. Dr Pamela Bell is a retired consultant in anaesthesia and pain management and she is chair of the Pain Alliance Northern Ireland.

So, what's been achieved in these last three years?

Dr Pamela Bell: One of the very big things to come out of the last Pain Summit was the undertaking by the Patient and Client Council to carry out a survey of the experience of people living with long term pain and how they felt about the services that are available for them here in Northern Ireland. And that was eventually published in February of last year as The Painful Truth. And that set out a great deal of information highlighting the burden that chronic pain places on our population, in terms of not just the physical handicap of chronic pain, but also the emotional and socioeconomic problem.

Prof Maureen Edmondson: I'm Maureen Edmondson and I have the privilege of chairing the Patient and Client Council in Northern Ireland. The Patient and Client Council was set up to be really the critical friend in the health and social care system in Northern Ireland. And our statutory duty is to listen to the voice of the patient, find out what they're thinking about the service they're receiving, or not receiving, and feed that back into the system at all levels.

Evans: Are you a governmental organisation?

Edmondson: Yes, we are. We are part of the health and social care family, we're funded by the health and social care system, but we have an independent voice which comes from the people we talk to and we talk to thousands of people each year and feed their voices back into the system.

Evans: And when you feed those voices back are they listened to?

Edmondson: On the pain issue we are really thrilled that in fact three years ago we issued the report The Painful Truth and had a number of recommendations in that, because chronic pain was not recognised as a condition within the system, so we were delighted that when we wrote to the minister and sent a copy of the report to him, that actually seven of the ten recommendations in that report were taken up. And so now you actually do have, first of all, chronic pain recognised as an issue and it needs to be dealt with, a condition that has a massive effect on people's lives, so that's recognised. There's now education for professionals in relation to pain and there are also service users involved in the strategies and the care plans in relation to chronic pain. So we've moved a long way, now we're on a journey, and we're not there yet because this is a big system, and there's lots of bits of the system, so there's lots more to go but we're getting there.

Louise Skelly: I'm Louise Skelly, I'm head of operations with the Patient and Client Council. The Painful Truth was published in 2014 – early 2014 – and basically it was 2500 patient surveys, people who were sufferers of chronic pain told their story. They told their story not

only in terms of the impact of chronic pain on their lives, but their experience of health and social care services. And that was a very explosive report in terms of what it had to say, a very human report. Patients and their carers were involved right from the very start in the development of the study and are currently involved in the implementation, the rollout of the recommendations. And that was really fundamental to the work that's happening at the moment.

Evans: The patient voice, those personal stories, those are the experiences that really make people sit up.

Skelly: Absolutely, they're so human and also they're the reality. Some of the patients I've been talking to today, for example, said that they found it really hard to just be listened to by their GPs, you know. It doesn't take money to fix that. We can change attitudes and I think we're someway along that line, but we have a lot of work to do.

Carrie: My name's Carrie, I'm a 27-year-old.

Evans: So you have a chronic pain condition?

Carrie: I do, yes. I have fibromyalgia, and it leaves me with a lot of muscle pain and weakness and aside from the actual obvious pain and fatigue, it can be very debilitating and very isolating. It leaves me kinda... it fluctuates from day-to-day. I can always feel it, I can always feel pain and I can always feel weakness of some level and I just have to learn to adapt to each day.

Evans: How did your GP help you?

Carrie: [laughter] Umm, I don't know how to answer that one without disrespecting them [laughter]. I didn't get much help or support. My mum helped me. I was working as a nurse for the healthcare system and I collapsed in work one day and that was the start of my fibro, and I was bedbound for twelve weeks. And it was only my mum that kept pushing for the doctors and kept pushing that they turned round and said to me that I just had to go to physio and to go to some cognitive behavioural therapy and I'd be fine.

So I jumped through all the hoops for them and I done everything they said and I went back to them and said 'I'm still no better guys. I've done everything you've said. Can you please try and help my now?' And they said 'here's some painkillers. This is you, learn to live with it'. And I had to fight even to get painkillers and to get different types and different strengths

and dosages. If it hadn't been for my mum, I think I'd still be lying on the bed in the corner no further forward.

Skelly: One of the big myths is that people with pain are malingerers, they want to go on benefits and all that. This report very clearly showed that the last thing to go is people's work, their social life will go first, then it will affect their family life, they will do everything but give up their work and it's the last thing to be impacted. So I think that was a very strong message right across government departments here in Northern Ireland as well.

Evans: What did your Minister of Health say about it, did he have any personal comments himself?

Skelly: At that time it was Minister Poots. What he had to say was that he endorsed the stories there and he said this was a situation that couldn't really continue. And his department was now charged with taking forward the recommendations which he endorsed. And he issued a letter formally along that line.

Evans: That was Louise Skelly, Head of Operations for the Patient and Client Council in Northern Ireland.

Meave McLaughlin MLA, that's Member of the Legislative Assembly, is Chair of the Northern Ireland Assembly Health Committee.

Meave McLaughlin: Clearly there is a challenge when we look at the amount of people who suffer from chronic or constant pain in our society. The statistics tell us that one in five people suffer. So there is a very clear need for the system to be able to respond to that need that is there. I suppose on a very human level today we'll hear directly from patients themselves, from service users themselves. And there are clear messages coming from them all. They're saying we do need a strategy that looks at the whole area of pain and the types of services and interventions that are required. So that, I think, is the clear message coming out of this today. There has been progress and we need to see the whole issue of how we tackle chronic pain, and constant pain, further up the political agenda.

Evans: The Painful Truth report that came out last year, the Northern Ireland Assembly accepted seven out of the ten recommendations. How are those being implemented?

McLaughlin: Part of the challenge that we have in relation to this issue – and many, many other issues – has been the way our system is currently set up. I think, clearly, in order to be able to fully implement the recommendations coming from that report – and, indeed, coming from many other reports – we need a system that can respond; we need a system that can

proactively strategise; we need a system that is very clear in terms of who's in charge and where the accountability is. We don't need a system as it's currently configured, that almost feels as if they are at odds with one another, that there is a certain policy direction and then what happens on the ground is something very different.

So I would be hopeful that, whilst there has been progress from The Painful Truth report, that we will see more once this reform of the system actually kicks in.

Evans: Healthcare is about money as much as patients, sadly. I'm a patient, you're a politician. One department is cut for another department to take money from them.

McLaughlin: Well I think the first thing I would say in relation to this is that health is being protected. I think the big issue in health – well, there are two big issues – first of all the dire need to reform the system, it's overly bureaucratic, it's complex and there is duplication in the system.

But part of the challenge then is actually where the spend goes. And whilst I think we could all and should all make a case for additional money at times, depending on need, we also need to be mindful of a system that pays 34 million to senior consultants for bonuses, at a time when you can't recruit the types of frontline staff who could assist, for example, with chronic pain. So there is a clear challenge in the system about moving towards a process that actually is a public health model, that is very patient centred and very patient outcome focused.

Margaret Peacock: My name is Margaret Peacock and I represent Fibromyalgia Northern Ireland as a Director for Northern Ireland. Why I'm so passionate about fibromyalgia is I'm a sufferer and have been diagnosed since 1997, so I am indeed living quite a while with the actual illness.

Evans: The fact that you were diagnosed in the first place 17 years ago, you have a diagnosis, that in itself is remarkable.

Peacock: Well, yes, it wasn't easy let me assure you. I had for two years, as they say in drama, I had busted the boards – that's not the right terminology – but I had tried every consultant I was told about that may help me, in fact, I saw six privately and on the seventh I was diagnosed with the illness. As far as I'm concerned it took a while, especially when you're emotionally in torment with pain and you just don't know what to do the next day. It really is a really, really chronic illness.

Evans: What are you picking up from the politicians speaking and healthcare professionals speaking?

Peacock: Well...[sighing]...if I could give a varied opinion, I have attended many conferences, I have attended many meetings and it's a struggle and I'm not picking up a great deal, sadly, again that could be a personal opinion, not a professional, but I would like to see movement. And I don't mean movement in – 'oh yes, we understand it is quite chronic to have fibromyalgia' – I mean movement, where people will get together, the powers that be I'm talking about, will get together and do something to help the many sufferers that there are in Northern Ireland.

Dr Anne Kilgallen: My name is Dr Anne Kilgallen and I'm a deputy chief medical officer at the Department of Health here in Belfast. And I've been invited to speak at today's event really to give some insight into the policy perspective on long term pain and our approach to developing and delivering services for people who live with long term pain.

Evans: So what did you tell the delegates?

Kilgallen: What I told the delegates was that probably the most significant impact on our policy has come from The Painful Truth. And the power of that report lies in the fact that not only does it represent, in survey and in statistical form, the realities of people who are living with long term pain, but it also presents the human face because they are very personal and very real stories.

And that report I think made ten recommendations, for me probably the most important of which a recommendation that long term pain would be regarded as a long term condition. And immediately on publication our department, the minister and our department, accepted that recommendation and has moved to ensure that within our long term conditions policy framework long term pain is now considered as a chronic condition.

Evans: What does it mean that chronic pain, long term pain, is a condition in its own right?

Kilgallen: The significance of that framework is that it charges us in health and social care with reorienting our services from episodic care to wrapping ourselves round or supporting people who live with chronic, long term conditions. So it's a significant policy framework for us and within that then the fact that certain conditions are preeminent allows us to identify populations for whom the policy is relevant.

One of the difficulties I think for people who've lived with long term pain is often the difficulty with the diagnosis. Historically pain itself was not considered a diagnosis, the question might

be what is the cause of that pain. And so the fact of recognising long term pain as a condition in its own right and of putting it in our policy context, charges us with partnership with patients, partnership with people and with their families. So, developing our services in such a way that they are supportive of the individual in the long term and not just in the episode when they might be particularly vulnerable or particularly in need of a health or social care service.

Evans: So, by giving chronic pain a label – it is a condition – it's almost like a mandate to politicians that they have to get it sorted.

Kilgallen: I think the reality is that – and many people have said this before me – is that a problem isn't a problem until it is named. And so in fact, yes, it is true that recognising chronic or long term pain as what it is, a long term condition in its own right, does allow us to formally think about the services we provide, and particularly this issue of supporting people in their daily lives and of really supporting them to self-manage. I think that's really the point of what I'm describing, is that rather than an individual coming to us for a service, the reality is this individual needs to be supported and helped to manage the condition themselves, with occasional or regular support from professionals and that's a partnership approach.

Tricia Bowers: My name's Tricia Bowers and I'm the Training Services Manager for Arthritis Care Northern Ireland and we deliver self-management programmes for people in the community who are living with long term painful conditions.

Evans: You were involved in the workshops earlier, what was your task?

Bowers: Our task was to look at self-management and come up with an idea, or a feel for, what does good self-management look like, and then identify three or four priorities that we would like to have processed at the top of a list, if there was a wish list for self-management.

Evans: Well Arthritis Care is already involved in very, very good self-management programmes, what were the findings of your discussion?

Bowers: You're quite right, we are at the forefront of delivering within the community sector, and we get our funding from health trusts. We had a number of patients who are living with chronic pain, including myself, around the table. And they were talking to us very much about the frustrations that they have to live with, in terms of waiting times for appointments to see a health professional, even their GP, some of them were saying they might have to wait up to three weeks to get a GP's appointment, much longer for a rheumatologist or a pain

clinic appointment. And the fact that when you're living in long term pain like that, it is what it is, it's a long term condition, and it doesn't go away, it doesn't necessarily get that much better and it's really frustrating to be told that you might have to wait 18 months before you will be able to see someone who may be able to help you to manage the pain better.

Evans: I think it's very important to know as well, that it doesn't matter what the long term condition is, there are things that we all feel, the frustration, the daily grind and the feeling alone.

Bowers: Absolutely. And, in fact, within Arthritis Care right now we have developed a project whereby those people who are so isolated that they can't attend community settings, we now have a one-to-one befriending service called Staying Connected, where we have trained volunteers, who also have a long term painful condition, will go out and visit the people in their own homes and talk them through the self-management programme, talk them through – as you say – the small changes that people can make to help them deal with the difficulties that they are having to live with on a daily basis. Whether it's the pain, whether it's the fatigue, depression, low mood, all of those things. And that's turning into a very, very successful project currently.

Zara: I'm Zara.

Aimee: I'm Aimee.

Evans: Zara and Aimee you've just given a fantastic talk to a room of 150 health professionals and you communicated what you go through with your chronic pain on a day-to-day basis. [**Zara:** yup] Aimee, tell me what you told them?

Aimee: I was just discussing my illness – and what I have is junior idiopathic arthritis – and just how I deal with it on a day-to-day basis and how it affects my life. So, my social life and family life and school life. And how it restricts me from doing some of the things I want to, and also how I get around the restrictions that it causes.

Evans: So how does it affect you?

Aimee: I struggle with stiffness in the mornings, so getting to school is quite a difficulty with stiffness, getting the bus, getting in on time and then once I do get to school, with the pain, it's hard to concentrate in class with fatigue and pain together. And then when you get home you're not really in the mood to go out because you're so tired and drained from the school day. So your social life suffers from that aspect. And while you're at home you isolate

yourself when you are in pain, so that also affects your family life in that way, where sometimes even when you are with your family you're not quite 100% yourself.

Evans: Zara, how does it affect you?

Zara: Well, because I not only have arthritis, I'm missing the three fingers from my left hand and a joint in the middle finger of my right hand and then I've developed tendonitis in the tendon along my right arm, it definitely makes things a lot more difficult. I describe myself as feeling like the tin man from *The Wizard of Oz*, when he was first found by Dorothy, because he needed the special oil that he had to relieve him of pain and stiffness. The only difference being that I don't have the special oil.

I talked about how it affected me when I was doing my GCSEs, because I had to get a laptop so I could type up the majority of them, as well as having to take a break every 45 minutes, just to stand up and stretch because it began to affect my knees. And getting up and down off of the bus, because with my bag on my back and the files in my hands, I don't always feel like I can support my weight, which is definitely not helpful because then I tend to hold people up behind me on the bus.

Evans: You've had the opportunity, and you did it very well, to speak in this Pain Association Northern Ireland summit – and there were a lot of health professionals, there were politicians there as well – what message do you think that they took from what you told them?

Aimee: I hope that, obviously, not just adults suffer from chronic pain, that it affects everyone and usually in the same kind of way that it does with adults, but there are obviously some differences in teenagers dealing with chronic pain and adults dealing with it. But, you know, it affects our school life, rather than our work life.

And I think a big thing with teenagers dealing with chronic pain is that they are embarrassed by it sometimes. I remember in the beginning if I had a limp one day, I'd be embarrassed limping up the stairs, that somebody would see me and think that there was something wrong with me, but I think once you've had it for a certain amount of time that doesn't really bother you anymore.

You know there's people who are like 'you don't look sick, so why are you saying that you're sick'. I think that's one of the big things with invisible illnesses, nobody can really tell that you're sick until you tell them. So I think it's just one of those things that I hope that they understand that we are affected just as severely as any other person who's affected by a chronic illness. Yeah, I also hope that they enjoyed the speech, because I put a lot of effort into it. [laughter].

Jillian Coward: I'm Jillian Coward, I'm a patient with rheumatoid arthritis, which I have experienced for over 30 years.

Evans: What have you heard this morning that excites you or disappoints you?

Coward: I've heard some very moving stories about people's experience of pain – and quite an age range of pain – that's been very informative. People don't realise that it can affect young people as well as older people. I've heard a lot about change within our health service, particularly here in Northern Ireland, and how there is an awareness amongst our politicians and amongst our health professionals about getting people out of their silos and remembering that pain connects patients across very wide user groups. I'm hoping that events like this will lead to better understanding about treating pain.

Evans: The Painful Truth document that came out last year, has that changed the way service users are treated?

Coward: I think that document has had a very wide reach in political circles and in the health professionals field. And I think if you are aware of it as a service user – I'm very involved with Arthritis Care and we became aware of that document – it's a shared vision that we have, we're trying to achieve those goals that are outlined in that document. And when you're either talking about your own situation in a patient situation, you can perhaps reach better outcomes because you're aware that the GP you're talking to, or the physio you're talking to is aware of the goals and targets that we're all trying to do.

I think for a service user with chronic long term pain, you have an enormous amount of contact with the health service and often you know as much about your condition as the health professional you're dealing with. And so knowing what's achievable is important for both of us and that document has helped in that way.

Christine McMaster: I'm Christine McMaster, I'm a public health consultant and together with my colleague Maria Wright, we lead the Pain Forum in Northern Ireland. Which is to take forward the recommendations from the scoping report we did in response to The Painful Truth.

Evans: I've heard the word 'scoping' many times today, tell me what 'scoping' is?

McMaster: In plain English it's to look at what range and quantities of services for people with pain we have in Northern Ireland. And the picture that we uncovered was a very mixed one. We had a little bit of everything, but not enough of anything anywhere, huge variation

and therefore inequity in services for patients with pain across Northern Ireland. Some health and social care trusts were relatively well equipped, others were lacking in bare essentials.

Now that we have that picture it is relatively easy to identify all the things that need doing, to do all of those would cost an enormous amount of money and we need to start somewhere. So we are currently working, with colleagues across Northern Ireland to identify priorities. And what I think is going to emerge is that we invest in more self-management in communities initially and at the same time develop capacity in primary care. We also need to find funding to close the huge gaps in our hospital services and I suppose there will be some opportunism in having plans for all of those things and then moving forward with what attracts the resources initially and that's not entirely in our own hands.

Evans: No, but short term planning, ploughing a lot of money into something now, like self-management, will save an awful lot of money in the future.

McMaster: You're talking to a public health practitioner and that's exactly the message that I would put out first, prevention is better than cure, but we must be mindful of the fate of tens of thousands of people in Northern Ireland who live daily with very severe pain, who do need help. We have a duty to care and we do need to equip our colleagues in hospital services, and in primary care, to help those patients. Everything is a balance act and a compromise, so the agenda is huge, otherwise we couldn't have spent a whole day talking about it. We'll have to make choices, but I think that will become clearer as we work.

Evans: Christine McMaster, Leader of the Pain Forum in Northern Ireland.

I'll just remind you, as always, that whilst we in Pain Concern 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 wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

So at the end of the second Northern Ireland pain summit, a lot of words have been spoken, lots of ideas developed and experiences shared – final words to Pamela Bell, Chair of the Pain Alliance Northern Ireland.

Bell: I'm just staggered at the amount of work that has been done today and the number of messages. First of all, I'm really pleased at how well engaged the patients are and I want to take some of that energy going forward, because it's their voice that really seems to make the difference here in Northern Ireland.

I'm also so pleased that healthcare professionals are continuing to follow us on this journey. And seeing many faces here today that were at the original pain summit and knowing where they have progressed in terms of how they're delivering the services. So that has been absolutely fascinating. We've learnt a lot, I think, from what is going on and the journey that Wales and Scotland are undertaking. I think we're dragging a little bit behind them, I must admit, despite the progress that we've made, but it is heartening to know that they're still continuing on their particular journey.

Out of the workshops we have a lot of work to take forward. And I think that what we need to do now is take a little sit down with those who ran the workshops and determine who takes which strand of the work forward. But I certainly feel we've got a mandate to push ahead with the educational organisations, with our health and social care board, with our department of health, with the health assembly, to encourage them to create the atmosphere where change for the positive benefit of patients can happen. So, yes, I'm delighted, but almost too much coming out of it to encapsulate in a few words.

Contributors:

- Dr Pamela Bell, Chair of the Pain Alliance of Northern Ireland
- Prof Maureen Edmondson, Chair of the Patient and Client Council in Northern Ireland
- Louise Skelly, Head of Operations at the Patient and Client Council in Northern Ireland
- Carrie
- Meave McLaughlin, Member of the Legislative Assembly of the Northern Ireland Assembly Health Committee
- Margaret Peacock, Chair of Fibromyalgia Support Northern Ireland
- Dr Anne Kilgallen, Deputy Chief Medical Officer, DHSSPS, Northern Ireland
- Tricia Bowers, Training Manager, Arthritis Care Northern Ireland
- Zara
- Aimee
- Jillian
- Christine McMaster, Pain Forum Northern Ireland

Contact

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

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

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

Follow us:
facebook.com/painconcern
twitter.com/PainConcern
youtube.com/painconcern