# *Airing Pain* Programme 21: Opioids and managing pain in remote areas

***How people in remote areas manage pain, and when and how to take opioids.***

*In this programme we hear about the challenges facing people with chronic pain in isolated parts of the country and how a pain management programme in the Highlands is helping such patients. Dr Cathy Stannard clears up some of the misunderstandings surrounding opioids and explains when they can and can't help with chronic pain and the possible side effects of taking them.*

**Paul Evans:** Hello, I'm Paul Evans and welcome to ***Airing Pain***. A programme brought to you by Pain Concern, the UK charity that provides information and support for those of us living with pain. This edition has been enabled by a grant from the Big Lottery Fund, Awards for All (Scotland) and with an educational grant from Pfizer Ltd.

**Dr Cathy Stannard:** Prescribing opioids really demands a high degree of trust between a doctor and a patient and it is a very much a partnership.

**Jackie Milburn:** She actually felt a fifty to sixty per cent reduction in her pain. She now feels that she is able to cook a meal which she has never been able to do for a long time, because she couldn't stand. Her mobility has improved – that has helped with her weight and the decision between herself and me that she stop, you know, 'I don't need to come anymore, I feel happy with what I've got' and we've discharged her from the clinic.

**Marion Beatson:** Breathe through the pain, let it go. It won't take the pain away completely but through time, you actually learn to shut everything out.

**Evans:** More on those stories later, but here on ***Airing Pain*** we want to feature pain management services throughout the UK and in April 2010, NHS Highland in Scotland launched its chronic pain service. Now the Highland region is the largest in Scotland in terms of area but the smallest in terms of population. So whilst, being a stunning area to visit, it's size and geography raises particular challenges for those with long term medical conditions and who live in the more remote areas. Gill Wilson lives in Achintraid, a small remote crofting township at the

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Eastern end of Loch Kishawn, and that's on the west coast of Scotland.

**Gill Wilson:** It will be my fiftieth anniversary of having pain this June. I was just a teenager, I was 18 and it was a minimal accident – I jumped off a rock on the coast and there was a spike of rock sticking up. I misjudged the distance, it was a long jump and I landed with this spike of rock in my left heel and my whole spine jarred over and apart from three years after a spinal fusion operation, I have had it 24 hours a day since.

We worked out once and that was 20 years ago, that I had spent £28K on my back – glory knows what it is now! I don't seek to do, I just put up with it more now – acupuncture, osteopaths, chiropractors, physiotherapy, surgery – you know – everything! I had a doctor, who actually said to me, 'I don't believe you have pain' and I said 'why?' and she said 'because the sort of pain you're talking about, I've never heard anybody describe pain like that'.

I actually feel like somebody has thrown a bucket of pain over me – with a horrible headache, I can feel nauseous – it's literally from my head, sometimes in my legs but anyway – from my head right down my back. I have just been in bed – this is my first full day up in fact, for a week, it's appalling at the moment and I can't think of anything else but, every day I say to myself 'have you had some enjoyment in today?' and as long as the answer is 'yes' and it's only five minutes, it's worth being alive for.

**Evans:** Gill Wilson who lives in the remote Scottish Highlands. So for people like Gill, access to expert treatment and advice on pain management is a high priority. Jackie Milburn is the clinical nurse manager for the chronic pain service at NHS Highland and John Knox went to speak to her for ***Airing Pain.***

**Jackie Milburn:** The service actually formally started in April 2010. Prior to that, we had a pilot study for two years to actually look at teething problems and see how we could actually develop the formal pain service when we got established funding. As you are aware chronic pain management services are for managing patients' pain – we are not here mainly as a curative service but to help patients manage their pain, whether that means through medication, means through other techniques of cognitive management, different strategies like pacing, coping, relaxation.

In our team, we have a consultant anaesthetist who is a specialist in pain management, a specialist lead physio, specialising in pain management and also a clinical psychologist who specialises in pain management, so we use different clinics. We have multi-disciplinary pain

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clinics; we have medication review clinics; interventional theatre procedure clinics. We have a formalised pain management programme that has been so successful in the last year that we have had to actually do two a week now, it is a 12-week programme. We also have our individual physiotherapy clinics and individual psychology, if that's required, as well. There is a whole host of different strategies that we use to maybe manage different types of patient's pain.

**John Knox:** Now you cover an area, some people say, it is the size of Belgium, something like that – it is a huge, huge area! How do you manage with this area problem?

**Milburn:** That's one of our biggest logistical problems. We're part of the biggest geographical area of any NHS service in the country, we're also very rural and very remote, and that's something we specialise in, in NHS Highland. So we've had to take this approach for our chronic pain service. A lot of stuff is using electronic referral for patients. We also use a system where we do a lot of tele-medicine – appointments, all our patients are triaged by telephone.

In some cases we can offer medication advice there and then on the telephone for the GPs to carry on in the community and then we actually try and set a plan up for the patient at this telephone consultation – it is a dedicated half hour slot for these patients that is actually run by experienced clinicians, the nurse manager, the physiotherapist and the doctor. We are finding that our first six-month audit is showing that patients are really liking that system. It is not to replace face-to-face consultations – that's not the reason – but it's to make sure that patients are seen in the most appropriate way and it cuts down on travelling time and also helps us clinicians make sure we see more patients because we are not having to travel to clinics either.

**Dr John Macleod:** My name is Dr John Macleod, I am the consultant anaesthetist with a specialisation in chronic pain management and I am the clinical lead for the pain management service here in NHS Highland. My previous experience was in providing a chronic pain service in Birmingham and clearly the challenges in a city centre location are very much different in a peripheral location. We have a preponderance of patients within the clinic who have tended to move to the highlands seeking a different sort of lifestyle, I guess as part of the way of addressing some of the pain and health problems that they have and they do have some difficulty in adjusting to the challenges of living in a remote and rural location.

NHS Highland covers forty per cent of the Scottish land mass but only 300,000 of its population and so it is very sparsely populated and we have some very remote communities. It is extremely difficult to provide the same level of service to each and every one of those people as you might

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be able to provide, say in the central belt, where you have 1.2 million people in the greater Glasgow conurbation and therefore a much easier task in terms of delivering service equitably.

We use a lot of telephone consultation to try and minimise the travel both for the staff and for the patients because, prior to setting up the service in the highlands, patients were referred to either Aberdeen or to Dundee, which clearly involved considerable travel. Because clearly, if you are in a lot of pain a four-hour road trip, round trip to a clinic is not something that you are going to relish and so we do two things: we try and do our initial assessments over the phone and this allows us to make some sort of management plan for our patients prior to them actually having to come to clinic.

We find that it allows us to explain the sorts of services that we provide and also we find that for some patients, it transpires that they do not actually need to travel – we can advise prescribing advice to general practice or indeed there are a range of other things that can be done over the phone. Clearly, for some patients, it will have to come to clinic but this at least maximises the use of the clinic and reduces the amount of travel. Then for patient follow up, we do a very large proportion of our follow up by telephone and again, for the same reasons, and so it does greatly help in terms of patient and staff travel.

**Milburn:** People are very resourceful in the highlands, we know we have to travel, we know the services are not going to be the same as in a big city centre, so we probably will accept a lot more than maybe, someone that's in the city centre.

**Knox:** Well, one thing that strikes me that might be a problem is that these people are out on their own, they are not in a city where they can meet up with other people with similar problems

**Milburn:** I can see where you are coming from, and I think that will certainly be addressed in the future. At the moment, we do have the Pain Association and we at NHS Highland do support the Pain Association and they actually come up to the Highlands every month and we actually have the Pain Association and that works really well.

I think you also have to remember that we are dealing with small communities as well – some people want to keep their pain private so to have group therapy can actually be a negative thing but, yes, there is that issue that people do feel isolated. We find in our pain management programmes, when that group of patients get together, they do establish their own networks as well – that is something we have noticed which is great but, yes that is a problem for any disease process – there is that role of isolation of where people live.

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**Macleod:** The other perhaps more surprising benefit that we have found from this is that our DNA rate, for patients not attending clinics dropped from somewhere around twenty per cent...

**Knox:** 'DNA' being?

**Macleod:** Patients did not attend, not contacting the service, not turning up for clinic was around twenty per cent, which is high but not unusual in chronic pain patients – this has fallen to less than five per cent since we started engaging with patients on the telephone prior to their attending clinic.

**Knox:** How are you getting on with the GPs? Because up to now, I suppose they have been handling the bulk of chronic pain patients.

**Macleod:** That's a very interesting question. As I mentioned earlier, I've had experience of chronic pain management in other areas and I would say that because there has been very little in the way of pain service provision in the Highland, our GPs are very much more adept at managing the patients and actually make my job more difficult, because many of the strategies that I might have employed – and that many other colleagues elsewhere would be more reluctant to employ, prior to sending a patient into clinic – they've already used in attempting to manage a patient.

What we have done is we have tried to engage with our GPs and we have carried out a number of educational events around Highland and I've tried to go out into practices and talk to the GPs directly about the sort of service that we provide so that they have some understanding of what we are trying to do with our pain service. We had provision for round about 400 patients per year but in fact our numbers are somewhere around 700 for the first year.

**Knox:** There's no question of the service stopping? It's a permanent service now for the Highlands – is it?

**Macleod:** Yes, we were granted funding by NHS Highland Board and that funding is ongoing.

**Milburn:** Well my success story is my consultant decided when he read the referral letter of a lady, that it was appropriate for me to actually see this patient. I saw this client, I did a telephone consultation which is a half hour explaining the service, then looking at what her problems were – because all patient have to complete a detailed patient questionnaire before they are referred to the service, so we really have an in depth knowledge of their pain before we do the conversation – and it turned out that she had previous knee surgery which actually was

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successful but she developed quite significant neuropathic pain.

This lady was working full time but struggling, wasn't able to cook a meal, wasn't able to stand for very long. I gave her some management for her GP to carry out in the community, then I took her into clinic because she wanted to try other approaches, so we tried different types of creams like capsaicin cream; we have tried drugs like gabapentin and she put on weight so then we managed to change her over to pregabalin, her weight stabilised and we also started up with TENS and she actually felt a fifty to sixty per cent reduction in her pain. She now feels that she is able to cook a meal which she has never been able to do for a long time, because she couldn't stand. Her mobility has improved – that has helped with her weight and the decision between herself and me that she stop, you know 'I don't need to come anymore, I feel happy with what I've got' and we have discharged her from the clinic but she knows she is always welcome if she needs to be referred back.

**Evans:** Jackie Milburn, Dr John Macleod and Gill Wilson talking to John Knox about the pain management service in the Scottish Highland region. You are listening to ***Airing Pain*** with me, Paul Evans and as always we issue a word 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.

Now, the use of opioid drugs to treat chronic pain probably raises more questions from those offered them, than any other drug treatment. Possibly, this is because of all the issues that heroin – itself an opioid – has laid at our doors. So let's try and clear up some of the confusion. Dr Cathy Stannard is a consultant in pain medicine at Frenchay Hospital in Bristol.

**Stannard:** Heroin is an opioid. The medicinal name for heroin is diamorphine and that is a drug that is used in the UK quite a lot, particularly for treatment of cancer related pain. But its recreational use obviously has a different preparation, because it is not a medicinal grade preparation, but it is actually the same drug with the same actions.

Opioids work really by dampening down the way that pain nerves send messages so that they reduce the traffic in pain nerves if you like, so it's more difficult to send a pain message. Probably the most common opioid drug that people would be familiar with would be morphine which is probably the most commonest used drug but other drugs that people might have heard

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of, would include weaker drugs such as codeine and dihydrocodeine and other strong drugs, ones that we commonly use in the UK as well as morphine are oxicodone, buprenorphine, fentanyl.

Opioids are very effective in treating short term pain, so if you have a broken leg or you have just had an operation, opioids would be one of the most effective interventions to treat that pain. For many patients who have cancer pain, opioids are also very effective. Obviously, this has led to the idea that they might be used to treat pain that is not associated with cancer, with injury or surgery and the data that we have there are a little more conflicting and I think that it would be fair to say – and this is just a broad brush figure – that opioids are probably effective in about thirty to forty per cent of patients who have persistent pain.

We think that the circuitry, if you like, of persistent pain is different and much more complex – it's not just an acute pain that persists, it involves lots of different parts of the nervous system. And the influences on the pain experience are very complicated – so emotions, previous experience, mood, expectations, all those sort of things have a very profound influence and we know how that works. We know from imaging studies that these things actually work by changing the way the brain operates, if you like, and I think that is why a simple drug which changes signalling in one pain system isn't always going to be quite so effective in the longer term situation.

Common side effects of opioids are constipation, which almost everybody will get and it tends to persist – it isn't something that settles with time. There are other side effects like feeling sick and feeling giddy which a lot of people will get when they start treatment but these will tend to pass off with time, although they can be disabling and they are reasons for people stopping drugs in the longer term. We have more concerns about what effects taking these drugs in the long term may have on for example, hormones. And we know that ladies taking opioid drugs in the long term, who are of child bearing age, may be infertile, they may have reduced sex drive, they may stop their periods. And we know that men taking opioids in the long term, for example, have reduced testosterone levels with all that implies for sexual function and mood and everything else, so we do know that these drugs affect the hormonal system.

There is also a concern that opioid drugs may affect the immune system so, obviously, the immune system is the means by which your body keeps you healthy and repels infections and generally surveys your internal environment. And we know from patients having very high doses of opioids, for example, at the time of surgery, that their immune function is compromised to a

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degree. And there is a literature that suggests that immune function may be compromised in the long term by using opioids but, it is very difficult sitting with a patient and being about to prescribe an opioid, [to know] how that will affect that patient and whether it is likely to occur. I think the hormonal effects are now quite predictable and we can warn patients about that, but the effects on the immune system are I think are, much more difficult and they are an area of very active research in the opioid world.

**Evans:** Now one of the worries you may have if you are prescribed opioids is the fear of addiction. Cathy Stannard again:

**Stannard:** I think it is very important to distinguish – and certainly I would do this in my clinic – for anybody starting opioids between addiction and dependence. That sounds like nit-picking but it is not really. Dependence occurs with opioids and other drugs and all that it means is that if you have been on the drug for a long time, you can't stop it suddenly because you will feel quite unwell with withdrawal effects. And what that means is that we would take somebody off opioid drugs very slowly, to avoid withdrawal effects and dependence is a normal expected effect for anybody taking this class of drugs.

Now that is different from addiction, which is much more a behavioural thing, which is to do with the way that patients take drugs and the features of addiction are craving, continued use despite harm, behaviours focused towards drug seeking and inability to control drug use. There is a difficult world literature on whether true addiction does occur to prescribed opioids for pain relief and there is quite a lot of controversy.

I think that it is fair to say, for patients who are not at risk – and by not at risk – the patients who don't have an addiction problem already and that would include addiction to alcohol, who haven't previously had an addiction – it is very rare for people to become addicted to these drugs, but it does occur. Because it can occur and because addiction is a very disabling condition for a patient – we will monitor opioid therapy very carefully to make sure patients don't run into trouble.

By the same token, that is quite reassuring for patients because a patient might come and say 'might I become an addict?' and the answer is there is a very small chance, it is very unlikely, but actually it is very avoidable, because there are warning signs of someone becoming addicted to their drugs and these can be noted and addiction can be avoided. I think prescribing opioids really demands a high degree of trust between a doctor and a patient and it is very

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much a partnership and we do recommend that patients on opioid therapy are reviewed fairly often, so we do get to know our opioid patients very well but that is important – we obviously want to look for signs that a patient may be running into trouble but I think a patient has to know, when they are on a powerful group of drugs, that there is somebody who can give them information and address concerns if they feel they have either side effects or they feel worried about how the drugs are making them feel, so it is a real collaboration.

My view is that opioids probably are currently over-prescribed. I think there is a poor recognition with opioid drugs that they may not always be effective for persistent pain and there is a strange way that these drugs are prescribed compared to other drugs. Many patients will have the experience that they will go to their doctor and they will be given an opioid drug and if it doesn't work, they will be given a bigger dose and a bigger dose and actually one of the things we are trying to encourage in terms of guiding prescribers is to think of opioids like any other painkiller and if it's going to work, it will work in a sensible dose and once a prescriber has to start escalating a dose, to get an effect, one should start wondering whether that really is the most effective tool for treating that particular pain.

**Evans:** That's Cathy Stannard, consultant in pain medicine at Frenchay Hospital, Bristol. There is advice and guidance for patients and professionals on the use of opioids at the British Pain Society website at britishpainsociety.org.

Now, from one form of pain management to another, here's Marion Beatson, she has lived with chronic pain ever since having a work-based accident some 11 years ago.

**Beatson:** We were taught at the pain management clinics that I attended, they went through everything, through to your mind, through to your body and they taught us how to do mindfulness. It's a form of meditation, but you do it at your own pace. It takes a wee while to learn it, like everything else – it is just sitting, relaxing but trying to take your mind off the pain. No matter what is going on round about you, you try and shut it all out. When I was taught and when I was doing it, I was listening to the voices that were telling me to relax.

Any meditation, you start from the head down to relax, then your arms, then down to your feet and everything else. But you are conscious of what's going on round about you but you learn to just say 'right, I've heard that, let it go'. If you get a pain, you give it 'right, breathe through the pain, let it go'. It won't take the pain away completely but through time you actually learn to shut everything out, but it is your time to take time out for yourself and relax. It takes you into such a

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relaxing state, that you do fall asleep – maybe you haven't slept all night and it's just a case, you need that wee relaxation and time out for yourself, even if you tell everybody 'I'm going to lie on the bed for half an hour, leave me alone, don't come near me' and just lie on the bed. You're not going to sleep, you are just lying there resting, you are actually resting your whole body. I just felt *soooo* chilled after it, I go 'right, OK, I'm ready to go on and so something else now'.

**Evans:** Marion Beatson. So what is mindfulness? Well Dr David Gillanders is a clinical psychologist who shares his time between the University of Edinburgh and Lothian chronic pain service:

**Dr David Gillanders:** Mindfulness is meditation. It is a technique that has its tradition in earlier Buddhist practices but a man called John Kabat Zinn who works at the Massachusetts Institute of Technology, really in the late 1970s and early 1980s, took this practice of meditation and stripped out the religious aspects to it and made it a secular practice. So, simply defined, mindfulness is paying attention in the present moment with deliberate focus in the here and now in a non-judgemental and self-accepting kind of way.

So typically we would use mindfulness meditation exercises. We begin with a mindfulness of the breathing and just ask someone to just notice their breath moving in and out of their nostrils, whenever their mind wanders away, just notice that it has wandered off and gently invite back onto their breath, with the same kind of patience and encouragement, that one might do, with a small child learning how to do something new for the first time. Trying to use this kind of exercise to cultivate a self-compassionate, gentle, inviting, willing, present-moment-focused perspective simply on the here and now and the breath.

We might start with an exercise like that of the breath and maybe run that for 5-10 minutes. We might also extend, asking the person to also become aware of the feeling of being sat upon your chair now, to notice the sense of temperature in different parts of the hands, to maybe notice what you can hear in the room around you, to notice any other sensory perceptions, including for example, notice what your body is giving you, what the sensations you can feel in your body.

We might have the person scan through their body – it's an interesting exercise for someone who has chronic pain because a lot of time, people take a stance towards their body of not wanting to feel what it is giving them and so it can be a significant challenge, even this – 'are you able to, sort of stand or sit willingly with whatever it is, your body is giving you'. So in that sense, even in that move of taking a mindfulness meditation exercise that has its focus on the

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physical sensations, there's an opportunity there for someone to learn 'am I willing to have this or am I fighting to not have this as part of my experience right now?' And so we try and use these exercises to try and encourage people to notice the way that you are standing towards that pain, that sensation right now, notice some of the things that your mind is giving you about that pain sensation and just to notice that there is a separation between the pain sensation, what your mind is telling you about that sensation and importantly also, notice that there is a person here noticing both of those things – an observer perspective through which you can observe both of these events.

Through exercises like that kind of an exercise, we cultivate greater awareness of the present moment, greater kind of being in the here and now, being less kind of hooked into feared futures or things that might go wrong, worries like 'what ifs', less dominated by brooding on past events – 'if only this had happened or that had not happened' – and really trying to live much more in the present, the here and now. And that is mindfulness.

**Evans:** So it's living in the now and it's not me saying 'Oh, tomorrow is going to be dreadful, I've done all this interviewing in Edinburgh and I am going to feel so rotten tomorrow'. I should focus on just the way I feel now, go through my body, feel my breath going in, drop my shoulders, just relax.

**Gillanders:** Well, it's an interesting point because we don't do mindfulness meditation in order to relax, we do it to get *more present* with where we are at right now. I've heard people say, for example, we don't do mindfulness to feel better, we do mindfulness to *feel* better. In relation to what your mind was just giving you in that moment, you know, 'I'm going to feel terrible tomorrow because I've been here in Edinburgh, doing all this interviewing', well we would use this device, of saying 'notice what your mind just gave you'.

And kind of talking about the mind in this third person way, helps one step back from the literal content of what your thoughts are saying to you so that you can kind of, make more of a choice about 'do I want to buy into what my mind is saying there, or do I want to notice it as just a thought?'

This kind of detachment is one of the features of mindfulness and one of the features of acceptance so what I do there, would be I encourage you to say 'just notice what happens if that thought, you know 'I'm going to feel terrible tomorrow' – if you buy that thought, if you let that thought take control of this vehicle which is your life, where does that lead you? Versus noticing

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that there's this thought here which is trying to grab control of your vehicle and does it have to be in charge, or actually are you driving this bus?

**Evans:** David Gillanders bringing this edition of ***Airing Pain*** to a close. You can find more details of this programme including download links for all the editions of ***Airing Pain*** or the pain concern website and that's at painconcern.org.uk. And don't forget that you can put a question to our panel of experts and make a comment about the programmes on our blog, message board, email, Facebook and Twitter. All the details including the address to write to, if you prefer pen and paper, well they are at the website too. I will leave you with Marion Beatson for the last words on mindfulness:

**Beatson:** I use it all the time. Sometimes you don't even realise that you have gone into it but the more you use it, you actually just shut everything out without even realising it. At the end of it you just give yourself a big deep breath [exhales deeply] 'time to move on, do something else'.

## Contributors

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