

Airing Pain Programme 49: The Impact of Pain on Society

Talking to representatives from a variety of pain organisations, including the Trigeminal Neuralgia Association, about the wide-reaching impact that pain has on society.

Christine Johnston heads to Brussels to investigate the impact that pain has on society as a whole at the Societal Impact of Pain lobby group's fourth annual event. She talks to Neil Betteridge of Neil Betteridge Associates which promotes a holistic approach to pain management. Betteridge explains that early intervention is beneficial not only for the patient but also for employers, as it leads to faster, more effective treatment and less time spent outside of the workplace. Jamie O'Hara, who works with Adelphi Real World and the Haemophilia Society, discusses the results of a survey carried out about the effect pain has on society, which found that those living with chronic pain and their carers experience disproportionately high levels of unemployment.

Christine also speaks to Jacqui Lyttle, an Independent Commissioning Consultant, who criticises the current care given to those with chronic pain conditions, citing wrong diagnoses and the subsequent delays in accessing effective treatment as the main issues. She explains that pain management costs more when it's not managed effectively than when it is, both in terms of money and in working days lost through illness.

Paul Evans then meets Jillie Abbott, the Projects Officer of Trigeminal Neuralgia Association, who describes the organisation's attempts to raise awareness of the little-understood condition within the healthcare profession, citing the high frequency of misdiagnoses and ineffective treatment as the motivation for this educational focus. She also shares some coping mechanisms that can help those living with Trigeminal Neuralgia and emphasises the need for better communication between people living with the condition and healthcare professionals.

Paul Evans: I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, a UK-based charity working to help, support and inform people living with pain and healthcare professionals. This edition's been funded by a grant from the Scottish Government.

Now, the Societal Impact of Pain (SIP) is an international platform with the aims of raising awareness of how pain impacts on our society's health and economic systems. Their fourth

annual event took place in Brussels back in May 2013 and the delegates focused on topics previously agreed in their roadmap of action, one of which was European best practices for the reintegration of chronic pain patients into the workforce. Pain Concern's Christine Johnson attended the event to gain a UK perspective.

Neil Betteridge: My name's Neil Betteridge, I'm at the SIP meeting representing my own company mainly, which is Neil Betteridge Associates, a patient consultancy. But I'm also, in the UK, the vice chair of the Chronic Pain Policy Coalition, which works with most organisations in the UK with an interest in pain, including Pain Concern.

I think there is a general lack of awareness amongst, I suppose, society generally and employers specifically really, and lack of awareness about issues like the importance of early intervention. I think too often there's a kind of stigma associated with pain; people are often reluctant to mention it, of course its invisible, it doesn't show often so sometimes it doesn't get raised with them. And often by the time people have worked out that they really have to talk about this, or do something about it, sometimes the pain has developed so far that it's harder to treat.

Whereas all the evidence shows that when there's early intervention, when there's a good employer or good trade union, or even just when the individual decides to sort of flag it early and take some action, then nearly always there's a much better outcome. Of course a better outcome is a great thing for the patient, but at the same time it's better for the employer, because it means they're less likely to lose that person from the workforce and have to pay to replace them and train somebody else etc., so if we can get that right then it's a win, win.

Christine Johnson: And what key changes are we talking about at the moment, what is being proposed as the best way to deal with this?

Betteridge: I think culturally all parties need to promote cultures within their workplace which promote prevention and good, honest, open dialogue about it, and I think government have a role to play there by providing support programmes, so that employers don't have to carry the full burden, financially, if they want to offer support to an employee who has pain. And I think it's also important that worker participation in programmes of that sort... is really important, so that management and workers can discuss together the best ways of offering support to people with pain, because after all it's in their mutual interest to get it right.

Often the best outcomes are arrived at when there's a sense of a kind of holistic assessment taken of the persons condition. Obviously it will vary, if we know what's causing the condition, such as, you know, a form of cancer, or muscular skeletal problem, then often it's

just about getting that person to see the right specialist. If the pain is undiagnosed and it's not clear what exactly is causing it, then after some sort of triage, and some sort of test to see whether we can get to the bottom of it, often it's best if that person gets to see a specialist in pain services, rather than a particular medical specialty. But I think the thing running through all of this is acting early, 'cause it's early intervention which gets the best results in the long term.

Johnson: And if it's too late for early intervention, when we're talking about later rehabilitation programmes, what's being proposed there?

Betteridge: Well I guess it's never too late, there's always something positive that can be done to help, so I think the message really is to patients is 'don't despair!' There's primary prevention, which can stop pain developing in the first place, and there's secondary prevention, which can stop deterioration. So, whatever stage the patient is at, there's always something positive that can be done.

I think, psychologically, knowing for the patient, or the employee, to know that they have a supportive employer is immensely important; it means they're often more prepared to be open and honest about how their pain is affecting them. And whilst they're getting the most appropriate medical support, their psychological, sort of bio-psycho-social model really, needs to really kick in, cos it's all too easy to become depressed by your pain, that depression can be worse if you're also pessimistic about your chances in the workplace for the longer term. So getting that kind of social support, and the psychological support, alongside the more medical and mechanical support, I think is the right package.

Johnson: And if we take this as a starting point, how soon do you think we could hope that these measures could be implemented, with the required support at each level?

Betteridge: Some places are doing it now, there are some really great examples of best practice. I think the challenge is to really capture that, and disseminate it and promote it so that those who aren't delivering to that standard realise that a) that it can be done and b) if they do it, they're not only going to be doing the right thing, but they'll be saving money in the long term too.

Johnson: And while we're discussing at European level, and that's important, can we talk about the UK model, because obviously there's differences between Scotland, between England, and so on?

Betteridge: I think the how, that these support measures can be delivered and developed will vary, quite rightly, between different nations across the UK, but the what, what it is that

we are trying to do, I think is common, it's a common challenge, it's about providing support for people early on so that they don't deteriorate, so that they're better in the long term, and the employer is better off in the long term.

Jamie O'Hara: I'm Jamie O'Hara and I work with Adelphi Real World and the Haemophilia Society in the UK. We've conducted a survey across the five main EU countries, looking at four thousand different patients, from both the physician and the patient perspective, and we've been able to develop a holistic burden of illness study so we can gain a better idea into the overall effect that pain is having on society as a whole.

And we've found some quite interesting things: that the level of unemployment for those suffering from chronic pain, particularly within the neuropathic parts of it, are only employed up to 40%, so obviously that's hugely different from the 7% average across the normal population. And not only that, we find that quite a large portion, around 20%, in fact, have full time care givers which is also again a huge societal perspective, a cost to society.

Johnson: So the consequences are felt by the individual, as well as by society as a whole, it's quite far reaching?

O'Hara: Well yeah, obviously because the majority of the care givers are often partners, friends or volunteers, so obviously these are either not paid at all, or subsidised by the state in order to provide this care to the patient. So this represents an opportunity cost, and within our sample of around four thousand patients we found that there was over five thousand lost working days from the caregiver alone, that's before we've even begun to quantify the total lost number of days from the patients themselves, which is even more substantial.

Johnson: We talk about preventing chronic pain, but how do you reintegrate people into the work place, what key changes are we talking about?

O'Hara: I think it's about strategy, I think the way that we currently assess pain care, and medical pain care interventions, and healthcare interventions with regards to pain is quite narrow, because we look at disease areas individually, whereas pain is by and large a symptom of many different disease areas. So I think the SIP initiative is very good because it calls for an overall strategy across every disease area in order to push the standard of care to support these patients. So particularly the strategy, as well as the process indicators that have been developed could be very, very helpful in improving people's lives, and not just the patients, that of the wider society as well.

Jacqui Lyttle: I'm Jacqui Lyttle, I'm an Independent Commissioning Consultant, working across the UK, working with CCGs (Clinical Commissioning Groups) and trust and health boards trying to improve patient care.

Johnson: Today we've been discussing the reintegration of chronic pain patients into the workplace, so what has the research indicated the main problems are for the patient if they're at work or if they are trying to return to work after a period of being off?

Lyttle: One of the biggest things that we found was the care wasn't seamless, and if patients got the diagnosis wrong at the beginning their journey was delayed, which meant that they were often away from work, or trying to get back to work and there were delays in the system, and actually a lot of people felt that their pain was not taken seriously.

We discovered that there was a real issue with initial diagnosis, and of appropriate diagnosis, and if patients got on the wrong pathway they could be referred to the wrong professional and they got stuck in the system, and actually as a consequence of that their condition often deteriorated, which meant they were either off work longer or it was more difficult to get back into work. There's a lot of time loss, there's a lot of delays, there's a lot of waste in the system, where people go from their GP [general Practitioner] to an orthopaedic surgeon, for example, then it's not an orthopaedic problem it's a gastro problem so they can get referred onto multi professionals and they go back into the system, by which time the patient's condition has deteriorated.

Johnson: And obviously there's a massive impact on the individual, but what about the cost to society as a whole?

Lyttle: I think that's more far reaching than people realise, the work that we did, we mapped not just the impact on patients but on... impact in primary care, so the number of times that a patient went back to their GP, the times that they accessed secondary care services, but also the time that they were away from work, people were then claiming benefits because they were obviously unable to go to work, so the impact is bigger than people understand, especially in the UK, especially in England with the changes in the NHS [National Health Service]. It costs more when pain is not managed that it does to actually manage it properly.

Johnson: You're one of five people who is drafting, or has drafted, the proposal for action – can you tell me what this is based on and what key changes it puts forward?

Lyttle: We mapped in great detail a number of patients from their initial attendance at the GP practice, through to when they and their professionals felt that their pain was adequately controlled, and the things that we discovered, that patients circled the system a number of

times, again depending on how the diagnosis happened, whether it was done timely, by the right person, whether actually they got the right treatment, the complications. And one of the things that we identified is that even though the burden of pain is greater than diabetes, asthma and COPD (Chronic Obstructive Pulmonary Disease) combined it doesn't have the same priority as those long term conditions. So what we're hoping for is that pain will be seen as a priority within the NHS in England.

Johnson: And is it significant to discuss this at European level, why is it important to do this?

Lyttle: I think it is actually, because I don't know if the UK is unique, I don't think it is, I think one of the things that we found that there was clinical variation across England, and I don't think it will be any different in the devolved nations in the UK and I don't think it'll be different across Europe.

Johnson: What support is required from individual governments? What do they have to do to support this?

Lyttle: I think, I can only speak for England, I think we need to get it on the priorities within the operating framework for NHS England, and then across the wider UK and I would imagine similar processes would have to happen in the other EU countries.

Johnson: And what impact, if this is followed through properly, will this have on a chronic pain patient who's in work or who's finding trouble staying in work?

Lyttle: If we were able to make even some improvements to the way which patients get treated it would mean that they could live more independently, they'd have better pain control sooner, and it would also mean that we would have less burden on the NHS, we would then hopefully be able to, sort of reuse some of that money to treat more patients, because one of the problems is that patients wait a long time for treatment, so I think it would just be improving the whole circle of treatment really.

From the work that we did last year we are now working with the British Pain Society and the Royal College of GPs to... we're in the process of writing a commissioning guide for pain and we're now trying to raise the profile of pain in England at the moment with commissioners. But I think there's a long way to go, and I really think it needs some more support and a higher profile nationally, from NHS England and the Department of Health down before we do see a sea change, 'cause at the moment we're competing with diabetes and asthma and other long term conditions, and I think pain should be seen as a long term condition in the same way.

Evans: That was Independent Commissioning Consultant Jacqui Lyttle, speaking with Pain Concern's Christine Johnson.

The Societal Impact of Pain is held under the umbrella of the European Federation of the International Association for the Study of Pain Chapters, and they've designated 2013/14 as the Global Year Against Orofacial Pain. This is pain experienced in the face and/or oral cavity. One such condition is Trigeminal Neuralgia; it's a condition often misunderstood by health professionals,

Back in the spring of 2012 Jillie Abbott, then Chairman of the Trigeminal Neuralgia Association UK, addressed the British Pain Society annual scientific meeting on that very point.

Jillie Abbott: Trigeminal Neuralgia is very severe face pain, neuralgia is a nerve pain and trigeminal refers to the trigeminal nerve, which has three branches either side of the face.

Evans: Let's call it TN from now on [yes], we've talked about TN before on *Airing Pain*, but you're here talking to health professionals on how to deal with it.

Abbott: Yes, it's wonderful to have that opportunity, one of our main concerns is trying to raise awareness of TN amongst medical professionals and it's come to our notice over the years certainly that people are not being treated properly. Diagnosis, I'm please to say, is quicker than it used to be, people are getting diagnosis much faster than in the past, but quite often they are not being treated effectively.

Evans: I suppose that's one thing, to get the diagnosis done, but in what way aren't they being treated?

Abbott: Quite often GPs don't know very much about the condition. Sadly, some of them don't seem prepared to research it and they're sometimes not prescribing the right medication and, sometimes, if they are prescribing the right medication, they're not telling the patients how to take the drugs.

For example, it's normally treated with anticonvulsants and these must build up in the bloodstream, so they need to be increased very slowly and if the pain isn't so severe they can be decreased slowly, but they mustn't be taken like pain killers: you can't just take it when the pain comes along. And patients are not told that, so, therefore, they're taking the drugs and they're not having any effective pain relief as a result.

They're also not told about the side effects so, quite often, because carbamazepine is the main anticonvulsant drug used to treat TN, they're not told that they do quite often have very

severe side effects; that you're going to feel dopey, spaced out, may have nausea... it does cause mental confusion in some cases, and because patients aren't told this, or warned [about] it in advance they will stop the drugs and think, 'I can't take that, I can't function, I'm too zombie like', so they need to be warned that this is the effect or could be the effect. So, therefore, it would be far better if there was a bit more communication between the GP and the patient *initially*, so they knew what to expect.

Antidepressants are also used to treat TN, and patients aren't told that they are being given antidepressants for *pain* relief, they say to us, 'I'm not depressed, or if I am depressed it's the condition that's making me depressed. I don't want to be given anti depressants', then, it isn't explained to them and that's the message that we're trying to get across.

Evans: You have trigeminal neuralgia?

Abbott: Yes.

Evans: Explain what it's like.

Abbott: It's an electric shock type pain. When it's at its worst it is like being electrocuted; it's like having a cattle prod in your face and it is so intense and so excruciating that while you're having an attack of pain you're completely incapacitated: you can't do anything, you can't speak, you can't think, it just rivets you to the spot, sometimes it will even bring you to your knees.

And, unfortunately, it's a progressive condition, so the pain attacks tend to become more frequent, they don't necessarily increase in intensity – they can't really – but they tend to become more frequent and it's this absolute fear of having another attack of pain that worries people so much. And because they're frightened they will take whatever action possible to avoid having another attack. It can be triggered by light touch, eating, drinking, talking, smiling, kissing, all these sort of things, so people become very isolated, they won't go out in the wind – even air conditioning in a shop can set it off – so they don't go out very much. They can't socialise because they can't eat and they find it embarrassing to try and eat in public, so they withdraw and they can become very isolated and that isolation in itself causes depression loneliness and more anxiety, so it can be a vicious circle.

If they have the right treatment and if they can talk to other people with the condition and get some help and advice and tips and coping mechanisms they will fare much better.

Evans: Tell me what that help involves and what the coping mechanisms are?

Abbott: Above all, what people say when they first contact us is how relieved they are to talk to somebody else who suffers from the condition, actually someone who really understands their pain and what they're going through, that's a huge relief to them. And being able to talk to somebody who is coping with their life is extremely beneficial; they can see that other people suffer from it. Alright, there may not be an effective long lasting cure, I mean there are various treatments, but there are ways of dealing with the pain, ways of coping with it, and that gives them hope and encouragement. So that's hugely beneficial.

Evans: What ways?

Abbott: If people start off with the right medication and first of all get their pain under control, that takes away some of the fear. We can then explain how others of us cope with pain attacks: if you can't drink you could drink through a straw; you can eat mushy food, or put your normal food in a food blender if you're having difficulty eating. We always advise people to talk to their employers, explain the situation. Because it's an invisible condition, employers can sometimes be very unsympathetic, but if they get brochures and information and leaflets from us and take those in to their employers, that helps for the employer to understand what they're going through and become more sympathetic and try and make arrangements about their working life to accommodate the difficulties that they might face.

There are lots of other tips, for example if you're suffering on a windy day or a cold day we say to people: 'wear a balaclava – don't be embarrassed about the fact that people may look at you rather oddly because it's not midwinter'. Food to avoid: different things we've found can trigger it, sweet foods, spicy foods, nuts... anything crunchy will cause it, so we give people dietary advice and just various tips on how to get round the situation.

Evans: What sort of response do you get from the professions when you stand up in front of them and talk to them about the problems that their patients are facing?

Abbott: I think to a degree most of them now are more understanding about the actual problems. When I talked to them in the meeting yesterday they were quite surprised about the fact that there are complaints from patients about the way they're treated; perhaps the people who came along to the meeting were the ones who are treating people properly.

But I think some of the horror stories that I was telling them were quite shocking to one or two of them, or to most of them in the room in fact. And I think they probably will be determined hereafter to treat their patients with a great deal more care and compassion and, in fact, all of the medical profession are going to have to do that because there's a NICE [National Institute for Health and Care Excellence] guideline, which came out in February

2012, which covers what patients in time will grow to expect from all their medical staff: information, involvement, choices and shared decision making.

Evans: You might have noticed the shock on my face – why does a health professional need a *guideline* to tell them how to treat a patient with respect?

Abbott: Exactly, you wouldn't have thought it would be necessary, but I'm afraid it is. We have collected quite a few stories from people which are actually quite heart rending. These are from records kept by our telephone helpline team:

- Her mother had seen a neurologist – she couldn't remember his name – who treated her, quote, with 'indifference' and said that she had migraine. The caller said that she thought the neurologist had no interest in her mother because of her age.
- Her GP is not helpful and tells him to forget about it.
- His dentist tells him that the patient is no longer his 'pigeon'.
- The GP has done a really good scaremongering job on all the procedures for TN, telling him that 'they were all far too dangerous and not performed often enough.'
- And, to end on a good one, her GP immediately recognised the symptoms and diagnosed TN.

Evans: Now that's a mixture of responses to your TN helpline, predominantly bad experiences?

Abbott: Yes, I mean it is true that the people who come to us could be those who are not getting the right treatment... but I do think a lot of people do get very good treatment, but people do still come to us and there should not be as many of these stories as there are. It's too often the case that people feel that they need to ask for further help with dealing with the medics – that shouldn't be necessary.

Evans: So when you read these to the room of consultants and professionals yesterday was there an audible gasp?

Abbott: I think there was, yes. I think this was quite a shock to most of them in the room.

Evans: What sort of questions did they ask you?

Abbott: One chap actually said that he felt it was disgusting and this ought to be referred to the General Medical Council.

Evans: At a British Pain Society event you may be speaking to the converted?

Abbott: Yes.

Evans: It's the unconverted you need to get hold of.

Abbott: I know, I know, and this is the difficulty we have. We would love to have the opportunity of running training courses for general practitioners and dentists. Our medical advisor is Professor Joanna Zakrzewska and she runs courses for trainee dentists on dental pain, facial pain... and she tells me that very few people turn up to these pain courses, but if there is a course being run on cosmetic dentistry the queue is down the road and round the corner.

So there is a difficulty there of getting the message across, we'd love to have more opportunity of training GPs and dentists. We have a joint patient and profession, healthcare professional, conference every two years and we try desperately to publicise this widely. We'd love the opportunity to do more of those and to get the message across... I mean I've no idea how many GPs there are in the country – probably something like 250,000 – but GPs don't, obviously, have enough time. But what they need to do, if they suspect TN, is to first of all sort out the right pain relief and then to refer on, so that they're referring then to a specialist who does have enough time to give to the proper history taking.

Evans: That's Jillie Abbott, of the Trigeminal Neuralgia Association UK. And for more information, go to their website, which is TNA.org.uk.

I'll just remind you of our usual words of caution, that whilst we believe the information and opinions on **Airing Pain** are accurate and sound, based on the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing; he or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

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A final word of advice on trigeminal neuralgia, for doctors from the patient: Jillie Abbot...

Abbott: Yes, it's very important I think for medics to provide time for the patient to be able to give their opening statement, to tell their story. Research has shown that not enough time is given to this, apparently, from a study recently in outpatients, of 335 patients the average time given to them was 92 seconds; 78% of patients finished in just two minutes.

And it's in the first few minutes of telling their story that professionals can sometimes make judgements, and I think they need to listen more to the patients and it's listening to the patients that will give them the diagnosis. There's no diagnostic test for TN, it's all down to the history taking, so this is what's very, very important: getting the right diagnosis is crucial because, if they don't get the right diagnosis and the medical treatments are not effective, patients sometimes go on to have surgery and that, if it's not classic TN, will make the situation far, far worse and then it becomes an intractable condition.

Evans: But in many ways you can't blame the health professionals for only having 92 seconds average with a patient, could the patient prepare for that 92 seconds?

Abbot: Yes, there are three different stages to this: while they're waiting for their initial appointment, they need to learn to accept the condition; they need to learn, hopefully from us, some coping mechanisms and focusing on their pain will be unhelpful and self-destructive; and, very importantly, failing to eat properly will lower the body's defence mechanism and its ability to heal.

At the consultation I think it's important that they expect that they may well get given questionnaires; they may meet someone other than just one specialist. These days there are multidisciplinary teams that are conducting these patient sessions, so they might have with them a neurologist, a psychiatrist, a registered nurse, perhaps, a biofeedback therapist, possibly even a neurosurgeon.

And we say to them keep a pain diary – that's really important – because that will give the medical professional an idea of when the pain is occurring, how often, what effect the drugs are having, what side effects they might be having... so that's very important. And they need to take along notes about the drugs and also lower their expectations sometimes: don't expect a complete cure, but expect a reduction in pain.

Contributors

- Neil Betteridge – Director of Neil Betteridge Associates and Vice-Chair of Chronic Pain Policy Coalition
- Jamie O'Hara - Adelphi Real World and elected trustee of Haemophilia Society
- Jacqui Lyttle - Independent Commissioning Consultant
- Jillie Abbott – Projects Officer of Trigeminal Neuralgia Association

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