

Airing Pain Programme 64: Patients, Pills and Policies

Making pain patients' voices heard across Europe and changing the prescribing culture.

Almost 100 million EU citizens have chronic pain, but there is still much progress to be made in improving diagnosis and treatment. Pain Concern's Rowena Jacobs attended the fifth Societal Impact of Pain symposium to find out how patient groups, healthcare professionals and policy makers are coming together to push pain up the agenda.

We hear about a successful initiative to change the culture around opioid prescriptions in Italy and the problems facing patients across the continent due an excessive fear of drug dependence, while Northern Irish representatives explain how the Painful Truth campaign has brought the patient experience of pain home to healthcare professionals and policy makers, leading to greater recognition of pain.

Pain specialists at the forefront of the campaign for better care explain why education and awareness raising is still such an important issue and Lars Møller, representing a Danish patient group, recalls his struggle to get treatment for pain in the face of ignorant healthcare professionals. Finally, people in pain are urged to get involved in the fight for better pain management services by putting pressure on politicians.

Paul Evans: Hello and welcome to **Airing Pain**, a programme brought to you by **Pain Concern**, the UK based charity working to support and inform people living with pain and healthcare professionals. I am Paul Evans and this edition has been funded by a grant from Grünenthal.

Chronic pain affects almost 100 million European citizens and that includes fifty per cent, *half*, of the older population. It causes 500 million days of illness per year, with a cost to the European economy of more than 34 billion euros. In November 2014, the European Pain Federation (EFIC) held its fifth symposium on *The Societal Impact of Pain* in Brussels with the aim of raising awareness of the impacts that pain has on our societies, health and economic systems. Now those statistics are mind-boggling – perhaps too large to comprehend. Put another way,

there are 100 million individuals who will have their own personal stories of how pain has impacted on their lives, the paths they have taken or failed to take, to receive adequate treatment or support. Lars Møller from Denmark has been a pain patient for seventeen years. He is Vice President of the Danish Association of Chronic Pain Patients and a member of Pain Denmark. He spoke to Pain Concern's Rowena Jacobs.

Lars Møller: When I was a little boy, I was always doing sports and stuff, I couldn't sit still. When I was around eighteen years old – I did a lot of windsurfing and athletics. One day after jogging and weightlifting, I was cycling up a hill and suddenly I felt like this burning pain in my shoulder. I went to the doctor and he checked me out but he couldn't really find anything and I kind of learnt to live with it. Actually, I started playing tennis with the left arm and started writing with the left arm but then came pain in the left shoulder. Two years later, I was in Australia, doing windsurfing training and when I came back, I was out doing some try-outs and I did a big loop and when landing it, I had the same pain in my forearms but this time it was much worse. I could not sleep. At that time I started a sports course at University and we had to do a lot of physical things – after one year, my whole life broke down – I could barely walk down the stairs. I was thrown around the health system – they could not really measure or see anything. They found some unspecific things but could not give me a condition.

Evans: Now Lars Møller's story of frustration will be familiar to many of the 100 million Europeans living with chronic pain. Chronic pain as opposed to acute pain is continuous, long term pain of more than twelve weeks or after a time that healing would have been thought to have taken place after trauma or surgery. Hans Kress is Head of Department of Special Anaesthesia and Pain Therapy at the Medical University of Vienna. He is a past President of the European Pain Federation

Hans Kress: Our problem is that even physicians, even healthcare professionals, even university teachers in medicine simply think that chronic pain is nothing else but a persistent acute pain due to another chronic disease. When you have this misunderstanding, when you misinterpret chronic pain as being nothing else than a prolonged acute pain, then you will not understand the problems of your patient, you will not understand that treatment is different and finally you will not be able to treat the patient in a proper way.

When you have this wrong belief, then of course you will accept and you will expect that when

the underlying other chronic disease is properly treated, the pain will automatically disappear. That means that when you no longer find the symptoms and the signs of the underlying disease, you believe there cannot be any pain any longer. If the patient still tells you that, 'I am still suffering from chronic pain', then many healthcare professionals blame the patient of exaggerating, of malingering, of being a hypochondriac.

That is a real problem for the patient who feels not understood, who feels really neglected – it is also a problem for the whole healthcare system because then such a patient will produce a lot of additional costs, not only within the healthcare system but for the whole of society because the patient still has pain and because of this pain, he will continue to look for a solution, to consult other physicians, to go to hospital, to undergo a lot of unnecessary but very expensive diagnostic or maybe even surgical procedures. So, one of the problems is to communicate to lay people as well as to healthcare professionals that you cannot see pain – pain is not visible – you cannot objectively measure pain but nevertheless when the patient tells you, 'I am still in pain', this is a fact.

Møller: I actually ended up with very bad depression and anxiety attacks. I gave up on the public system and went to New York. I was given some herbs there which gave me anxiety attacks and on return I was committed to a psychiatric unit and was given electro shocks. I was there for half a year. I kept saying to them that they had to give me something for my pain but they kept giving me antidepressants. They said the depression was the cause of the pain but I knew that it was the pain that led into depression. It seemed like they were blindly trying to find a somatic reason, like a physical reason, and of course you should always do that but you have to, in the meantime, start some form of treatment or guidance – I did not get any help.

Every time I encountered a new doctor, they were really arrogant because they did not find anything and when I tried to tell them I did not care about the diagnosis, I just needed some help with the pain, with being able to sleep, being able to go to school, being able to go shopping/buy groceries... But it seemed like they had blindfolds on – they just focused on a diagnosis.

Kress: We have to educate the physicians of the future so that they understand the difference between acute and chronic pain and that the treatment concepts for chronic pain completely differ from acute pain. Of course, we have also to educate our politicians and the decision makers in our health system because the decisions are not made by physicians in our

healthcare systems – the decisions are made by regulators, by administrators, by politicians. They must understand what it means to properly treat chronic pain patients and that it finally will even save resources that can then be used for other things and other purposes.

Evans: Dr Hans Kress of the Medical University of Vienna talking to Pain Concern's Rowena Jacobs at the 2014 European Pain Federation's Societal Impact of Pain symposium in Brussels.

Professor Giustino Marassi is a pain doctor in Italy:

Giustino Marassi: I appreciated very much the discussion about educational and cultural approach. Those are two completely different things in my opinion and I was a little bit impressed that the audience this morning voted that the most important aspect is education. To me, the most important aspect is culture because education is just one small part of the culture – nothing else than this.

To give an example, which is very clear, in 2000 in Italy, every doctor had received clear education on the effects of opioids, the efficacy, the side-effects, etc., etc. However, we were still in a moment of our history, like it is for many other countries where we had this concept of opiophobia deriving from an old, old story that was the war of the opium in China... that had completely confused the mentality of the doctors – putting together the use and abuse of opioids for addiction and the use of opioids for therapy, which are two completely different things.

At that time, a doctor in Italy, did not have (as it is in many other countries still today) the possibility to prescribe opioids. First of all, we just had morphine (injectable morphine) as a drug and it was almost forbidden. It was used just in very exceptional cases, which was stupid, *completely stupid*, because, we need opioids to care for pain. So you cannot oblige people to prescribe opioids on a [triplicate] form with completely different rules inside of the hospital law, outside of the hospitable law.

At that time, if a doctor was found with a vial of morphine in his bag, when he was going to visit a patient at home, he could have been arrested, because it was forbidden to carry out the opioids. This was the consequence of a bad culture. Since then, we have made many, many, many steps forward and that is why we now have a completely different cultural approach.

But, going back to my previous topic, doctors did not know at that time, less on the use of

opioids than what we know now – this is education, which is something different. So, you can have a good education on the use of drugs, but you can have a completely mistaken cultural approach and so you don't do anything.

Evans: Italy's Giustino Marassi. Now cultural barriers which stop people who need controlled medicines like morphine for their pain is an area of research for Dr Willem Scholten and his team. They analyse the legislation and policies of twelve European countries from the Baltic States in the north to Greece, Turkey and Cyprus in the south.

Willem Scholten: If you have so many barriers, it is like a water pipe where you have twelve valves or more in it and the water starts running, only after you opened the last one. So it is very important to have a good analysis and to take away all these barriers.

Legislation barriers can be that the law says in some countries, that a patient can get the medicines only for seven days at a time – when you are a chronic pain patient, it is quite a burden to go after new prescriptions every seven days. Sometimes it is even worse, because you can solve this maybe, by having the doctor prescribe multiple prescriptions at a time, but if there is also a limit on the validity of the prescription, then you need to go to both the doctor and the pharmacy every so many days.

Other things are legal limits on the dosage and legal limits that are lower than sometimes needed for patients. There are limits on who can prescribe – pain is almost in any medical specialty so every medical doctor should be allowed to prescribe. Of course, he should make sure he has the knowledge of how to treat pain – once he is knowledgeable on the topic, he should be able to prescribe. In many countries, it is only an oncologist or only a GP who is allowed to prescribe and other doctors are not allowed to do so.

These are the legal barriers but what we experience also – in many countries the people there told us – that the medical education on how to treat pain is limited just to two/three hours. The people who get really good education in pain treatment are the veterinarians, so our cats and dogs are better treated than we are treated.

Another issue is the attitudes, some people think that they will become dependent immediately when they are treated with morphine for their pain but actually, it is a very low percentage of people that become dependent on these substances and then we can treat them and help them

to get off these substances – it is not the end. When you are for a long time in serious pain at that moment the symptoms should be treated, instead of not being treated because of a fear of becoming dependent on something. That likely will not happen.

The Italian initiative is another sign that the pain management is getting more and more important in politics. Also, last summer, the World Health Authority adopted the resolution recognizing that people have a right to health – that is a human right. That right to health is served by having good access to pain medicines. And the Italians have been building forth now on that resolution. Also at the same time they introduced a law for their own country, but I want to stimulate that other countries also take measures. I think that is a very positive sign but other countries in Europe will need to pick up because, finally, it is the country that decides. And Italy can tell others that you need to treat your patients well – but the country's role is to create the conditions for being able to do so. Of course, being as it is a human right, the patient can always go and file a complaint with a human rights body, either at a national or international level. Unfortunately, the large majority of patients just let it go.

Evans: Dr Willem Scholten. Neil Betteridge is Vice Chair of the Chronic Pain Policy Coalition – a forum that brings together a wide range of professional bodies, patient organisations, including Pain Concern, parliamentarians and industry representatives in the UK. It works closely with an all-party parliamentary group in Westminster.

Neil Betteridge: One of the things, that is very important to get the support of any politician or policy maker is that, if they listen to you, are they confident that you are representing the whole community or is somebody else in chronic pain going to come along tomorrow with a different agenda? The more we can reassure them that we are speaking with one voice and that there is a consensus behind what we are saying, then that is the thing that gets you off to a fantastic start – that is a big green light.

Therefore, I hope out of today's event, *The Societal Impact of Pain* meeting here in Brussels, that one of the things that we drive towards is a more focused and prioritized agenda with maybe one or two key messages, key requests that we want to take to our policy makers. If we are then consistent, same messages but different messengers (different people doing it) but the same things being requested at local, national and international level, we are far more likely to be successful and effective. That is the duty we owe to our patients – to be effective.

Personally – and I think to an extent, I am speaking for the coalition – we need to be clear about our evidence base – numbers affected – but there are so many numbers, we need to choose the ones that will have the most positive impact. As I mentioned on the panel discussion here at the meeting, it is easy to use the big numbers because we want so many people to be aware that this a massive problem. But there is a danger there – a risk that the numbers might seem so large that surely, if everybody is affected, it can't be that serious. Or the other danger is that if the numbers affected are so big – 'Well, I'm a politician. I've only got a year left in my post. What can I do?' – so they don't do anything.

So, I believe, yes, it is important to articulate the prevalence – of just how many people are affected – but then quickly move to more specific groups of patients, where there are specific solutions that we can offer. I think we need to get the evidence base right with statistics, but everybody using the same statistics to support the messages.

I think we need to develop what we believe, best practice looks like and I am not speaking just about pain medication there – that's important, of course – I am also talking about how structured self-management can be brought into the pathway; I am talking about the undergraduate training that is needed. If we can recognise, if we can describe what best practice is and all of the stakeholders – from patients to clinicians – all agree on that, then we have got something to lobby for. As long as we are taking rational arguments with evidence behind them, then that is the thing that is going to make us successful.

I think this community itself has got a job to do, because at the moment, I am not sure whether, at the European level, we could take that sort of consensus to the policy makers. If I am right in that, we have got some urgent work to do because we might win the support of individual policy makers and then not have the solution to give them and that would be catastrophic.

Evans: Neil Betteridge, Vice Chair of the Chronic Pain Policy Coalition in the UK.

Health care is of course devolved to individual nations within the UK. In Northern Ireland the Patient and Client Council provides a powerful, independent voice for patients, clients, carers and communities on health and social care issues. You can hear more about their work in ***Airing Pain*** programme number 43 which you can still download from the Pain Concern website and that is painconcern.org.uk. Louise Skelly is its Head of Operations:

Louise Skelly: A few years back, a number of patients came to us, talking about their experiences of living with chronic pain and also their experiences of the health and social care system in Northern Ireland. Within the Patient Client Council, we linked up then with the Pain Alliance and we recognised then that this was a voice that had not been heard in the system, very much an invisible voice in the system. We set up a steering group made up of, not only of clinicians and people from the Patient and Client Council, but also of patients and we set out on the journey of going out and finding out what it was that does not work for patients across the province. That culminated in the publication of the Painful Truth which came out early last year. We then issued that widely to decision makers across the system. The Minister launched it. At its launch, he announced that chronic pain was to be recognised as a condition in Northern Ireland. That was a fairly major step forward.

The Painful Truth made ten fairly significant recommendations and as we sit at the moment, seven of those have been accepted and some of them partially accepted – so we are still working on a lot of the outcomes of the Painful Truth.

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

Dr Pamela Bell is Chair of the Pain Alliance of Northern Ireland:

Pamela Bell: I think that this has been a most remarkable survey – I know of no other that is quite like it. First of all, this was a voice from across our population, of all those who suffer from chronic pain, not just focusing on those who attended a Pain Clinic or people with one particular type of pain, but right across the population. It was very large and that reflects the enormous PR campaign that there was to raise awareness that the survey was going on, involving quite a large number of patient support groups and charities in focus groups to help to inform the overall structure and style of the report.

It has just been such an unusual and unique report, which, if not exactly opening our eyes to things that are new, in terms of problems that people have when they live with chronic pain or really showing us particularly where the gaps are in the services for them, but it has just coalesced everything into one major report where we have had both statistical analysis allowing us to present to our population and present to the members of the legislative assembly, if you like, the facts and figures of chronic pain.

I think more importantly, is what has come out of the qualitative analysis – those patient stories, have really made clinicians, carers, politicians sit up and take notice. It has been hard to listen to – some of the stories are extremely poignant and some of the messages for healthcare professionals are not easy to listen to. It would be lovely to say that we were doing a really good job, but if we knew we were doing a really good job, there would have been no need to do this survey and to publish this report. So we have to listen to where we are falling down.

Part of that is accepting that people have pain – it may not be very easy to diagnose, it may not be very visible, but it is nonetheless real and has a very real detrimental effect on their physical, their emotional health and their financial health too. I think, by getting those stories out there, there are a lot of people for whom those stories will have resonance; they recognise that they are not alone and, hopefully, be not quite so stigmatised.

This is something that we continue to want to do – we want to continue to engage with a variety of patient groups, but particularly those patient groups where we have identified that perhaps the services that they have are not now, currently, as good as the services that they used to have, because that gives us real power to go and say to those who are responsible for commissioning and delivering our services: ‘why is this happening? And these people have a very real need – can you help us to do something about it? Can we help you to make the services more appropriate to them? Can we help you (this is particularly the role of the Patient Client Council) to engage with our commissioners and with those who deliver our services to make sure that your voice is heard in all of this?’

Evans: Dr Pamela Bell of the Pain Alliance of Northern Ireland. You can read more about the Patient and Client Council’s work in Northern Ireland at their website – patientclientcouncil.hscni.net (‘HSCNI’ stands for health and social care Northern Ireland). Before we finish this edition of *Airing Pain*, I’ll just say that we at Pain Concern believe the information and opinions expressed 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. Don’t forget that you can still download all editions of *Airing Pain* from painconcern.org.uk or you can get CD copies direct from Pain Concern. The last words from the European Pain Federation symposium on The Societal

Impact of Pain go to the Federation's President, Dr Chris Wells. He is speaking with Pain Concern's Rowena Jacobs:

Chris Wells: Twenty per cent of the population have pain and that actually means 100 million people in Europe. Now, they are not all in severe pain – of course not and they have not all got disability from that pain, but a significant number have got pain and disability and reduction in quality of life, and they are voters – they need to vote and we need to link up throughout Europe with all the different people, lots of patient groups and actually use the patient groups to inform politicians and in particular to mould policy.

For instance, we were talking today about the fact that in the UK, if you have back pain, you are supposed to be seen by a multi-disciplinary team within six weeks and two of the patient groups said, 'we did not know that'. They should know it and they should tell all their people and all their people should explain that this is what should be done. If you get acute back pain in England, you should go to your GP and say, 'this is what is supposed to happen'. The GP does not know either, so do it.

Only, four per cent of patients attending with pain when they first have their diagnosis got any information – that is awful – it is all there – it is all on the internet. So we should make sure that there are good sources on the internet of informed communication. If you can do that, then patient groups can inform each other about this and it could be viewed.

People have criticised GPs and said that these GPs are a health risk. The problem is not that the GPs are necessarily a health risk – they do not have great tools – but unfortunately, non-steroid drugs and the opioids and the other drugs that we use for pain don't work particularly well. So they know, when they have tried one or two simple things on the patient, it is going to be a long and hard road. Of course they don't really want to see the pain patient because they don't really know how they can help them. If you come in with a sore throat and a nice suppurating mass in the back of your throat, the GP is delighted: he puts you on antibiotics; he knows if you see him again, you will say, 'oh thank you doctor, you are wonderful'. That is great, but when somebody comes in with back pain, it is not quite so easy – 'we'll put you on these drugs' – then you come back and say, 'well, these gave me side-effects and those didn't help' – he doesn't really want that hassle, so we have got to help them.

We have got a difficulty in the UK with what works. We have got a difficulty with access because we do have multi-disciplinary teams, physios... who are very good. I work in Liverpool and Bolton also – it is a great team there: they see the patients; they help who they can with physio, with exercise; they refer them to orthopaedic specialists if there is any suggestion of surgery or anything else might be required; but they also refer them to the Pain Clinic – so, I actually get patients in Bolton, with eight-week, ten-week histories of pain. Those are the ones who I look at. When I look at my results, everyone else has got much better results, but the ones with five-year history, my results aren't as good. Early assessment, early management, prevention of chronicity is much better in the future for quality of life and actually that saves money. If we could just spend a little and modify the pathways, then we save money in the long term. This is what all politicians have to do.

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- Neil Betteridge, Vice Chair of the Chronic Pain Policy Coalition in the UK
- Louise Skelly, Head of Operations, Patient and Client Council, Northern Ireland
- Dr Pamela Bell, Chair of the Pain Alliance of Northern Ireland
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