

Airing Pain Programme 2: Nerve pain and how to manage it

How problems with the nervous system can give rise to chronic pain, a personal success story of pain management and a Q&A with pain specialist Dr Mark Turtle.

Elizabeth Carrigan of the Australian Pain Management Association talks about how pain management techniques helped her come to terms with chronic neuropathic pain after spinal injury. We speak to experts on neuropathic pain about how nerve damage can lead to prolonged pain and the drug treatments available, including amitriptyline, anti-epileptic drugs and the more controversial opioids. We also take a look at the issue of chronic pain after nerves are damaged in surgery or chemotherapy.

Also in the programme: Dr Mark Turtle is in the chair for our Q&A session providing answers to your questions about living with and managing pain.

Rachel Yorke: Hello and welcome to **Airing Pain**, a programme brought to you by Pain Concern. We're a UK charity that provides information and support for those who live with pain. We won first prize in the 2009 NAPP Awards in Chronic Pain, which has enabled us to make this series of programmes. We also have additional funding from the Big Lottery Fund's Awards For All programme and the Voluntary Action Fund community chest.

Dr Beverley Collett: There are 7.8 million people in the UK with chronic pain – that means one person in every four households has chronic pain.

Dr Sherrill Snelgrove: There are reports from patients that they are not understood very often and that they feel they are given a low priority in the health services.

Kiera Jones: I've been through the whole rigmarole of doctors, specialists, MRI scans, x-rays, ultrasound scans - the lot.

Yorke: I'm Rachel Yorke and I've been in chronic pain for six years. Each fortnight, **Airing Pain** will look at the topics that affect us: the coping mechanisms, medical interventions and therapies that might help us to regain control of our lives.

Dr David Laird: On a good day we want to do things – we want to *achieve* things – and that means that we overreach, we're overactive, and we want to live our lives without the pain interfering. And that's part of the whole aspect of the loss that pain induces.

Yorke: But look, the programme isn't just for those who have chronic pain. It's for our family members, friends, supporters and carers, and also for health professionals

who wish to have a better understanding, and share the views and strategies of colleagues and patients.

Dr Steve Allen: More and more we're beginning to understand what goes wrong with people who have pain and more and more we can do something to fix that.

Yorke: But first a word of caution – that whilst we believe the information and opinions on **Airing Pain** are accurate and based on the best judgements available, you should always consult your health professional, who's the only person who knows you and your circumstances, and therefore the appropriate action to take on your behalf.

Now, in the last edition of **Airing Pain**, Lionel Kelleway outlined some of the basics of pain. Don't forget that you can still download that programme from www.ableradio.com, or obtain copies from Pain Concern. I'll give you details on how to contact us later in the programme. Earlier in the month Pain Concern were fortunate to receive a visit from Elizabeth Carrigan. She's founder and secretary of the Australian Pain Management Association. She was diagnosed with chronic pain in 2008 following a spinal injury and the subsequent operations to try and repair the damage.

Elizabeth Carrigan: While I was recovering from those operations, the pain wasn't improving. I was having physiotherapy and rehabilitations and those sorts of things. And it was the physiotherapist that said to me, 'Look, there could be nerve damage which is really causing you ongoing pain.' And she referred me back to the surgeon, who then referred me on to a pain specialist.

When I did, I got the appropriate medication which really took away the pain, maybe 30-40 per cent. So I wasn't great, but it was a lot better than it had been. One of the other things that he recommended that I could do if I wanted was to attend a pain management programme, so I did. And that was when things changed around for me. So, it was learning about self-management principles; it was learning about the nature of persistent pain; and it was then applying that pain management regime on a day-to-day basis. So I couldn't let up, I had to do those things daily and I still have to, so it's still a daily management process for me.

Yorke: We'll be following Elizabeth Carrigan's progress throughout the programme. But let's explore in a little more depth the point she raised about understanding the nature of persistent pain, particularly the type of pain that affects her and countless others: neuropathic pain.

Dr Steve Allen: Neuropathic pain is nerve damage pain, things like shingles pain, diabetic pain; it's a whole wide range of things.

Blair Smith: Other types of pain are caused by damage in the tissues – the bone or the skin or the joint. In neuropathic pain, there are abnormal signals being sent through the nervous system up to the brain and it causes a particularly unpleasant

sensation which is there all of the time.

Lionel Kelleway: The best way I can describe it is that it's like having my hand in a big pan of boiling water and just being unable to take it out.

Jan Barton: It felt like somebody had stuck a blender in the back of his leg and turned it on.

Yorke: Speaking there were Jan Barton, mother of Sam whose story you'll be hearing in the future; broadcaster Lionel Kelleway; Blair Smith, who is professor of Primary Care Medicine at the University of Aberdeen; and Dr Steve Allen, a consultant in chronic pain management at the Royal Berkshire Hospital in Reading.

I'm Rachel Yorke bringing you this edition of *Airing Pain*. In these programmes, we'll be focusing on topics and questions that you've raised with us. Dr Steve Allen mentioned shingles in connection with neuropathic pain and that's a recurring topic. One questioner has asked: 'Ten weeks ago I developed shingles. Although the rash has gone, I'm still in quite a lot of pain. How long will it last and what can I do?' We phoned consultant anaesthetist and pain specialist Dr Mark Turtle on your behalf.

Mark Turtle: The pain that you're experiencing is normally referred to as post-herpetic neuralgia. Herpes is the virus which causes shingles – it's actually related to the virus which causes chickenpox. That's thought to be a recrudescence – that is the virus that has lain dormant in the body after an attack of chickenpox suddenly releases itself. What we think happens is that the virus breaks out and you experience a rash, but the virus has a tendency to attach itself to the local nerves, and that's the reason why the rash is localised to a particular part of the body.

Initially, the pain – which sometimes precedes the rash – will be related to the acute activity of the virus. But as that virus calms down again, pain continues and one presumes that that is because the nerve itself has been damaged. And so, the patient then experiences a pain due to nerve damage, which is a type of neuropathic pain. Now, the number of people experiencing this post-herpetic neuralgia declines quite sharply with time over the first six to eight weeks and thereafter that improvement becomes very, very slow. So I'm afraid I've got to give a very nebulous answer as to how long it will be, but there's a jolly good chance at this stage that we're going to have a problem that could last for many months.

Now, the management – well, it's important to go and see your doctor about this and depending on his knowledge or interests, he may need to refer you on to somebody. But just very briefly, simple painkillers – paracetamol, anti-inflammatory drugs or opiate drugs – can be quite helpful; local stimulation techniques such as a TENS machine or a local massage can be quite helpful; there is a specific type of cream called 'capsaicin cream' which can be very useful – it actually is absorbed into the skin and the nerve cells and passes back along them to the spinal cord, where it's said to have an inhibitory effect, but in the meantime it can cause a little irritation. If

the person is experiencing a great deal of sensitivity on the skin, there is a patch called 'Versatis', which contains lignocaine, which is believed to absorb in the skin and counter some of the hypersensitivity of the nerves.

There is possibly a place for local anaesthetic nerve blocks, which temporarily reduce sensitivity, and blocking of particular sorts of nerves called sympathetic nerves. This is quite a specialist procedure, although very easily done by somebody who understands it and does them regularly. It's quite controversial, but there is some evidence to suggest that if these are done within the first few months, they can be quite effective.

There's another group of drugs which can be very effective. Firstly, we have the tricyclic antidepressants, such as amitriptyline, which can be very effective on this type of neuropathic pain and the second group is the antiepileptic analgesics. Two commonly used examples are gabapentin and pregabalin. These are particularly useful if there is a lot of hypersensitivity or if there's lightning momentary shooting pains. Finally, if the drug therapy hasn't really proved to be of any value, we really look at toleration of the situation and this involves a cognitive behavioural-based pain management programme.

Yorke: That's Dr Mark Turtle answering your questions about shingles. And don't forget that medical advice specific to you can only be given by your own GP or health professional. You're listening to *Airing Pain*, with me, Rachel Yorke and we're talking about neuropathic pain. Dr Mike Serpell is a consultant in Pain Medicine at the Western General Infirmary in Glasgow.

Dr Mike Serpell: Neuropathic pain, by definition, is pain that's caused by damage to the sensory nervous system. So that could be a peripheral nerve injury – such as a laceration at the wrist cutting the median nerve – or it might be something more proximal, what we call 'central neuropathic pain' – such as occurs after spinal cord damage causing paraplegia, or even after a stroke where you're left with post-thalamic pain syndrome.

The nerve damage may be cured, it depends on what the lesion was: if it was a laceration, for example, yes, that can heal completely if the nerve is not displaced or it may need resuturing back into place by a surgeon and the chances of recovery are very good. But, generally, nerve injury can be prolonged. Nerves aren't very good at recovery and you can allow up to two years for the nerve to recover, but after two years you're likely to get no further improvements. So up to a degree they are recoverable, but you really need to fully assess that and treat early on.

Carrigan: I remember really clearly that first appointment with the neurosurgeon where I roused on a little bit and he said: 'Look, really you'd be in a much better position if you'd come and seen me when you could still walk, rather than just leaving your condition to go on so long and not getting appropriate medical treatment for it.' And I guess that's a little message I'd like to give others: if you've got excruciating

pain – which is generally a warning sign in the body that something's wrong – to really act on it, promptly.

Yorke: Elizabeth Carrigan. And with that in mind there are several forms of management for neuropathic pain, but let's start with conventional drug treatment. Dr Steve Allen of the Royal Berkshire Hospital in Reading:

Allen: For neuropathic pain, normal conventional analgesics are rarely of any benefit, because the physiology's different, the way in which the pain is produced is different. So we've got to use a whole wide range of different drugs, and the posh term for that is co-analgesics. The two common groups are the tricyclic antidepressants, of which amitriptyline is probably the most commonly used, and the antiepileptic drugs.

Now, why are we using antidepressants for pain? Well, it's because it's all to do with the physiology of your brain and the chemicals in your brain that are involved. When you're depressed, you don't have enough in your brain of two chemicals – one's called serotonin; the other one's called noradrenalin – and the antidepressants raise the level of these in the brain and lift the mood and lift the depression. The same two chemicals involved with depression are involved with the bits of your brain which deal with pain. So there's a crossover effect for some patients. Not only are antidepressants an antidepressant, but they can help the pain as well. And interestingly we need probably, what, a tenth, a fifth, of the antidepressant dose to be analgesic. So yes, they're antidepressants, but they're being used in a very, very different way.

With neuropathic pain, the pain's being produced by a sensitive nerve, if you like. The similarity with epilepsy and why we use antiepileptic drugs, is that an epileptic's got a sensitive bit of brain which fires off when there's no need to do so and stimulates the brain to produce a fit. So you damp down selectively that very highly-sensitive area with antiepileptic drugs. If your pain's being produced by a very sensitive pain nerve, then you can use the same drugs to damp down that pain nerve and try and reduce the patient's pain.

And there are a wide range of those again that we use. When I first started, the common ones were drugs called carbamazepine, sodium valproate and epilim, which weren't particularly useful. The best thing that happened to neuropathic pain in the last ten years was a group of drugs – one's called gabapentin and the other one's called pregabalin. And it's just to do with the way they work – they're much better at what they do and they're much better at controlling the neuropathic pain.

Yorke: Dr Steve Allen. Now, one group of drugs often used to relieve acute pain is opioids but their use for neuropathic pain is more controversial. Dr Mike Serpell:

Serpell: Opioid medications are painkillers derived from opium, which is the morphine base. So they're a combination of different drugs. The most commonly

used ones that people might be familiar with are the names of codeine and morphine. Some pains are more responsive to opioids; inflammatory pain is more responsive than neuropathic pain, but even neuropathic pain is responsive to a degree. Some types of neuropathic pain are less responsive than others; for instance, central neuropathic pain is much less responsive. So partly it's the pain model, but also partly it's the patient.

There are certain risks with everything in life. The risks with opioids are obviously the well-known pharmacological side-effects of opioids which are well documented, things like constipation, nausea, drowsiness. But there are other side-effects which we're not quite sure about in the long-term use, such as effects on the immune system, the hormonal system...

There's always the risk of addiction and we are very mindful of that. But I think there is a fundamental misunderstanding about opioids. Step two opioids like codeine and dihydrocodeine are probably used far in excess, certainly for chronic pain. I think they're fine for acute pain, but for chronic pain, I think there needs to be a re-evaluation of how we prescribe them. And the new British Pain Society guidelines go some way to doing that. But we need to keep the work up, keep on researching it and keep on improving the education and the monitoring of how we prescribe opioids to make sure that we are continually getting feedback and improving the way that they are administered.

But opioids are one form of analgesic – there are many other types of analgesics and generally opioids are used as one of the last types of analgesics because of the very issues of them. And so there are plenty of other analgesics. And it's our job really as a pain clinic service to make sure that patients are exposed to everything appropriate before they come to opioids, unless there's a particular reason for opioids being used very early on.

Allen: It's sometimes actually very difficult to know which is the best treatment and certainly there are no hard and fast rules. Yes, perhaps for neuropathic pain, tricyclic antidepressants and anti-epileptics would be the first line drug of choice, but you can't always say this is the best treatment for any particular condition. Now, there are arguments between experts about what you should do first and there are many of my colleagues who like injecting, there are many of us who find a different approach and we use drug treatments first.

My viewpoint is that if we're going to try and treat chronic pain better, we have to do that earlier and better in the community. Now that means, really, drugs have to be – pharmaceuticals have to be – your first line treatment, and psychology; because you can't do complex injections in general practice. Now, I'm not saying drug treatment helps everybody, but it will help quite a large number of people who are undertreated. If you can treat them in the community, possibly with drug therapy first, then I think you're going to advance things more quickly.

Carrigan: Most people I know with chronic pain need some degree of medication or there might be medical procedures, but there's a whole other sort of role that I think you can take on yourself. And it is about managing a long term condition and learning to do that takes time and patience and also education. So if you have the opportunity to do a pain management programme, I'd strongly advise anyone listening to do that. It is difficult on a daily basis to get off to those programmes, but you'll meet other people with similar long-term painful conditions and you can get some strength from other people.

You can also learn lots and lots of skills. So those skills will be about relaxation, they'll be about pacing, they'll be about planning ahead and getting to know what pain is all about and how it's changed your central nervous system.

And it sounds a bit extraordinary that your body can do that. But when it does do that, you need to do things to calm down and quieten that central nervous system. So at the end of the day, you're telling it that really there's nothing for it to get excited and worried about. It's a bit like having a fire alarm going off in your body even though there's no fire – the smoke detector, the alarm, just won't stop ringing. So you've got to do things to tell your body that there isn't a fire there and quieten it down.

And you can have a good quality of life even though you've got pain and you can get that pain down to five, or below, out of ten, I think, with self-management techniques and with medical intervention.

Yorke: That was Elizabeth Carrigan of the Australian Pain Management Association. This edition of *Airing Pain* is presented by me, Rachel Yorke. And we'll stay with the subject of neuropathic pain, but move on to how it affects some cancer sufferers. Paul Farquhar-Smith is a consultant at the Royal Marsden Hospital in London. He was involved in writing the British Cancer Pain Guidelines, which is for all health professionals, and there's also a version for patients.

Dr Paul Farquhar-Smith: It's estimated in studies... it's been shown that after breast cancer surgery, up to about 50 per cent of women get a chronic post-surgery pain. And when you imagine the number of patients having breast cancer surgery, this is a large problem. And, indeed, I would say about half of my patients I see in the clinic have this sort of problem.

There is also the chemotherapy-induced neuropathic pain, and that varies very much depending on what sort of chemotherapy agent you had. There's some that you're very unlikely to get nerve pain from, and others that you are quite likely to get nerve pain from. The one I'm thinking about is the so-called 'Velcade', which is the treatment for myeloma, and that has a pretty high instance – about 35 per cent of people get significant nerve pain, or nerve problem, that may include pain after their treatment.

Yorke: Dr Julie Bruce is a senior research fellow at the University of Aberdeen. She has a particular interest in the risk factors for chronic pain following surgery. One study focused on women who had undergone surgery for primary breast cancer.

Dr Julie Bruce: Three years after the operation we found that 40 per cent of women reported chronic post-surgical pain. Then we followed up this cohort of women nine years after their original operation and we found that of those who had pain, half of them still had symptoms nine years post-operatively. And for the other half, they had got better. We were able to look at quality of life, and compare quality of life scores, and we found that, unsurprisingly, the women whose pain had resolved, their quality of life had improved, whereas for the ladies who still had the pain, their quality of life scores were lower than you would expect.

Farquhar-Smith: These women who come for example with the post-breast cancer surgery pain, they often think that it's a recurrence of the disease because they don't understand how they can have pain in an area that's completely healed up and there's no reason for them to have pain. We know that there's a good reason why these people have pain, because of the alterations in the nerves that have been interrupted and bothered by the operation.

So it's a type of nerve damage – the small nerves around the area that's been affected by the surgery. And these nerves get upset and think they have got pain when there's no reason to have pain. And these nerves can carry on feeling like this for months or even sometimes years after the surgery.

There are quite a few effective treatments that can address this, and these are usually the same sorts of treatments as we use for other types of nerve pain, such as the antidepressants – not being used as an antidepressant but as a specific anti-nerve pain medicine – and anticonvulsants – and, again, not being used because we think anyone's got epilepsy, but because they try and calm this over-activity of these bothered and damaged nerves.

Bruce: There are a number of things that can happen during an operation so that nerves can be damaged or they can be cut and often this is an important part of the operative process. So, for example, if surgeons are trying to remove the tumour, they have to ensure that the whole tumour has been removed and this may involve dissection or cutting of the major nerves and this is essential to achieve full recovery.

But the unusual thing is that, even though a group of patients are subjected to the same procedure or broadly similar procedures, we know that for a third of patients that they have symptoms post-operatively. Yet for the other two-thirds, they recover without any problems. So we have to learn more about why these differences occur. So, really, the research is trying to focus on being able to predict who might be likely to have a poorer outcome, to see whether we can help try and prevent this condition occurring.

Farquhar-Smith: The treatments for cancer pain are very varied and we have what we call a multi-disciplinary, multi-factorial approach. So, the pharmacological side, the medicines and tablets, is only one element of the whole picture, including psychological support, physiotherapy, operational health, palliative care input. And all these things act together to try and address the pain, because the pain is not just the electrical conduction down nerves that cause the brain to recognise pain – the pain is a human cognitive emotional experience and we have to address that in the treatment of it.

Yorke: Paul Farquhar-Smith. Before him we had Julie Bruce.

Back to our message board and one question we get asked frequently – and one that has no doubt been asked by the 7.8 million people with pain – is quite simple: ‘where can I go for help?’ Answering your questions today is president of the Welsh Pain Society, Dr Mark Turtle.

Turtle: The most important contact point is your local general practitioner. He is the key to it. He can give you a fair amount of support, he can tell you what services there are locally to access once it is established that there’s nothing important that we need to miss. And, for example, if you want to go to the pain clinic or some other hospital or facility, he can arrange access.

Most pain clinics will take people who are referred from their own general practitioner. There are a few that will take people off the street, but not all that many. There are also a few that will only take people from other specialists within the hospital. If you do have any difficulty, it’s worthwhile phoning, for example, NHS (National Health Service) Direct, who can tell you what facilities there are locally, and if they are able to actually give details of the local pain clinic, you can go back to your general practitioner and say: ‘This is the local pain clinic, to which you, my general practitioner, have access. Please can you make a referral?’

Yorke: That was Dr Mark Turtle, one of our panel of experts who will answer your questions. So please do contact us at Pain Concern via our website, painconcern.org.uk, Facebook, twitter, email or good old-fashioned pen and paper.

And, finally, just to prove that you *can* have a fulfilling life, even with chronic pain, we’ve been following the progress of Elizabeth Carrigan – from debilitating pain two years ago to her arrival this summer at Pain Concern’s offices near Edinburgh. So has her pain-management strategy been successful?

Carrigan: Well, I’d like to think that, given I’ve travelled from Brisbane in Australia to Edinburgh in Scotland that it’s been relatively successful, because one year ago even, I wouldn’t have contemplated a trip like this. It was just not on my horizon. I would have thought it was far too difficult a challenge and if I’d set it as a goal, I would have thought it was quite unrealistic. So, in a year, I have made quite dramatic improvement.

And it's a daily challenge and it's a daily management process. So, for me, that starts as early as, you know, 6-6:30. So I wake up and I actually take medication then. The mornings are actually very difficult for me; it's when I have sort of most pain, so I don't move until the medication has really taken effect. But during that time – about half an hour later – I'll start doing some stretching exercises and then I'll plan the day.

And generally I plan it so that I'm staying within my physical limitations. I'll also make sure that I've set aside some time, generally between five and six, when I rest: so I'll do some relaxation and again some stretching exercises during that time. I make sure I eat quite healthily and generally stay active and fit. And then at night-time I take the medication again so I can get up and get dinner ready and do all those sort of things that we've got to do in the evening because life doesn't stop.

But I always plan something nice for myself at the end of that day too. So I don't know whether this is going to help anybody else, but I used to wear lots of browns and greys and blacks and things, but I just find since having chronic and persistent pain, just being able to dress up in brighter colours really helps as well.

Yorke: Elizabeth Carrigan, founder and secretary of the Australian Pain Management Association. This edition of *Airing Pain* has been presented by me, Rachel Yorke, and I'd like to end with two observations about pain management from Elizabeth Carrigan and Dr Steve Allen.

Allen: Very often we can't reduce the actual intensity of a patient's pain, but what we *can* do is help them to cope better. Now that may be me on my own talking to the patient, it may be through more formal psychology, pain management or whatever.

So I think what we should never do is just take the reduction in pain as itself to be the only sign of success. It's all about what we call 'quality of life'. And to be honest when we used to go to international meetings ten years ago and you said the words 'quality of life', people laughed at you. And now they don't. And that's been a huge change in the last ten years – that we need to look at the patient as a human being and as a whole.

Carrigan: The quality of life can still be very high. So you can still do fabulous things like go on holiday overseas, you can still do things that benefit the community. So your work life might be very different, but it will still be a positive life.

Contributors

- Dr Steve Allen - neuropathic pain
- Kiera Jones, living with pain
- Elizabeth Carrigan - living with pain
- Professor Blair Smith - neuropathic pain
- Lionel Kelleway - living with pain
- Jan Barton - growing up in pain
- Dr Mick Serpell – neuropathic pain
- Dr Paul Farquhar-Smith - post-operative pain
- Dr Julie Bruce – post-operative pain

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