

Airing Pain Programme 12: Trigeminal neuralgia, pelvic pain, and cannabis

Using cannabis as a painkiller, pelvic pain in men and women, and living with trigeminal neuralgia.

Paul Evans looks at the often uncomfortable subject of pelvic pain and how both women and men can get help. Dr William Notcutt, expert on medicinal cannabis use, talks about the potential for pain relief, side-effects and future possibilities of the controversial drug. Nicky Jones tells her story of living with trigeminal neuralgia, with Jillie Abbot and Prof Joanna Zakrzewska providing more information.

Paul Evans: Hello and welcome to ***Airing Pain***: the programme brought to you by Pain Concern, the UK charity that provides information and support for those of us who live with pain.

Pain Concern was awarded first prize in the 2009 NAP Awards in chronic pain and with additional funding from the Big Lottery Funds Awards For All programme and the Voluntary Action-funded Community Chest, this has enabled us to make these programmes.

I'm Paul Evans and in this edition of ***Airing Pain***...

Jillie Abbott: It's known as the worst pain known to man, sometimes known also as the suicide disease. It's a dreadful condition to suffer from and we do know of people who have committed suicide.

Dr William Notcutt: Cannabis offers us a different way and we know that the mechanisms whereby cannabis works are different to all the other medicines that we use. Therefore, it gives us potentially an alternative approach, either instead of the drugs they are using or maybe in combination with one or two, that they will get improved relief of pain.

Prof Joanna Zakrzewska: Patients there were wearing little lapels with a picture with a molar tooth and I said: 'Why are you wearing these?' 'Oh, we are what's called the lost tooth brigade'.

Evans: More on those stories later. But one of our aims on *Airing Pain* is to find answers to questions you've raised with us. One listener asks: 'My husband is experiencing discomfort in his pelvic region. He's too embarrassed to go and see his GP, so how can I persuade him to go and see a doctor about it?' Answering this question is Dr Steve Gilbert who is an anaesthetist and pain doctor working in Fife, Scotland:

Gilbert: In your pelvis there are lots of things that could be causing discomfort or pain and I think that it is very important that your husband goes to see his doctor about this. Often, as you get older, there is some difficulty with passing urine and usually this is just a harmless enlargement of the prostate, which is a little gland that lies at the bottom of the bladder around about the tubes that you pass urine through. So this is fine, something to be expected as you get older. Very occasionally, of course, there is a chance of there being a growth there, something you might need to get checked out with a doctor, with a GP or with a specialist.

Of course also your bowel runs through your pelvis and, as you get older, it's very important to look out for any change in the way that your bowels are working. If you find it difficult to pass bowel motions and especially if there is any blood in your bowel motions, then you would need to go to see your doctor straight away to exclude any serious disease. So I would say that if this problem has started and he's carrying on getting symptoms, but it's not just cleared up by itself, then he should go and see his doctor and see whether there's an underlying cause for this.

Evans: That was Dr Steve Gilbert.

Natasha Curran: Urogenital pain can affect people in numerous ways because with pain in the pelvic area, people get pain when they are walking, for example, when they are sitting, when they are lying down, so it affects all aspects of movement. But they also get it because the pelvis is very important for several functions: for example, you've got to be able to pass urine and faeces and have sex in the pelvis and a lot of people can't maintain this, so even going to the toilet is very difficult. And also it can be very difficult in relationships, if their sex life is affected.

Evans: Natasha Curran is a consultant in anaesthesia and pain medicine at University College Hospital, London and she specialises in urogenital or pelvic pain medicine.

Curran: There can be numerous causes for people to have a pain in the urogenital – which basically means the renal or genitals system or the pelvis. People can have pain from

infections or from previous disease – for example, many women have endometriosis which causes pain in the pelvis – operations or any other reason why people can get chronic pain. So people often have chronic pain from the muscles, which can be really underestimated. And like any other chronic pain, it's a pain that goes on for more than 3 to 6 months – this makes it what we call *chronic* pain.

So it's an ongoing or persistent pain and it's not that dissimilar to people having conditions like chronic back pain. But I think that most people think, or there is perception in the public perhaps, that if a woman has pelvic pain that's something to do with childbirth. Or often people have thought that there are psychological causes – but there are really many, many reasons why people can have pelvic pain.

A common presentation for me to see in men is a chronic prostate pain. For example, a man may start off with prostatitis (an infection in the prostate gland) and normally that's self-limiting, that is, it goes away or it may be treated with antibiotics, which men commonly go to the GP for, have it treated and it disappears. Now, for most men that's the story – as in, for most men – or women having a bladder infection (cystitis) – but unfortunately for a small number of people they may get a recurrence of the symptoms, so they experience the symptoms as if they are having prostate infection, although they haven't got an infection, they've got a chronic pain syndrome.

Often I see people who are very happy to talk about their pain and say 'Oh, I've talked to everyone about this. I have no embarrassment whatsoever'. But I recognise that pain in the vagina or the testicles or the penis or the back passage is not something that people are able to necessarily talk about with their family or friends, whereas if they had back pain, for example, they might be more willing to share that. That sharing of information is only really done with medical professionals and it might be something that they're reticent to bring to their general practitioner or even their urologist or gynaecologist, particularly if people don't ask about it.

So one of the things I do in my consultations is to very much... so at the beginning of the consultation, there will be some questions I ask you which may not be relevant, but I know that if I don't ask you, sometimes there may be things it can be difficult to tell me about. So I ask people about their sexual relationships, because sometimes it might be something that is very important to someone, like, 'I've got this pain in my vagina or my penis which is preventing me from having sex with my partner'. But if someone is not able to say that, that's why I ask them questions.

I think if someone is listening to this and they realise they've got urogenital pain and it's been chronic, as in it's been there for longer than 3 or 6 months, I would suggest going to your general practitioner and you can be referred to a pain clinic. There are certain pain clinics which have specialists in urogenital pain like us at University College London, but also there are people around the country that are becoming more proficient and learning more and more about treating pain in this part of body.

Evans: Natasha Curran of University College Hospital in London. And you may be interested to know that the Bronllys Pain and Fatigue Management Centre in Wales that we've featured in an earlier edition of *Airing Pain* is running a two-week residential programme for female chronic pelvic pain and endometriosis in June 2011, that's this year.

You are listening to *Airing Pain* with me, Paul Evans...

Now cannabis, its use and misuse is a subject guaranteed to raise tabloid temperature, particularly when questions of its legality are raised. Cases that hit the headlines sometimes involve people with chronic pain being prosecuted for their use of what is essentially an illegal street drug.

Dr William Notcutt is a consultant anaesthetist at the James Paget Hospital in Great Yarmouth. He specialises in pain medicine and has been researching the use of cannabis-like medicines for about 15 years. Initially this was on synthetic cannabinoids, but in 2000 the research was able to start using extract of the actual cannabis plant.

Notcutt: We know an awful lot about how it works, why it works, why it helps in multiple sclerosis and as time has gone by, we've managed to find out and show the benefits that these cannabis extracts can have, particularly with multiple sclerosis and also with other pain problems as well. For a drug that has been around 5000 years – there are writings of it in ancient Chinese literature – it is always difficult to use because people did *not* have a standardised purified extract and they *didn't* know how to use it properly, but getting a licence for cannabis as a medicine is a massive leap forward.

Evans: So the drug Sativex became licensed for use in the UK in June 2010, but what pain conditions will it be used to treat? And whilst some people may be aware of the effects of taking illegal street cannabis, is this what medicinal users can expect and in what form will it be taken?

Notcutt: The initial condition that the licence is going to be for is for the treatment of spasticity in multiple sclerosis. Spasticity is a condition whereby the muscles go into spasms, are very tight, and that, as one can imagine if you've ever had a cramp, can be an excruciatingly painful condition. Now, this is the first area that this has been looked at, but we also know that it's valuable in other causes of pain with multiple sclerosis, and I think in time the license will be developed so that it can be used in other pain problems.

Inevitably with any drug there are side effects and every single drug that we use at the moment for treating pain has side effects, some of which can be lethal. Cannabis itself *does* have side effects and in the controlled way we've been using it with patients these side effects can be minimised. And the likely side effect that patients can get is feeling a little light headed or dizzy. It's certainly not the euphoria that people usually associate with the recreational use of cannabis. They don't go anywhere near that level of intake. And what we've found is that at comparatively low doses of cannabis, that patients can get the therapeutic benefit. They get it at low level, far below the level at which they would be expected to be high, as they would do if they were using it recreationally.

The traditional way of using cannabis has been to smoke it, which is an effective way of delivering the drug, but it is very likely that in taking it, it gets into your body very quickly and can produce the high. The other way that cannabis is traditionally used is by eating it. It's often baked into cakes or other food. The problem with that is that the absorption is much slower and much less reliable and so it's much more difficult for a patient to get the dose exactly right. What has emerged from our research has been the use of the cannabis extract sprayed under the tongue. It's then absorbed by the lining of the mouth and this gives a much more precise effect than if it were swallowed.

Evans: As I alluded to earlier, the licensing of what was – and is – an illegal street recreational drug will always create a headline. Dr William Notcutt again:

Notcutt: I think for a long time there is going to be a controversy over cannabis. Maybe there always will be, because although it does help a lot of patients, it doesn't help some patients at all and there *are* problems with cannabis and we know this.

There's been a lot of press about the potential for psychosis with cannabis users. As time goes by we've understood more about that and it's probably a problem essentially in the very young, particularly the adolescent users of cannabis and the response of the adolescent brain to cannabis. Older people, who comprise almost all our patients, if they haven't had

any significant psychiatric problems or even drug dependency problems, are very unlikely to develop any psychosis or dependency problems with cannabis. It's probably mainly a problem with the very young and the recreational user who uses high doses.

But there *are* several dangers for people who buy it of the street, one of which is the quality of the material they are getting. They really don't know exactly how effective it is going to be, they don't know what the composition is. Cannabis itself has a number of different elements to it and what we know, for example, is that the two particular elements when put together make it much safer than a lot of the cannabis that's on the street at the moment – so-called 'skunk' and that type of cannabis.

So if someone is getting it on the street, they essentially don't know the quality or quantity, they don't know what it's mixed with and it may be mixed with pesticides, heavy metals, fungi, bird droppings, all sorts of chemicals – you just don't know what it is there. Then they have the problem of administering it: how do they do it, how do they go about it? And then knowing how far to go, what the experience might be... it's just a massive problem and it's the same thing with drugs like heroin and other drugs you can get off the street: you just don't know what you are getting and you may be alright one day and another day you may be in real problems.

I mean, I would like to see medicinal cannabis become another tool that we have for treating pain. In my mind, there's no doubt that this is going to prove a valuable addition to the drugs that we have at the moment, but there is a huge amount of work to be done on it. We've been working on morphine for 200 years and still studying it to this day. Well, I might say there's 200 years of work to do on cannabis, makes me shudder at the thought [laughs]. But there is a lot of work to go on to this, to develop it, to potentially develop it out not only into areas of pain, but possibly into many other areas of medical practice as well.

Evans: Dr William Notcutt. And at this point I will 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 related 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.

This is ***Airing Pain*** with me, Paul Evans.

Nicky Jones: It's like being hit by a bolt of lightning or I would imagine that it's like having a Taser gun aimed at your face. It just knocks you off your feet when it happens, there's nothing you can do, you can't function, you can't speak, you can't think.

Evans: Trigeminal neuralgia is a relatively rare condition that affects 4 or 5 people out of every 100,000 each year in the UK, yet to those unfortunate enough to have it, it can be devastating. Prof Joanna Zakrzewska is the Facial Pain leader at University College London Hospital's NHS Foundation Trust and she works at the Eastman Dental Hospital:

Zakrzewska: It's a facial pain on one side of the face which results in sharp shooting pains that last for seconds but are of great severity. And then you may get many of these provoked particularly by light touch activities such as washing your face, shaving, brushing your teeth, eating. And it really stops you dead in your tracks. You can get multiple attacks every day and then suddenly it could disappear for weeks or months, but gradually it tends to keep recurring and the attacks get longer and the pain gets more severe with time.

Jillie Abbott: When it first happens it's a bolt out of the blue and you recover from it quite quickly but the shock is astronomical, it really is very frightening. And what tends to happen, it's a progressive condition unfortunately and these attacks become more regular and can happen in a volley of attacks. So you can get this sort of zap-zap-zap sensation in your face, which just renders you incapable of doing anything and the fear of the next attack is what most our members say is one of the worst things. It's like torture and you know you are going to be tortured again.

Evans: That was Jillie Abbott, Chairman of the Trigeminal Neuralgia Association UK. Nicky Jones now, in her late thirties has had the condition for eight years:

Jones: It started out of the blue. I was sitting watching television, it was as if somebody put a cattle prod to the side of my head, just WHACK! – this immense electrical, intensely painful pain. And I literally hit the floor. WHACK! And it's never stopped.

Zakrzewska: Patients very often think, when they get their first attack of pain, that it's a dental condition because it tends to be in the lower part of face. So the general perception is 'If it hurts around my face' – because it can start to hurt inside the mouth – the general idea is: 'Oh, it must be a toothache'. Patients will go to their dentist and the dentist, of course, being very mechanically trained, will look for a dental cause, may find a tooth that looks a bit suspicious and start some dental treatment. Neurosurgeons claim that up to 60 per cent of

patients will have had some dental treatment done before the penny drops. And some of these patients will have even their teeth taken out or root canal treatment.

And I must say, when I went to the first trigeminal neuralgia support group meeting in the US, patients there were wearing little lapels with a picture of a molar tooth and I said 'Why are you wearing these?' 'Oh, we're what are called the lost tooth brigade'.

The problem with trying to make the diagnosis is that the diagnosis relies on history alone, there's no easy test like for diabetes where you can do a blood test and show, 'Oh this is a blood glucose'. So it's a matter of sitting down very carefully and piecing out the timing of the pain, the character of the pain and listening to the words patients use, because they will often use the words 'It's like an *electric* shock, *lightning* going through my face', which also gives that feeling of rapidity and severity of the pain. And the fact that this is a *sharp* pain rather than a dull achy pain, which is what a lot of toothaches are like.

Evans: You are listening to *Airing Pain* with me, Paul Evans and we are talking about Trigeminal Neuralgia. Prof Joanna Zakrzewska of the Eastman Dental Hospital:

Zakrzewska: Trigeminal neuralgia, in the majority of cases, is thought to be caused by pressure of a vessel on the nerve, right inside the brain. Just as the nerve enters the brain, there is a weak point where the myelin changes. Pressure of a big vessel on there causes the myelin – that is the insulation of nerves – to disappear, so that suddenly you can get crosstalk between light touch fibres and pain fibres – because normally they are insulated from each other, like a wire is insulated from itself. And in some rare cases it can be due to multiple sclerosis or it can be due to a tumour sitting in that part of the nerve or on that nerve. So that's why these patients need to have some scans like an MRI scan to exclude those much rarer causes – but in the majority of cases it's just this vessel.

Evans: So? Can it be treated? Jillie Abbott of the Trigeminal Neuralgia Association UK:

Abbott: TN is treated primarily with antiepileptic or anticonvulsant drugs. It is a forever treatment and antiepileptic or anticonvulsant drugs are not something you can take as and when you get the pain – you have to take them regularly for the dosage to built up in your blood stream. And we do get situations where the side effects become intolerable and patients find that they just can't cope on the level of drugs that they are having to take to try and control the pain.

Jones: Carbamazepine completely knocked me for six. I couldn't function at all, I couldn't walk, anything like that. Didn't know any better, so I didn't persevere with it. He then put me on gabapentin, which seemed to slow the pain down and I struggled with it. I was on stupidly high doses and I couldn't work, I couldn't feel my fingers or my toes and I stuttered a lot and couldn't find any words, you know, it really had an impact on my mental capabilities as well as my physical.

Zakrzewska: Virtually *all* of these drugs will give severe side effects and then we move on to surgical treatments. In a way, the best surgical treatment is to address the cause, that is, the nerve being compressed by a vessel. But this is a major procedure called a microvascular decompression and not everybody will want to have a major surgical procedure that has a mortality rate associated with it – which is fairly low, as low as for any operation, but is always there – given that is not a disease that results in death. But this will give the best results: 70 per cent of patients can expect to be pain free up to 10 years. That's as long as the data we have.

If patients aren't fit enough for this, then we have to think about destroying the nerve, slightly lower down in the passageway of the nerve and this is by, very crudely put, by cooking it, putting glycerol around it, a neurotoxic drug or even by compressing it. But all of these result in destruction of the nerve and therefore patients are likely to have a sensory loss, like a dental injection. And it can vary anything from the real, full deadness that you get with a dental injection, to the one coming through with light touch or pins and needles type feeling and about 60% of patients will complain that that's an unpleasant sensation. That gives pain relief on average for about 4 years and then it needs repeating again.

So you've got to toss up your different decisions for which procedure to have, which can be very difficult for patients to make, about whether they go for medical or surgical treatment, and then if they go for the surgical treatment, *which* of the surgical treatments to choose – and that's very difficult.

Jones: At that point I went on the internet and I found the Trigeminal Neuralgia Association. I rang their helpline and got a lot of information that I hadn't got from anywhere else, a lot of emotional support and they gave me a consultant surgeon's name. So I went to see him and he looked at my bad MRIs and said 'You've got a massive compression on your nerve route, a blood vessel is compressing the nerve as it comes out of the brain stem'. So he said he would operate. Massive artery pressing on my nerve route, so he patted it all up and I woke up and I was pretty much pain-free and it was great and I came back home to recover

postoperatively and the pain still seemed to have gone. I returned to work and was made redundant, so I then immediately just went to another job, but I'd only been there for about 3 weeks and the pain suddenly came back.

Zakrzewska: The nerve tries to regenerate and reform the myelin and this is why you get periods of pain remission, because the body is successful in re-coating these nerve fibres, but if that fails, then the pain continues.

Jones: The pain gets so bad the constant pain, and, you see, when the constant pain is bad the stabbing pain joins the party. It can get intolerable. Mr Simpson, my consultant, says I should go to a hospital and get Ketamine at this point, but I can't even move, there is no way I can drive or be driven half an hour to the nearest hospital who would then spend three hours trying to figure out what to do! So I dose myself up with my opioids that I have here and try and just go through it. The longest one of those bad things lasted was just over 24 hours, usually after 8 hours or so it does lessen enough that I can start to sleep.

Evans: And do you know what triggers that with you?

Jones: A major trigger is activity and that means doing anything other than going for a very short walk in the morning and sitting in my chair all day. I mean I get instant pain. If I touch one of the trigger points on my face I will get instant pain, WHACK! But if I do that too much, the next day it's like the nerve just has a complete breakdown, just has a party, a very bad party.

Abbott: It's known as the worst pain know to man, sometimes known also as 'the suicide disease'. And because of this terror of going outside, of talking, eating, laughing, smiling, you become very isolated, you become very low, very depressed. Several patients become very, very emaciated because they find they can't eat, some can't even drink and they end up being taken to the hospital because they are dehydrated. It's a dreadful condition to suffer from and we do know of people who have committed suicide.

Evans: Jillie Abbott, chairwoman of the Trigeminal Neuralgia Association UK:

Abbott: The most important thing I would advise anybody with this condition is to join the Association and the support that they get will be invaluable. There is information on the internet – a lot of which is incorrect – but all the information that we give out is checked by our professionals, by our medical advisory board and by our medical advisor, Professor

Joanna Zakrzewska, so it *is* correct – so they are getting up to date, correct information as well as health and guidance.

Jones: Oh, the TNA was an absolute lifesaver to me, I don't know what I would have done without it. I mean, to me it was the intense relief of finding somebody who had the condition, who could understand, made a massive difference – it made THE difference. And that's why I volunteer on helpline, that's why I do what I can even when it hurts like hell to do it, because there are other people out there hurting as well. And other people who need to know that they are not alone and that other people understand.

Evans: What sort of people get in touch with you?

Jones: It's a massive range of people. We get carers who are worried about their relatives and think that the relatives haven't got enough information or aren't being treated properly or just want information. We get sufferers who are suicidal, who've had enough of this and can't go on and they're just crying out for help. We get people who just need information about possible treatment options. I've even had somebody emailing and asking for help for a horse who had the condition, which was interesting.

There is a theme through them, in my opinion, that GPs don't treat this well, that they don't know enough about the situation. If they recognise it, they will stick the patient on carbamazepine and if that doesn't work, they are at a loss. I'd prefer to see people who aren't treated easily by carbamazepine being sent straight to see a neurologist, not to let these people continue suffering, because that seems to happen a lot and people get desperate and that's why the TNA is there. That's our important role, is to stop people feeling so desperate and allow them to get the information they need.

Evans: My thanks to Nicky Jones who went through an awful lot to pass on her message about the Trigeminal Neuralgia Association UK to others with the condition. Their website is www.TNA.org.uk. That's T N A – stands for Trigeminal Neuralgia Association – dot org dot UK. Please do pay it a visit.

Now, before we finish I'd just like to say that if you or someone you know has benefited from listening to these programmes and want them to continue, then please consider making a donation to secure **Airing Pain's** future. It's very easy to do, just go to our website at www.painconcern.org.uk where you'll find a 'Make donation' button. You can also download all the past editions from there and if you would like to put a question to our panel of experts or just to make a comment about the programme, then please do so via our blog, message

board, email, Facebook or Twitter or even pen and paper, in which case you will need the address:

I will leave you with Nicky Jones:

Evans: I've come to your home today. You are wrapped up, sitting down in your chair, staring out the window basically, you are sucking your lollipop – what's the lollipop?

Jones: It's fentanyl, a strong opioid.

Evans: So, you are having to do that to talk to me?

Jones: Yes.

Evans: How is you talking to me going to affect you tomorrow?

Jones: Just the action of talking triggers the pain, it's the nerve endings in my mouth, the roof of my mouth and my tongue. It's like they get used and the nerve just misinterprets those signals as intense pain.

Evans: And since we've been talking we've had to stop twice.

Jones: It's pretty bad at the moment and it's triggering off in my mouth and the roof of my mouth.

Evans: Right. I think we ought to stop. Thanks very much indeed.

Jones: Thank you.

Contributors

* Dr Steve Gilbert – Q+As on back pain, pelvic pain in men

* Dr Natasha Curran – pelvic pain

* Dr William Notcutt – cannabis and pain

* Prof Joanna Zakrzewska – facial pain/trigeminal neuralgia

* Jillie Abbott – trigeminal neuralgia

* Nicky Jones – living with trigeminal neuralgia

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