

Airing Pain Programme 85: Pain in Europe

Why pain is a matter of life and death, the struggle for diagnosis and challenging misperceptions of palliative care.

*Around 20 per cent of Europe's adult population live with chronic pain and the consequences for individuals and society are devastating. In this edition of **Airing Pain** we head to the Societal Impact of Pain meeting in Brussels to hear from the patients, healthcare professionals and policy makers coming together to improve the lives of people in pain across the continent.*

Dr Chris Wells explains why pain management is a matter of life and death and how to put pain higher up the political agenda. MEP Theresa Griffin takes up the baton with a call to make the workplace accessible to those living with pain.

Jane Moejlink describes the challenges of getting a diagnosis for interstitial cystitis and Sjögren's syndrome in the face of sceptical doctors and the language barrier, while Professor Ilora Finlay makes the case for a different view of palliative care. Plus: an update from Ireland and bursting balloons to raise awareness.

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 funded by a grant from Grunethal.

Now at the time of recording this edition of **Airing Pain**, that's the end of June 2016, the people of the United Kingdom have just voted to leave the European Union. That doesn't get away from the fact, however, that around 20 per cent of Europe's adult population, that's 80 million people, suffer from chronic pain, and this costs, directly and indirectly, one and a half to three per cent of Europe's total GDP – that's gross domestic product.

Those are the stark statistics presented to delegates at the European Pain Federation's Societal Impact of Pain Symposium, or SIP, held in Brussels in May of 2016. It's the sixth such symposium to discuss the socioeconomic impact of pain for individuals and societies. And it went under the banner headline Time for Action, calling for the prioritisation of pain as a disease in its own right in the EU health programme. It brought together over 200 pain experts, patient representatives and policy makers representing 28 European countries.

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Back in 2011 the symposium launched its roadmap for action at the European Parliament, and initiative to make pain more visible at the level of national and international policy makers. Tom Green, editor of Pain Concern's magazine *Pain Matters*, was there to meet delegates, starting with Dr Chris Wells, who is a pain relief specialist in Liverpool. He's also president of the European Pain Federation, EFIC.

Dr Chris Wells: The roadmap to action is really an assessment of how we're doing. We take policy decisions that we think are important and we identified that five years ago. So we look at the roadmap and we can see in some countries some things are being instituted and, unfortunately, in other countries very little has been instituted. But at least it flags up where there are weaknesses so we can now try and mover forward to addressing that, which is something that we're going to do.

To all people, they just think that pain is a nuisance and usually people have had pain, so they had a toothache and it was upsetting but it went away the next day. So they don't really understand the misery of chronic pain, Politicians have no idea about the cost to society. They are beginning to be aware of the problem in restriction of quality of life. Quantity of life is a new issue and we've now got data to show people with chronic pain have a reduction in quantity of life – they die sooner. And the corollary of that is also information that shows us that if their pain is adequately treated, for instance with a non-steroidal, their quality of life and their quantity of life both improve. And this is hugely important, so people can live longer in a more healthy way.

Tom Green: How much life is being lost, how much life could people expect to lose if they have untreated chronic pain?

Wells: The data is not good enough to really put that across the whole population of, in Europe a hundred million chronic pain patients. But we just know that some are losing their lives through immobility, through despair, through problems with their treatments that they have and just being ignored. I started doing cancer pain work and there's no question to me, you can see people that fought and fought against their cancer and did ever so well, and eventually there came a time when they just thought, 'no, the pain is too much. What's the point in going on living?' And I could see people just quietly giving up and saying 'this is it'. So we've not been able to prove that one yet, but we all know it as clinicians.

But the data that we have on disability from pain, for instance, in osteoarthritis, that is very solid.

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Green: So that's a strong message to take to the European Parliament and also to the UK national parliament.

Wells: We can't afford to ignore pain, although the politicians are frightened because we go along and we say we want more of this, we want more of that and they understand that there isn't more. However, if we can show that we want more of this and it saves money in the long term, then I think we have got an important message and that's what I think we should be doing.

There's no point in us doctors just being shroud-wavers and saying our patients need this, because we've all got vested interests. Even there's no point in patients just saying that, but we can say, look, this is the cost, we could reduce that. And we need to look at better treatment but as a specialist coming out here, better prevention, better education for doctors and better education for patients. And that's one of EFICs strong points, education, that's what we do.

Green: How close do you think we are to really transforming education for doctors, and perhaps for the general public as well?

Wells: Well it's improving and you can see that from the roadmap. And, again, in the UK now one third of medical schools use pain in the curriculum for medical students, and that's good. Two years ago I think it was none. So if we're rolling that out and in another six years it's all of them, fantastic. Then we're going to have doctors in the future who understand more about pain.

Green: And from the patient's point of view what does that mean?

Wells: From the patient's point of view that means that hopefully they can see their GP and get a sensible answer. And I think that, we've already had discussions on that, it's not just me, it's not just the patient groups, the GPs accept, first of all, they don't have the time; secondly, they don't have the experience to teach things like self management, they don't know how to do that.

And this is by far the best SIP we've had because we've got much more patient involvement and much more MEP involvement, which of course matters. There is no point in healthcare professionals sitting around talking about what wonderful ideas we have. It'll never happen



unless we get the patients and the politicians on board and I think we truly have. So that's why it's very exciting to me.

Jane Moejlink: I'm Jane Moejlink and I'm chairman of the International Painful Bladder Foundation, which is for patients with interstitial cystitis, which is today mainly known as bladder pain syndrome and we cover all the comorbidities, chronic pelvic pain and everything related to that.

I'm here as a patient advocate and by profession I was a translator, writer and editor, and I've been able to use that now in the voluntary work for the patients. So I try to write a kind of report, not only for patients, patients can understand, but it's also read by various health professionals.

Green: So what will you be reporting back from this meeting?

Moejlink: There's been an awful lot of talk about what should be done but I'm still waiting to see something actually being done. And I must say I was rather concerned to see the European Parliament does not have a section dedicated to health, that health is hidden somewhere under environment, which sounds utterly ridiculous today. It's vital that we ensure that people are healthy because our whole system, certainly in Western Europe, depends on people working paying into the system before they can take out, so you've got to have a kind of balance between the two. Because if you've got too many sick people and they're not paying taxes into the system and you've got a lot of people, far more people, taking out, the economy is simply going to crash. So I would have thought it was a priority to have health as a very important section.

Green: So you're a passionate advocate and that comes partly from personal experience?

Moejlink: Yes, it certainly does, because I'm a patient with interstitial cystitis, but I also have Sjögren's syndrome and many other comorbidities, but it took me 29 years to get a diagnosis of interstitial cystitis and actually almost 40 years to get the right diagnosis of Sjögren's syndrome.

I got first of all the diagnosis for IC and I then discovered that there was no information available in the Netherlands, where I was living, I am British but I live in the Netherlands married to a Dutchman. And there's no information, and so together with a couple of other people we set up a patient movement which ultimately led to a patient association.

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And I felt that I couldn't turn the clock back, when it's taken so long to get a diagnosis you tend to feel very angry: 'why didn't they give me the diagnosis? why did they allow these diseases to wreck my life, really?' I had to change my whole ideas of a profession completely. And my whole family suffered under it because I didn't have any treatment, and not only that, if you don't know what's causing your problems, and I was sometimes very ill, you become extremely stressed and you start to doubt yourself.

Now, I wanted to avoid this happening to other people as far as I could. Well I'm now in my seventies and I'm hoping I can carry on for a bit longer because there is still so much to do, people are still not getting a diagnosis and as Joop van Griensven said today, patients are often not believed by the doctors and even I face this. That the favourite word of, for example, neurologists, is 'somatisation' and that stresses patients even more if they feel the doctor isn't believing them, and stress makes many illnesses worse.

Green: By 'somatisation' what do you think they mean?

Moejlink: 'Psychological' – in the past they would say it, they would write it to your family doctors, psychological. Now they've changed the word. 'Somatisation' is the favourite word but it means the same, they don't believe you.

And I found a particular difficulty in the fact that I'm English but live in the Netherlands, so when I go and see a doctor I'm speaking a foreign language. And describing pain, especially neuropathic pain, which I have, is extremely difficult in your own language let alone a foreign language. It's so difficult to find the right words, and I find that doctors often are very impatient about this and they don't even help you to find the right words. They just say, 'oh that's not possible it doesn't exist', when it's simply because you've chosen the wrong words.

We've now got Europe full of migrants so I hate to think what is going to happen in hospitals when these people with a very limited knowledge, if any, of the host country's language are trying to explain their health problems. And this should be taken into consideration very seriously.

Green: So, in English, how would you describe your neuropathic pain symptoms?

Moejlink: Stabbing, burning, tingling and just horrible sensations sometimes. And sometimes it's in one place and sometimes it's in another place and trying to explain that to a doctor, that this pain is moving around. And one day it's very bad and another day you

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might not feel it at all and it comes suddenly, it may be short and stabbing, or it may be long and nagging, or it might be quite different, that you sort of have half sensation. Now describing that to a doctor is very difficult, they say 'you can either feel it or you can't feel it'. I say 'no, I half feel it'. 'That doesn't exist in our book.'

Evans: Being understood as a patient is one thing, but when health professionals can't even agree amongst themselves on the simple definition for chronic pain, what hope is there for the rest of us?

Dr Martin Johnson was at the 2016 Societal Impact of Pain Symposium representing the Chronic Pain Policy Coalition and the Royal College of GPs and he chaired the session to discuss the definition of chronic pain. Is it a disease in its own right, or a symptom of some other disease? Now to the layman and even some health professionals I guess, this may be pure semantics, so Tom asked him why it really matters.

Dr Martin Johnson: I think that's one of the first questions, does it matter? One of the things we've done quite a lot of work in, in the UK and we had a big debate about it, was it three or four years ago. That probably from our perspective it didn't matter, just purely from a clinical point of view, what it mattered was to make it into a condition, which is what we managed to achieve.

Whether it matters for patients – and this is something that I always... I'm always sitting on the fence with this – I actually personally think it does matter. I think it's very important for patients to know that they've got a diagnosis, 'cos it then gives them a way forward. Now actually some patients don't necessarily agree with that but it's going to be an interesting debate.

Green: Have you had discussions with patients that you can call to mind who've been aware that this has been a particular problem?

Johnson: For some patients as long as you've managed to give them some sort of management plan that to me is the important thing. But there's the occasional patients where I see where they've not been handled in the right way and it's simply because a diagnosis of some description has not been given as part of their plan. And I'm well know for saying that it has to be assessment, assessment, assessment, because if you don't get the right the journey – it's like if you don't get your ticket right at the start of a journey you end up in the wrong place – and it's exactly the same if you don't get the right diagnosis.

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And I think there is potential that – we're still in early days there is no international consensus, and maybe SIP can help us do that – because then we can translate it through. There's a very interesting article that Ann Taylor and colleagues produced earlier this year. They've done a complete review article on whether or not pain is a disease or symptom.

Evans: That's a debate which seems to go on and on, even though EFIC, that's the European Pain Federation, and IASP, the International Association for the Study of Pain, made a declaration to the European Parliament as far back as 2001, that pain is a major health problem worldwide. Although acute pain may reasonably be considered a symptom of a disease or injury, chronic or recurrent pain is a specific healthcare problem, a disease in fact in its own right.

If you've got an hour and a half to spare you can watch and listen to Doctors Ann Taylor and Martin Johnson supporting the motion, chronic pain a disease in its own right, in a debate recorded in 2012. You can find the debate by going to the website paincommunitycentre.org and putting the words masterclass 2012 into the search box in the top right hand corner.

Ilora Finlay: I'm Ilora Finlay, Baroness Finlay of Llandaff, and I'm Professor of Palliative Medicine in Cardiff and Palliative care lead for Wales. I chair the National Council for Palliative Care.

Green: From the Societal Impact of Pain meeting here in Brussels what's your sense of how pain management is going to get taken forward at a European level, and what can Europe really do for pain management?

Finlay: Well I'm very glad to see that there's been a lot of talk about integrating palliative care into mainstream cancer services, and integrating rather than having it as a tack on, an add on. I'm also glad to see that there's been a stress on the assessment of pain and then appropriate management.

In the group that I was in we discussed the impact on carers as well and on the family witnessing somebody in pain. I think I've also been quite shocked actually at the number of stories of really bad clinical decision making that I've heard, for instance, the concept that consent is not valued unless it is fully informed really seemed to come as a bit of a surprise to some people. It was almost as if consent to treatment was a given and people just signed on the dotted line. And in the group that I was in I was stressing the ability of patients to



refuse treatments if they didn't want them, if they didn't feel they were working. And that they still must receive all care, including ongoing monitoring of pain and pain relief.

So this meeting has been very important in bringing people together, in raising awareness of the need for integration and actually bringing pain as the fifth vital sign into mainstream cancer treatment and thinking.

Green: And what does that mean, 'pain is the fifth vital sign' in cancer treatment? What would that change?

Finlay: I think what that would change is that it is everybody's duty at all times to listen to the person in distress, to listen to their pain and to do something about it. And it doesn't matter whether you're the therapeutic radiographer or whether you're a care assistant, a nurse, a physio or a porter, let alone if you're the doctor or a nurse on the ward, if the person is in pain, then they *must* be listened to. Pain is where the patient says it is, you need to look at the different components, the different causes and remembering that the acute unrelieved pain that goes on and on becomes chronic pain. But also that in the cancer patient pain is often a sign of something that may be reversible, because it's a signal of disease in itself. So if you ignore pain you ignore the very essence of the warning lights that are there.

Green: What is different about pain management in cancer care?

Finlay: I would like to say something about the model that we've in Wales and the Llandaff cancer centre, because we have totally integrated palliative care with oncology. That means that all the patients are automatically under palliative care, whatever stage of treatment they're at. So that we look at symptom control, distress, if they're doing really well with their chemotherapy, that's great – we don't see them again when things are sorted. However, if they are in the unlucky group where things aren't going well and disease progresses, we've already got to know them, we link them to services outside, into the community when they go home, into other hospitals.

We're part of the acute oncology meeting that happens in the hospital and often lead that meeting. We're supporting the juniors in training and we're supporting other staff across the hospital. At the end of the day the oncologist carries the final responsibility for the patients' care – we're responsible for everything we do but we report to them. And over all the years that we've been running that system we haven't had any problems, thank goodness, in relationships with other people, but we've had an awful lot of patients who we've helped

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improve their symptoms and improve their quality of life who, otherwise, if we'd been waiting for a referral, we probably would have never heard about.

Green: When I hear, as a layperson, the words 'palliative care', it makes me think that's for people who are dying.

Finlay: That's really sad, the end of life story has taken over from actually the helping people live well until they die story, which is what palliative care is all about. We're all going to die, we all have to plan for the worst, but we can hope for the best and in whatever time we've got left – and let's face it none of us know when that is – in that time we can do all we can to improve patient's quality of life. And if we do that, and we support the carers, then when that person dies the impact on the carers and the family will be far less damaging if they have prepared for their death, if people know what they want.

So I would hope everybody listening to this will make sure that they personally have made a will, they have told their family what they want when they become ill and when they die, they've thought about being an organ donor perhaps. All kinds of things that if they're not sorted out when somebody dies their family is left with a terrible, terrible burden.

Evans: That was Baroness Ilora Finlay talking to Pain Concern's Tom Green.

John Lindsay is chair of the patient information and support group Chronic Pain Ireland.

John Lindsay: When you travel to Europe, mainland Europe in particular, and you hear what's happening in other countries you then appreciate that what you have back home is not that bad after all. So I don't think there's any particular country in Europe that could put its hand up and say we are doing extremely well for people living with this horrendous condition.

Green: And what would you say would be what you would hope would come forward out of the Societal Impact of Pain meeting we've had today?

Lindsay: I think the most important thing is creating awareness among the medical profession to start with, particularly GPs, and at consultant level maybe neurologists and rheumatologists, who still don't quite get this whole chronic pain condition. So I think educating all the members of the medical profession. And I think everybody has to have a look at their medical schools and change the curriculum and have pain medicine as a module and I think that should be absolutely number one priority.

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Green: Where has Ireland got to?

Lindsay: Pain medicine has been declared a medical specialty and as a result of that our six medical schools are now looking at the curriculum for trainee doctors and they're going to have pain modules for all of them. Because at present I think for every hour that a medical student spends on pain a vet spends five hours. So that needs to be addressed. It is changing and hopefully it will change throughout Europe. So that's the first thing coming out of today. And then generally to create awareness, but there's no point in creating an awareness and getting people's expectations up if there are no services there to back up what is required to treat somebody with chronic pain and there is no doubt they need a multi-disciplinary team approach.

Evans: Now creating awareness is the aim of the red balloon project launched at the 2016 Societal Impact of Pain symposium. As its headline says 100 million people suffer from chronic pain, help turn statistics into voices.

Joop van Griensven: My name is Joop van Griensven, I'm the president of Pain Alliance Europe, and we're starting today with the awareness campaign called the red balloon project. You can find it on the hashtag #Releasethepain, you can find all the information over there, or on the website www.theredballoonproject.eu.

Green: So what's the idea?

Van Griensven: The idea of the project is to raise awareness for chronic pain, it's about a red balloon which stands for the pain you have and you try to release the pain, so get rid of the balloon. You can do that by popping it, or leave it in the air – for pollution reasons better not put it in the air. It's raising awareness for chronic pain.

Green: So the idea is to get how many people to do this?

Van Griensven: We would like to get one million people having a picture with a red balloon on one of the instagram, facebook or twitter accounts and then we can in Brussels, here, to the European politicians say, 'well, so many people want to have something done on chronic pain, now it's time for you to do something'.

Evans: And to do something, get involved in the red balloon project go to #Releasethepain on social media sites like twitter and instagram, or the website which is theredballoonproject.eu.

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Don't forget that you can download all editions and transcripts of ***Airing Pain*** from Pain Concerns website, which is Painconcern.org.uk. There you will find information and support for those of us with chronic pain, our families and carers and for healthcare professionals. There is also information on how to order Pain Concern's magazine Pain Matters.

Now before we end this edition of ***Airing Pain*** at the European Pain Federation's Societal Impact of Pain 2016 symposium I'll just remind you of what Dr Chris Wells, the president of the European Pain Federation said to Pain Matters editor Tom Green at the start of this programme.

Wells: There is no point in healthcare professionals sitting around talking about what wonderful ideas we have. It'll never happen unless we get the patients and the politicians on board and I think we truly have. So that's why it's very exciting to me.

Evans: So you've heard from the patients and their representatives, last word to the politicians.

Theresa Griffin: My name's Theresa Griffin and I'm with the European Parliament for the North West of England. What I hope comes out of today, Tom, is real recommendations that we can take forward as members of parliament, in terms of putting chronic pain and acute pain higher on the agenda, but also enabling people to have the wherewithal to return to work if they wish to by being treated as a whole person. Four hundred million citizens in the EU suffering from this kind of pain, they have to be able to play a full part in society, we've got to be able to support them. It's not just that bit of your body, it's the contribution you can make as a person to society, it's your family, it's your work colleagues, it's what you do in your local community, this is too important, it's got to be holistic.



Contributors

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- Jane Meijlink, Chairman of the International Painful Bladder Foundation
- Dr Martin Johnson, Chronic Pain Lead at the Royal College of General Practitioners and Co-Chair of the Chronic Pain Policy Coalition
- Ilora Finlay, Professor of Palliative Medicine, Cardiff University
- John Lindsay, Chairperson, Chronic Pain Ireland
- Joop van Griensven, President, Pain Alliance Europe
- Theresa Griffin, MEP for the North West of England

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