Airing Pain Programme 123: Opioids and Chronic Pain

Rethinking long-term pain management

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The opioid crisis reached its peak in the United States in 2017, where addiction and overprescription have led to 218,000 deaths from prescription overdoses between the years of 1999 and 2017. The side effects of opioids can affect the day-to-day activities of people managing long-term or chronic pain, yet society as a whole has yet to fully evaluate the relationship between opioids and addiction.

*In this edition of **Airing Pain**, producer Paul Evans talks to two leading pain specialists. First off, Paul Evans meets with Dr Srinivasa Raja, who discusses opioids effects on the body's opioid receptors and how the human body processes pain. Dr Cathy Stannard then talks about the increase of opioid prescriptions in the UK and how the opioid crisis in the United Kingdom developed.*

In the second half of the programme, Paul speaks with Louise Trewern, a chronic pain patient and patient advocate, about opioids' detrimental effect on her quality of life and how she was able to transition towards more effective methods of chronic pain management.

Finally, Paul sits down with Dr Jim Huddy, a GP in Cornwall, who explains how the medical community is re-evaluating the relationship between opioids and chronic pain.

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 those who care for us. I'm Paul Evans and this edition of ***Airing Pain*** has been supported with a grant from Kyowa Kirin.

Louise Trewern: Hyperalgesia was one of my biggest problems. I couldn't have dental treatment properly. I had to have multiple injections because they couldn't numb me. It was gradually, over a period of months, suggested to me that the dose I was on was not helping me, it was making me worse, and that a lot of the symptoms I was suffering [from] was as a result of my opioid use.

Evans: In this edition of ***Airing Pain***, I want to look at the use of opioid medication for the management of chronic pain. The so-called opioid crisis or opioid epidemic in America came to a head in 2017 when, contrary to the reassurances of pharmaceutical manufacturers that

patients were less likely to become addicted and an aggressive marketing campaign, addiction, overdose and death rates soared.

Before we delve into how this affected people with chronic pain in the UK, I want to try and come to grips with some of the science behind the drugs and how they work. Now opiates are naturally derived from the opium poppy plant. They include morphine, codeine, heroin, and others, and have been used for medicinal and recreational purposes since prehistoric times. Opioids, on the other hand, which include tramadol, methadone, pethidine, fentanyl, and others, was originally coined to denote synthetically sourced opiate-like medicines, but confusingly to me anyway, the term opioids is now used to also include the naturally-derived opiates. So, for the sake of clarity, an opioid is a compound that acts on opioid receptors in the body. So, what's an opioid receptor? Professor Srinivasa Raja of Johns Hopkins School of Medicine, Baltimore, in the United States is internationally recognised for his research into neuropathic pain.

Srinivasa Raja: One of the scientists and neuroscientists, Solomon Snyder, worked on this in the 60s, and he asked what now looks like a very straightforward and simple question. He knew and most of us, physicians or healthcare providers, know that drugs such as morphine work well in treating pain, particularly things like pain after surgery. So, the question he said [asked] is: ‘There must be something in the body that should be the site where these drugs are working’. And he found these receptors called opioid receptors, and he found that they were present in multiple areas not only in the brain, but [also] in the spinal cord and other sites. You know, one of the questions is ‘What is the role of these receptors?’. Are they there only for drugs given by physicians to work in the human nervous system? So, you know, the question he asked is: ‘What is the role of these receptors in the body?’. And he came to the understanding that there are endogenous pain control mechanisms, that the body has a way to control pain. And, often, the good example given is athletes who are in the middle of a game – a World Cup – and, you know, can be injured but continue to play and don't perceive the pain till the end of the game when they find something that they hurt themselves. There was a good example of a US gymnast who did her last jump with a fractured ankle. It wasn't found until after that. So, I think that the body, especially at times of stress, releases endorphins or these endogenous opioid peptides, which then work on these receptors to control pain. So, I think it's a protective mechanism that fortunately most of us have.

Evans: It's fairly common for top class athletes and football players, rugby players, whoever to go through what they call the pain barrier. Why are they more capable of doing that than say, the man or woman in the street?

Raja: Wow, that's a challenging question. And I think the answer to that is complex in the sense that the pain experience is a very personal thing and, given the same injury, different individuals perceive the pain differently in terms of intensity and emotional aspects of it. I think [that] as far as the athletes [are concerned], there may be two reasons. One, there may be a bit of training, you know, prior experiences, saying that this injury usually lasts for a few days, I'll be better and, you know, I need to move on. They go through these repeated injuries, maybe there is a bit of adaptation to that injury. So, they don't experience the pain in the same way. The other aspect is, it's interesting how people talk about motivation and the result of the pain and how you react to the pain may have some implications for an athlete. You know, if he exhibits pain, he may be pulled out of the game and maybe he doesn't want to do that. Similarly, we noticed that given similar injuries in a developing world, people move on because what that means to them is loss of their day's work, you know, if they don't go to work, they don't get paid.

Evans: They don't have the option of giving up.

Raja: Exactly. They don't have the option. They may be experiencing the pain, but how they react to that pain experience may be very different.

Evans: Now, there are people who don't experience pain. Is there a relationship between that and the opioid receptors?

Raja: The most common type of absence of pain or that group of patients that have been well studied is not necessarily from opioid receptors, but more so from a specific sodium channel that signals pain. But there are mutations of the opioid receptor that have been observed and reported in humans. The implications there have been that how these patients may respond to opioid medications may be different, and their pain experience after things like surgery may also be different.

Evans: We've just had an interesting case in the news recently of a woman who can't experience pain. She only knows when her hand is on the hot plate of the cooker because she can smell it burning, but also, she experiences no anxiety.

Raja: That's an interesting observation. And it tells us that these receptor systems in the nervous system are often not having a single role. They often have multiple roles and they are multiple sites. And this is the challenging part of basic science and the translation of basic science to clinical new drug development. A very good example of that: there was a lot of work done on what's now known as the chilli pepper or hot pepper receptor – the TRPV channels. These channels are well characterised and drugs were effective – antagonists or

drugs that block these receptors are very effective in animal models of pain – so much so that it did go all the way up to clinical trials. What was observed in these clinical trials was that these animals developed hyperthermia or increase in body temperature. And this was totally unanticipated from the earlier studies in experimental animals. Subsequent studies found that not only do these TRPV-1 receptors or channels are involved in pain signalling, but they're also involved in thermal regulation or regulation of body temperature. So, when you block these receptors, you do have effects on pain, but you also have an undesired effect on body temperature.

Evans: Professor Srinivasa Raja of Johns Hopkins School of Medicine, Baltimore, in the United States. With the American opioid crisis coming to a head in 2017, *The Times* newspaper warned that 'the UK is hurtling towards a US style crisis' where super strength painkillers have killed more than 91,000 people in the past two years. Now, to be clear, NHS guidance says that opioids are very good analgesics for acute pain and pain at the end of life, but there's little evidence that they're helpful for long-term pain. Despite this, they were widely prescribed for long-term or chronic pain. Opioid prescribing more than doubled in the period 1998 to 2018. Dr Cathy Stannard is a leading pain medicine specialist now working with the NHS Gloucestershire Clinical Commissioning Group. She is an internationally-recognised expert on aspects of pain management and opioid therapy in particular.

Cathy Stannard: It is a fact that pain and pain prescribing has this almost unique position where people are left on medicines even if they still have pain. So, if we treat somebody for blood pressure, and they come back and their blood pressure is still high, we do something else. If somebody is in pain, and they come back and the pain medicines aren't working, we either put up the dose or just leave patients on it. And it's very understandable that patients, who are taking medicines but not observing much in the way of pain relief, would make the not unrealistic assumption that if they reduce their medicines the pain would be worse. We know that's *not* the case. And often people can feel better and more alert and shed side effects when they're supported to come off medicines. But if you're in a very short, pressured medicines use review, if you're not reporting active adverse side effects, it's our experience that nobody will have had a conversation as to precisely how well those medicines are doing what they say on the tin. And, actually, that's where the results are often disappointing. So, it's not something that can be resolved with a superficial, you know, what's this medicine doing? What are the side effects? It is much more complex about the way that the medicines are working for that patient.

Evans: The way these things are communicated to patients is often interpreted in completely the wrong way. The opioids are being taken away from me. I'm now a drug

addict. I'm criminalised. Maybe the press is at fault, maybe we're at fault. How do you communicate these things? The problems the patients are feeling?

Stannard: I think that's really important. And there's been a huge frenzy of variable quality reporting, particularly around the opioid issues at the moment. And there's an undoubted public health disaster of biblical proportions in the United States, initiated by people taking opioid medicines for pain and now moving on to various illicit substances. I think there are lots of protective factors about our own healthcare system in the UK and I think it's unhelpful to make quick decisions on the basis of what we see at a United States population level. I think it is important to communicate, with people using these medicines, what we're trying to achieve. And the most important message to get across is that we do not want to expose people to the harms of medicines that aren't working,

Evans: How to get it over, you know, this isn't doing you any good, you will be better, taking fewer drugs.

Stannard: It's not that easy and nobody finds it easy to have that conversation. I think it's about bringing people to that realisation themselves. So, when I assess a patient, I will spend maybe half an hour talking about the patient, what life is like for that patient living with their pain, what limitations that pain brings. Then we get onto the medicines' history. And you know, they may be on several medicines and I kind of will say to the patient: 'You said how difficult your pain is and you're taking these medicines, do you think the medicines are making much difference?' And there is a dawning realisation that it's just like taking Smarties – is something that we commonly hear. We know that patients are fearful of reducing because of course, if your pain is bad and you're on medicines, what if it's worse? It's very difficult and it depends on the individual's perceptions and so on. But we do have evidence from a huge number of patient reports that, freed from the many burdens and side effects, people feel much more alert, able to engage with their families and engage themselves in strategies which help manage their pain. So, we know that most of the medicines that we prescribed for pain which actually stop the way that nerves talk to other nerves do have side effects which make people sleepy, sedated, giddy and so on. And all those things make it very difficult to start trying to manage people's lives to try and mitigate the effects of long-term pain. It is more about the balance of benefits and harms and it's more about getting people to reflect how well they think the medicines are supporting them, which is often that they're not.

Evans: Dr Cathy Stannard. Louise Trewern has lived with pain for most of her adult life. She was prescribed opioids for over twelve years and was the first inpatient at Newton Abbot Hospital in Devon to come off them.

Trewern: The day before I went into hospital, I had clocked up something like twenty-five steps on my pedometer, probably that was from the bed to my chair, the chair to the bathroom and then back to bed. And I was touching twenty-five stones in weight, and my life was pretty non-existent by this point. I'd been on opioids for over twelve years – high dose. And it was suggested over a period of time that I needed to come off this medication because, in actual fact, it wasn't helping me.

Evans: How was it put to you that you should stop?

Trewern: It was gradually, over a period of months, suggested to me that the dose I was on was not helping me, it was making me worse. And a lot of the symptoms I was suffering was as a result of my opioid use. And I definitely – hyperalgesia was one of my biggest problems. I couldn't have dental treatment properly. I had to have multiple injections because it couldn't numb me. I couldn't have the cats walk over my legs, because the pain was *intense*. And then I suffered a couple of quite severe medical episodes, which meant I was an emergency admission to hospital, which met the criteria to have me in and get me off these opioids. My initial week in hospital was where I came— they halved my dose overnight and the doctor said to me that, in the morning, your pain will not be any worse, I can guarantee that and I had to put my trust in him and it was true. It wasn't worse. Since then, we're talking two years now, I've lost seven stones in weight. I know walk up to five miles a day. I still live with pain on a daily basis, but I deal with it without medication apart from perhaps a couple of paracetamol.

Evans: Louise Trewern. Jim Huddy is a GP. He is Cornwall Clinical Commissioning Group Clinical Lead for Chronic Pain.

Huddy: Cornwall has always been a heavy prescriber of opioid analgesics for pain and that is *not* a good thing because we know that the higher levels of opioids in a population, then that is associated with, well to cut a long story short, higher levels of misery. So, we really wanted to bring that level down. A lot of people talk about reducing doses and it is really important to put out there that there are some people who are on the right dose for them and we really don’t want to be taking away drugs that work for people, but what we think from the medical side is that the vast proportion of people with chronic pain who are on opioid medications, those medications probably aren’t working very well. And, more importantly, if

they were on a much lower dose or possibly even off the drugs, then not only would they feel better but their lives would get better. So, that's why there is a big emphasis on this. It's not purely a money-saving exercise although it does save a lot of money which we can then sort of put into other directions which is quite exciting, but it really, honestly, and science does back this up, but a lot of the time people don't feel any worse or a lot of people talk about getting their lives back, and that's particularly if they are on very high doses. The Faculty of Pain Medicine have put out what I describe as a 'national speed limit of dose' and that is 120mg of morphine and over this dose the science is clear that this is going to be more damaging than good for you. So, that group of patients who might be on 200, 500, maybe even up to 1000mg of morphine per day are very likely to be more harmed than benefited by that. But the problem with those drugs is that they have effects on the mind and the body that make the mind and body need their doses each day. And the idea of reducing or stopping the drug is so scary for patients that, very often, they don't believe that that's in their best interest. So, it's a very interesting and challenging consultation, where sometimes the doctor and the patient have very opposing views, but we have got some expert patients that are helping us and, actually, we've got a video from NHS England that's about to be released of one of our patients called Sean, and there's a little bit of me on this video, that tells Sean's story. It's only a three- or four-minute little bite that could be watched in consultations and Sean's absolutely engaging with explaining his sort of epiphany of life could be better without these strong drugs. And now he's not on the strong drugs and he's back on his jet-ski. It's a great story. And that's why we believe a lot of people out there would have better lives if they're deprescribed their medication.

Evans: It's a conundrum, isn't it? The fact that people are on these higher doses of opioids prescribed by their doctors. Did that last one work? No, have a bit more, have a bit more again, have a bit more again. So, doctor has said this is good for me. And now doctor's saying it's not good for me?

Huddy: Yes.

Evans: How do you square that circle?

Huddy: Yes. Well, the way I explain it to patients is that, you know, medical and medical understanding, medical beliefs are an ever-changing field and for various reasons, which aren't very sort of wholesome or particularly nice. I think over the last ten, twenty, thirty years pain specialists were led to believe by drug companies that if you give high enough doses of opioid medications, you will get people pain free, and it's their right to be pain free. And this was when I was at medical school in the mid-90s. This is what was taught to us the WHO

analgesic ladder, you keep going up the ladder until you get someone pain free. And we all believed that that was the way to go. We now don't believe that. We now kind of know from the science that the data that that was based on was flawed, let's put it politely. And, more recently, we're getting research that is showing that, just as you described, when you start these medications very often there is a, there's a temporary benefit that then wears off. So, then, you have a dose increase and there's a temporary benefit which then wears off and, just as you described, people get on higher and higher doses and sometimes some very, very high doses. Now what's really tricky is that when you do the reverse process, the reverse process happens. So, when you drop the dose, their pain gets worse for a bit, and then it goes back to the baseline, and then you drop the dose again, and the pain gets worse. So, we are embarking on a treatment schedule which might, you know, go on for six, nine or twelve months. It has to be done slowly and the patient has to realise that, you know, there is a bit of a storm coming, this isn't going to be an easy ride. But the benefits at the end of it, if you talk to the patients who've done it, are worth that pain. But for a doctor to be suggesting a management approach for the next few months that's going to be painful for you is quite a tricky one. That's not what we're trained to do. And it is a complex and quite challenging consultation that I certainly haven't mastered. I'm, you know, trying to perfect it and some patients are more up for it than others, but they do have to believe and we do believe that having alternatives to make things easier during this process is a really important part, which is why we're emphasising alternatives to pills at the moment.

Evans: That's GP Jim Huddy. Louise Trewern, having been the first inpatient to come off opioids at Newton Abbot Hospital in Devon, is now working with a doctor to help her to help others reduce or give up their opioid use for the management of their chronic pain.

Trewern: I am working with the doctors that helped me come off the opioids and back twelve months after that because I needed that long to recover as it were. I've been working with them, and it's a multidisciplinary group, on a committee called the Rational Use of Opioids. So, I'm helping the team make patient leaflets and videos for the website, this is in Torbay, for proper use of opioids, which will hopefully help those that don't seek help and those that *do*, inpatient and outpatient leaflets. So, because the things I experienced, both before and after, are not all in the journals, they're not, it's not all written down. Some things they've heard about, but they didn't know for sure that it was happening. And it's not just me. There're several patients now in Torbay that they've helped since and it's just that I was the first inpatient that they did this with. So whereby certain things they thought would happen, they're now going to put this in a warning in the leaflet. You know, if you come off opioids too quickly, this could happen. And we've been told this happens and not necessarily to

everybody but it, it can happen, just so that people are aware of the dangers. You can't just stop these drugs, but not everybody knows this. So, they're taking my experience plus, putting it together with the medical side and physical therapy. All the different areas are coming together to make these leaflets that will be circulated in GP surgeries and on the website. And so yeah, it is working. And I'm sure with Torbay, it's not just in this with opioids, it's with other things as well. And so yeah, it's hopeful that, that will continue and it needs to be countrywide, I think.

Evans: So rather than like the leaflets we get in all our packs of medicines and tablets, they list all the everything that could happen to you and more. These are coming from your voice. This is, this has happened to me. And this is what can happen after.

Trewern: That's it and one of the key things that we've gone out of our way to make sure of is that, between the team, the language is what can be understood by the person taking those opioids.

Evans: Louise Trewern and there is information on the use and withdrawal of opioid medication at Torbay and South Devon NHS Trust Pain Services website. I just entered the words ‘Devon’, ‘pain’ and ‘service’ into my search engine to get me there. In neighbouring Cornwall, where Jim Huddy is a GP, the overprescribing of opioids has come down by 18% in three years.

Huddy: An 18% reduction is a much bigger reduction than most of the CCGs in the UK and we assume that a large part of that is because of the work that we've done.

Evans: So, what has brought that down?

Huddy: Some of this is assumption and some of this is hope. But we also think that some of it is logical, that a lot of our work has been based around GP education, and GP education that the way to deal with someone who's got chronic pain is *not* to just reach straight for the prescription pad, which is our tendency as doctors because that's kind of how we're trained. We decided to write some information for patients and write information for doctors, and we did that, and it was all brilliant, and we published it on one of our websites, and no one read it because it was long-winded and everyone's busy. At that point, we thought, okay, we need to rethink this. So, we decided to move in a direction of video education. So, we've now made three videos, mainly for prescribers, really, we're going to move on from that in time. But the videos that we've got, one is about sort of safe opioid prescribing, one is about safe deprescribing of opioids. It’s quite a sort of chunky thing. It's about half hour of like me narrating a PowerPoint presentation about identifying what patients might be right for

deprescribing and how to engage them and how to do it safely and how to support them during it and also consultation skills and practice-based strategies. How to make yourself more robust against patients that might be quite keen on continuing their doses, let's say. Then the third video that we've done more recently is entitled ‘If I don't prescribe, what do I do?’, which starts introducing ideas of how to talk about self-management as a strategy for chronic pain, moving away from pills and tools, the alternatives. We split up the rest of the video into twelve mini-sections because if you suffer from chronic pain, Frances Cole's work has suggested to us that there are twelve consequences of chronic pain, you're very likely to be suffering from one or maybe all of them – things like physical inactivity, social isolation, sleeplessness, emotional problems, relationship problems, work-related problems, and there are twelve of these things. So, we've split up the rest of the video just going through each of those one by one and giving the doctors ideas of what can be done and, more crucially, on our website, we've got written information for patients which is in electronic format. It's kind of crude because our website is kind of crude and basic, and that's something that we want to work on. We slightly sort of grandiosely called it ‘Chronic Pain – The Answers’ and it goes through each of these twelve consequences of pain and gives the reader just things that we've cobbled together from online stuff and Cornwall-based stuff of what would be relevant to sleep for example, or to emotional stuff or ‘boom and bust’ stuff, the stuff that you, you know all about, but trying to bring it all together into one place.

Evans: Jim Huddy, Cornwall Clinical Commissioning Group Clinical Lead for Chronic Pain. Now the website address for those resources is a bit of a mouthful. So, I suggest you put ‘opioid prescribing for chronic pain Cornwall’ into your search engine. It's well worth a visit. As always, I'll just remind you that, whilst we in Pain Concern believe the information and opinions on ***Airing Pain*** are accurate and sound, based on the best judgments available, you should always consult your health professional on any matter relating to your health and well-being. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf. You can find all the resources to support the management of chronic pain including details of our helpline, videos, leaflets, all editions of ***Airing Pain*** and ***Pain Matters*** magazine at painconcern.org.uk. Now, last words of this edition of ***Airing Pain*** to Louise Trewern about her journey with opioids,

Trewern: I'm choosing not to be upset about it, because I think the doctors at the time that prescribed it were working with the information they had at the time. Now, of course, we know that long-term use of opioids doesn't help chronic pain conditions at all. And so, I'm trying to get the message out there that there are other ways of coping with your pain other than just taking painkillers.

Contributors

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- Louise Trewern, Vice Chair of the Patient Voice Committee at the British Pain Society
- Dr Jim Huddy, Cornwall GP and Clinical Lead for Chronic Pain at NHS Kernow Clinical Commissioning Group.

More information:

- British Pain Society – britishpainsociety.org
- Opioid prescribing for chronic pain guidance – england.nhs.uk/south/info-professional/safe-use-of-controlled-drugs/opioids
- Faculty of Pain Medicine's opioids resources – fpm.ac.uk/opioids-aware

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- Helpline: 0300 123 0789
  (For up-to-date opening hours, please visit painconcern.org.uk)
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- To make a suggestion for a topic to be covered in ***Airing Pain***, email production@painconcern.org.uk

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