

## ***Airing Pain* Programme 20: The social costs of pain**

### ***The societal and economic impact of pain and driving pain up the agenda.***

*Pain has a huge impact not just on individuals but also on society, healthcare systems and the economy. **Airing Pain** takes a look at how the International Association for the Study of Pain's Declaration of Montréal and EFIC (the European Federation of International Association for the Study of Pain Chapters) are working to drive pain up the political agenda. We interview experts in healthcare policy and chronic pain treatment as well as patient groups at EFIC's European Societal Impact of Pain symposium for their views on how the way society and the medical profession respond to pain could be improved.*

**Paul Evans:** Hello, I'm Paul Evans, and welcome to ***Airing Pain***, a programme brought to you by Pain Concern, the UK charity that provides information and support for those of us who live with pain. This edition is supported by an educational grant from Grünenthal.

**Gina Plunkett:** One of the first things that we all must recognise across Europe is that chronic pain is a *very serious* healthcare issue.

**Mary Baker:** I'm sure there will be family breakdowns. There'll certainly be loss of work; if there's loss of work, there's loss of income and, of course, if you're out of work, you're on benefits and once you're on benefits, you become an economic burden.

**Plunkett:** It is a *huge* issue, not just in terms of the cost, but it's incredibly important for people living with pain to be given that recognition that pain is very real and that it *is* a disease. Then things will start to change.

**Evans:** In September 2010 more than 260 pain specialists from 62 countries attended the inaugural Pain Summit of the International Association for the Study of Pain in Canada. The outcome of this was the Declaration of Montreal, which recognises as a human right that all people should have access to pain management without discrimination, that people in pain should have acknowledgement of their

pain and be informed about how it can be assessed and managed, and that all people with pain should have access to appropriate assessment and treatment by adequately trained healthcare professionals.

Earlier this year, EFIC, that's the European Federation of International Association for the Study of Pain Chapters, convened at the European Parliament in Brussels for the second European Societal Impact of Pain Symposium. Now, the Societal Impact of Pain is an international platform which was formed to raise awareness of how pain impacts society, health and the economy. As such, its delegates are not just healthcare professionals, but pain advocacy groups, those working in the insurance sector, health authorities, regulators and those who hold the purse-strings – the politicians. Janet Graves attended the event for ***Airing Pain*** and she spoke to Beverly Collett, who's a consultant in pain medicine at the University Hospitals of Leicester and Chair of the Chronic Pain Policy Coalition.

**Beverly Collett:** I have been treasurer and council member of the International Association for the Study of Pain. Now there are many chapters of IASP within Europe and they have joined together to form the European Federation of IASP Chapters. And that's extremely important because Europe is a unique locality and, of course, we have a European Parliament.

Now, the Declaration of Montreal has been extremely important because that has stated that access to pain management is a fundamental human right. And that declaration is extremely important because it says, for the first time, that people actually have a *right* to access to pain services. It's vitally important that society, and also politicians, understand the importance of pain. And I think that there's a real need for better education of the general public, of the media, and also of politicians and members of the House of Lords, about chronic pain – the new pathophysiological mechanisms that we understand now take place within the spinal cord and the brain when people have chronic pain and also how that impacts people in everyday life.

For too long, pain has been ignored or stigmatised or thought to be too difficult or just not important enough for people to pay attention to. And I think that's highlighted when you look at various documents from the Department of Health. Pain is very rarely mentioned, even in national strategies for cancer or diabetes, you know, the pain that people with these conditions can have is just not mentioned.

**Evans:** Beverly Collett. But pain *would* get mentioned and certainly move up the political agenda if it could be quantified in terms of cost. And whilst there are figures for the UK economic burden of specific conditions like endometriosis, rheumatoid arthritis and back pain, there's no accurate measure of the total cost of chronic pain as a condition in its own right.

Now, as you'd expect, the European Societal Impact of Pain Symposium brought together participants from all over Europe, one of them being Brian McGuire. He's a clinical psychologist from the National University of Ireland in Galway, where he works in a pain clinic and co-directs the Centre for Pain Research.

**Brian McGuire:** We did a study where we looked at the cost of pain at an economic level and then sort of extrapolated or worked out what that would cost at a national level for people with chronic pain in terms of health service costs and lost productivity, welfare payments and so on. We found that for people with the most severe level of pain, it'd cost around €30,000 per year in terms of healthcare costs and lost productivity. And then when we extrapolate that up to a national level, it was working out at €4.7 billion per year, which is about 2.5 per cent of gross domestic product in the country, so it's really a staggering figure. Unfortunately, a lot of the money is being funnelled in the wrong place, from the point of view that obviously people who can't work need disability payments, but I think that some of those monies could have been directed towards service provision to people who were in the early stages of pain and might've prevented, for some people at least, the development of a chronic course.

We've heard that people can take many years to get to see a pain specialist or to get to receive treatment for pain problems – as long as seven years, one of the stories we heard yesterday – and I think that happens for two reasons: I think, first of all, there aren't enough services – there are inadequate services available for people, with very long waiting lists – so in my own hospital, we have a two-year waiting list to see a pain specialist. So I think that's one of the reasons: there just aren't enough people there. The demand is great, we know, from all of these prevalence studies that very, very large numbers of people in the population have chronic pain, and so there just aren't enough doctors, nurses and other health professionals available – that's one reason.

I think the other reason it takes so long for people to see a specialist is that it takes a long time to actually get referred, because I think that many GPs still don't understand chronic pain and still think of pain as something that should resolve

quickly. And each time the person comes back to their GP, they're almost treated as an acute case again and sent down for treatment again, almost as if it was a new experience of pain, rather than seeing the person's pain as being on a longer-term trajectory and referring the person to a specialist service earlier. Of course then, when they're referred, they will still have to wait for the service, but the access problem and the lack of education are two of the reasons that people wait so long.

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**Collett:** One of the things that has struck me about this conference is the patient voice.

**Plunkett:** My name is Gina Plunkett and I've been living with chronic pain for 15 years and I'm also chairperson of Chronic Pain Ireland, which is a national support group for people living with chronic pain in Ireland.

**Collett:** The patient voice has been really strong and I think it highlights that we all need to be aware that we should put the patient at the heart of any pain services that we're organising, so that the patient is at the centre and we organise services around the needs and for the benefit of the patient.

**Plunkett:** I was involved in a road traffic accident 15 years ago. I was rear-ended – I was stationary at the time. It was quite a severe impact – I hit my head on the headrest, and the first thing I noticed was numbness in the roof of my mouth. By the time I got out of the car, I experienced pain travelling from my neck right down to the base of my spine. I knew that this was whiplash, but I thought, well, this will only last maybe three months, [but] as time passed, it actually got worse. The pain, it just got worse and worse, and I felt that by the end of a two-year period it had reached a crescendo and it was unbearable.

I was a practising barrister at the time and, strangely, in my field of work, I would've done a lot of work in terms of personal injury compensation claims and I worked on the side of the insurance company as a defendant. And therefore I was very sceptical of pain and I would've read many medical reports of people who'd had a similar accident as I'd had. I doubted my own pain because I felt that it should've cleared up after three months, and then I thought six months, and then I thought a year. And

despite my knowledge and, I suppose, my professional background, the journey through the health system was a minefield and it actually wore me down considerably.

I felt that I had to find out who I needed to see next to get help. And even though my GP didn't doubt me, I don't think he knew what to do. I used to long – and I say that, absolutely *long* – to push through a door and I'd imagine myself like some person crawling out of a desert, just [getting] through a door and on the other side of that door would be all the professional people who could care for me and pick me up, and give me the attention and the care – medical care – that I needed. That's what I longed for most. And I kind of thought of it as a one-stop shop, but I never found that one-stop shop and I found that extremely demoralising.

The lack of awareness of chronic pain generally in society and among my friends and my colleagues added to the burden of living with chronic pain. I actually felt very isolated. Ultimately, I had to give up work. As a barrister, I was self-employed, and I did that with a very heavy heart, a very heavy heart, after all the years of study and establishing a practice. I have to say that the day I left the law courts, thinking I was only going to leave for a few months, just to give myself a rest, to what I then saw as recuperating, because I still felt the pain would go away if I gave myself a chance. I left that day with tears rolling down my face because I felt utterly defeated.

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**Michael Zenz:** I'm Michael Zenz. I've been chair of Anaesthesiology and Pain and Palliative Care at the Ruhr University and I'm past-President of the German Pain Society. Most of my academic work is focusing on pain treatment – I established the first pain clinic at the University of Hanover in '79, so, many years ago. I also held the first chair with the name 'Anaesthesia and Pain Therapy' in Germany. I think that was an important step forward to make pain visible as a real topic, in a time when people said pain is only a symptom and not an illness in itself.

So, science has made enormous progress, but the reality for the patient is still very much back[wards], so there is a huge gap between first-class research – for example, in Europe, we have a real first-class research in pain. But the reality for the

patient in diagnosis and treatment still is very weak, so we have a huge gap between all what we know and what we really do.

The only way to get rid of the problem of chronic pain is not to treat the chronic patients, but to make prophylaxis [preventative measures] that the patients not *develop* chronic pain. So we have to start at the real beginning and the real beginning is acute pain and that has to be diagnosed and treated effectively and that can prevent chronic pain. When you take the example of back pain, God has not made the back in the wrong way, but how we treat our own back, that's the wrong way. So in the very beginning, we have to say, okay, you are overweight, you have not enough motion, you have stress at your profession, you have possibly stress in your family... and we have to treat all these and diagnose all these together.

One of the most important points is that the first-line doctors should be trained in diagnosing – not only treating, but really diagnosing – and then effectively treating pain.

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**Evans:** Now at this point, I'd just like to remind you that whilst we believe the information and opinions on ***Airing Pain*** are accurate and sound, and 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.

This is ***Airing Pain***, and we're reporting on the second European Societal Impact of Pain Symposium at the European Parliament in Brussels.

**Judy Birch:** I'm Judy Birch, Chief Executive of the Pelvic Pain Support Network. It's really important to be part of what's happening in Europe, because pelvic pain has been excluded from a lot of the work that's been going on in pain for many years. And we feel that by working with others on a common agenda, we are much more likely to get progress faster than we could possibly on our own, even in our own country.

It's very difficult to come to terms with pelvic pain because it's not generally talked about. It affects more women than men, but men can have a range of pelvic pain conditions: conditions affecting the bladder; the genital organs, just as women. There are more conditions that affect women, but the numbers are huge, in fact. And some of the patients are very young when they present to a GP. We know that it takes, in the UK, around seven or eight years to get a diagnosis of endometriosis, for example. A lot of damage can have occurred in that time.

We had the statistics for the numbers of women with pelvic pain in the UK published in the Chief Medical Officer's report in 2009 and when you have a statistic in an important public report, then it gives less possibilities to exclude it from the agenda. And so now we have something we can use to insist that it is included. The figure for the UK, in women, is one million – and that's without the men. And it's hard to imagine how it was ever not part of the agenda.

**Evans:** Judy Birch of the Pelvic Pain Support Network. So statistics *are* important. Mary Baker is President of the European Brain Council and of the European Federation of Neurological Associations:

**Baker:** We've tried very hard to get a lot of data collected. If I just tell you quickly about one of the projects: this is working with one of our partners, which is Parkinson's. They developed, in their *Parkinson's World*, a PDQ – Parkinson's Disease Questionnaire – 39 questions for people *living* with Parkinson's – nothing for the carers. The carers have to rely on another measurement. And so we negotiated with Oxford University that we would like to develop the Carer Strain Index for people looking after people with Parkinson's.

Very interestingly, the young person who did the work for the Parkinson's disease patients offered his services again to do the carers'. He lasted just four months, as he found the distress from the carers much harder to bear than from the patients themselves. So, a change of researcher and the results are coming out. We're going to launch them in Budapest.

Lots of people shake their heads wisely and say they understand about caring. But, not until you really read the answers in the carers' questionnaire, will you appreciate what it's really like to take on the responsibility of another person who, however hard you work, however hard you try, is deteriorating before your eyes. The strain is enormous.

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**Ros Meek:** My name is Ros Meek and I'm the director of the Arthritis and Musculoskeletal Alliance. So often we really look at the issues that NICE looks at, which are more about quality of life in terms of cost, i.e. cost of treatment. But, actually, if, by having ankylosing spondylitis at the age of 25, within a year, you're going to be out of the workplace – that's a massive impact, both personally and also to society, because society will then need to support you through the benefits that you will claim to keep you going. And so it's really important for us to be able to quantify what the societal impact is. So whilst the costs initially of drug therapy given at an appropriate time might sound very large, actually, if you look across a person's lifetime from the age of 25, the cost of drugs diminishes as against the cost of the social insurance cost of enabling people to be on benefit for many years.

**Evans:** Ros Meek. Now going back to that Declaration of Montreal, there was much discussion in this European Societal Impact of Pain Symposium on the acknowledgement and treatment of pain as a human pain, and also whether pain should be classified as a disease in its own right. Ceri Phillips is Professor of Health Economics at Swansea University:

**Ceri Phillips:** I don't think we can fully eradicate pain from any condition and any society, but to make it manageable, to make it tolerable, to make it appropriate to manage is something which we should all aspire to. We need a concerted approach from a multi-factorial perspective, with all agencies involved. The politicians ultimately make decisions as to who gets what resources and there's an obligation there to ensure the management of chronic pain perhaps features higher up the priority list than it currently does, where it seems to be very near the bottom.

But I think there's also the realisation that clinicians need to do better; that they need to utilise effective treatments and they need to remove those treatments which serve no purpose whatsoever. There needs to be further research to determine what works and what doesn't work and in what circumstances it works. We need to ensure that we use resources wisely and efficiently – we do not want to waste resources. We also need to ensure that patients themselves are empowered through education, training and knowledge of what works and they can be involved in the management



of their own condition, which I think would then go back to the point made earlier about [pain management] being a human right – they can actually contribute to the establishment of what is a tolerable level of pain.

The notion that pain is a symptom – pain is a subsidiary condition of other conditions, I think, will always be debated, but what the evidence does show is that if pain is appropriately managed, the ability to cope with the other condition, the other health problems is made easier. Pain has such a negative impact on quality of life that even patients with heart disease who have tolerable pain are in a better health state than those patients with heart disease who've got considerable pain. So there's an urgency and an emphasis: we need to address pain irrespective of where it's located; irrespective of what the other conditions and health problems are.

**Evans:** Health economist Ceri Phillips. Here's Gina Plunkett again:

**Plunkett:** The best way to describe the level of pain that I was in is really to describe how I, for example, would feel that my arm had been crushed and crushed by a concrete wall. And I often thought to myself, why is my brain telling me that this arm is crushed by a concrete wall and not a steel girder or a fallen tree? I don't know why... It was like my brain was battling with the reality, which was that I had a perfect arm. And I used to think I would like to hack it off and throw it away. And so that was the level of pain I was dealing with.

And as Professor Krauss here, the next president of EFIC, put it, he described chronic pain as 'a persistent torment' and that would be exactly how I would describe it. All I really wanted was for the pain to be brought down a level that would enable me then to start living again.

So I always had the hope that if I did get the right person and the right treatment and care, then I could do the rest myself. And a huge part of that was being believed. So once I was believed, then I could start believing in myself again, that I had something which was *very* real, that it was a disease. And then I could do the rest myself with the pain management techniques we all know of: pacing, relaxation and distraction, but – with the hope – I was able to start working on changing my life and adapting to my new situation, which was living with pain. Up to that [point], really, I think I went into denial, because it was my only way of coping, where I felt that there was no support or no recognition that what I had was very real.

**Baker:** Pain is not just hitting your thumb with a hammer – it is much greater. And I have to say I thought I was pretty well-versed in understanding disease and pain, but it's not until I actually start rubbing shoulders with people who've lived years with pain that you begin to see what they're really up against, because there's no outward sign of their disease.

**Evans:** Mary Baker, president of the European Brain Council and of the European Federation of Neurological Associations. Now she chaired a meeting at this Societal Impact of Pain Symposium to explore the possibility of setting up the Europe Pain Alliance. This would add the essential patients' voices to talk about pain within the European Commission and Parliament.

**Baker:** There are many so-called 'diseases', and it's quite easy to distinguish them, for instance, there's the European Parkinson's Disease [Association] – a clear remit to improve quality of life for people living with Parkinson's disease. The public know a little bit about the illness. They can actually see the illness with the well-known pill-rolling tremor and they also know people living with Parkinson's disease. But pain has a greater challenge. People make judgments about pain. People are hysterical with pain. People are taking time off from work. It's really important that we can actually define pain as a pain disease, rather than just 'with rheumatoid arthritis, you have pain' or '[with] cancer, you have pain'. It needs defining as an entity in itself, and to be better understood.

EFNA is a federation of neurological associations, and unfortunately at the moment, pain hasn't even entered our radar. We're just conscious that it's not on the radar. So we've been doing projects to try to make generic things across all the diseases, because, you know, we have stroke and Parkinson's and multiple sclerosis; dystonias, ataxias, Huntington's... You've got to try to find a common formula, so we've looked at carers; we're now looking at the pelvic organs, would you believe. But, you know, the neurologists are not always in tune with asking questions about bladders, about bowels, about sexual dysfunction, which are a major part of quality of life. They're not always aware of mood changes. So all these things we've been looking at, but the one thing we have not been able to look at, because there's no voice for us to talk to, is pain. That's why we're really interested in seeing this group emerge.

We're acutely aware that one of the things that all of the diseases sitting around our table [share in common] is they all suffer pain. What we need now is the voice of pain to join us and to help sort out what sort of projects need to be developed and to see if

we can improve the quality of life of people living with chronic pain *plus* people living with diseases which have pain.

One of the most important tasks for this new emerging patient group, Europe Pain Alliance, is to raise the profile of pain. Because, you know, there's one thing about getting delivery of services, but there's also another very major point in being a patient organisation – it's trying to effect change, and we need a lot of change in the management of pain.

I must confess I don't know the future of pain management, but one thing I surely know is you don't just want doctors and nurses making decisions without the patients' voice. And if you do have a European organisation, there *will* be a patient's voice sitting at that table. And it's really important because although doctors and nurses understand the mechanics and the development of pain, the thing that the patient brings to the table is what it's like to *live* 24 hours a day, every day of the week, every day of the year, with pain.

**Plunkett:** I felt it was very important for the patient's perspective to be heard; for the story to be heard. I mean my story is a narrative that everyone, I think, living with chronic pain would agree with. And there are certain issues that are common to everyone living with chronic pain and therefore I felt what I was saying was being said for the millions of people living with chronic pain.

**Evans:** Gina Plunkett. Now before we end this edition of *Airing Pain* at the second European Societal Impact of Pain Symposium, I just want to remind you that you can put a question to our panel of experts or make a comment about these programmes via our blog, message board, email, Facebook, Twitter, or even pen and paper. And the contact details as well as the link to download all the editions of ***Airing Pain*** are at our website, which is painconcern – that's one word – [painconcern.org.uk](http://painconcern.org.uk).

**McGuire:** We're here speaking at a very important meeting in Brussels on the societal impact of pain and even in well-developed countries our services generally are not adequate. So you feel heartened and a little disappointed that there are so many countries in the same predicament. But the positive aspect, I guess, is that all the countries are coming together with a common agenda, which is to make service provision better for people with chronic pain, so I think it's a positive development.

**Zenz:** The work of EFIC could be very important and is very important because EFIC is promoting, really promoting, much more than some national societies. And EFIC,

as we can see in this meeting here, has the force and the power to collect all the important persons together and to promote pain diagnosis and pain relief.

**Meek:** I think politics is the main way that we can achieve change. We need to look at all the stakeholders that are involved in changing policy, changing public opinion. And so I think in looking at what our European Members of Parliament can do – how they can actually impact on our national policies – is a vital part of the equation when we look at trying to change the sorts of things that will make life better.

**Baker:** I thought we were going to face a lot of hurdles about the splitting down of pain, you know: back pain; face pain; pelvic pain; neuropathic pain. Not at all – there was *passion* around that table to take it forward as *pain*.

**Plunkett:** I am highly impressed. I think it has been a fantastic event. I think it's going to set the scene for serious action here in Europe and I really hope what happens here now – and we're talking about a written declaration drafted and drawn up to be presented to the parliamentarians – I really hope that that will start a serious campaign to have chronic pain put on the agenda of the European governments and the national governments.

## Contributors

- Dr Beverly Collett, Consultant in Pain Medicine, University Hospitals of Leicester NHS Trust
- Dr Brian McGuire, Senior Lecturer in Clinical Psychology, National University of Ireland in Galway
- Gina Plunkett, Chairperson, Chronic Pain Ireland
- Prof Michael Zenz, Chair of Anaesthesiology and Pain and Palliative Care, Ruhr University
- Judy Birch, Chief Executive, Pelvic Pain Support Network
- Mary Baker, President, European Brain Council and European Federation of Neurological Associations
- Ros Meek, Director, Arthritis and Musculoskeletal Alliance
- Prof Ceri Phillips, Professor of Health Economics, Swansea University

## Contact

Pain Concern, Unit 1-3, 62-66 Newcraighall Road,  
Edinburgh, EH15 3HS

Telephone: 0131 669 5951      Email: [info@painconcern.org.uk](mailto:info@painconcern.org.uk)

Helpline: 0300 123 0789

Open from 10am-4pm on weekdays.

Email: [help@painconcern.org.uk](mailto:help@painconcern.org.uk)

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