

***Airing Pain* Programme 14: Recent developments in nerve pain and how to get a good night's rest**

What is a spinal cord stimulator and could it help you to manage your pain? Plus, complex regional pain syndrome, mirror therapy for phantom limbs, and how chronic pain affects and is affected by sleep.

Paul Evans meets Edith Mowatt who has nerve root pain and hears how she has learned to manage her condition and about her experience of spinal cord stimulation. We hear a doctor's view on these machines from Dr Steve Gilbert, and how they can also be used to treat complex regional pain syndrome. Dr Candy McCabe tells us more about this condition, as well as the use of mirrors in therapy for phantom limb pains.

Finally, Professor Mark Blagrove and Dr Nicole Tang explain how pain affects sleep, and how a good night's rest with the help of cognitive behavioural therapy can ease pain symptoms.

Paul Evans: Hello and welcome to ***Airing Pain***, a programme brought to you by Pain Concern. A 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 Fund's Awards For All programme and the Voluntary Action Fund community chest, this has enabled us to make these programmes.

I'm Paul Evans and in today's programme:

Mark Blagrove: It is starting to be realised that insomnia can have, not just have the inability to fall asleep, the impossibility of being asleep, but what is called 'NRS' or 'Non Recuperative Sleep'. So people can be asleep, but it not do them very much good.

Edith Mowatt: It kind of colours your whole life but you begin to learn to control it and not let it control you.

Candy McCabe: It sounds very strange to talk about mirrors in relation to a pain that is so great that it can't be relieved by some traditional painkillers and that seems somewhat bizarre and wacky.

Evans: More on those subjects later. But we will start with one person's story of how she copes with chronic pain. Edith Mowatt has nerve root pain and that is where the root of the nerve coming out from the spinal cord is irritated, pressed on or damaged. And those with it feel the pain along the course of that nerve, say, down the leg, even as far as the foot where the pain is often worse than at its root in the back. Some people know this as 'sciatica', but it can range in severity from mild or as in Edith Mowatt's case, excruciating.

Mowatt: If I could describe it in a sound, it would be like a continuous high-pitched scream which radiated from the base of my spine right down to my feet. I fell at home, I fell over my own feet and twisted as I fell, damaging the discs in my spine. I was an officer in charge of a home for the elderly at the time and I worked on with it for about four months until I realised that there was something seriously wrong. I saw my GP and I was in the hospital the next day and that was the end of my career.

Evans: We'll hear more about how Edith copes with her nerve root pain at the end of this programme. But you will know by now that one of our aims on **Airing Pain** is to put questions you've raised with us to our panel of experts. One listener has asked, 'What's a spinal cord stimulator? How can it help people in pain and can you get one on the NHS [National Health Service]?' Well having being fitted with one of these devices, Edith is in the perfect position to explain the patients' viewpoint and following her, Dr Steve Gilbert of Queen Margaret Hospital in Fife will explain more.

Mowatt: A Spinal Stimulator is a machine a bit like a TENS machine, except it's implanted in me. The electrodes go either side of my spinal cord and the machine is just by my side where I have access and I switch myself on and off. It is easy to work but it takes a long time to get used to it.

Steve Gilbert: A spinal cord stimulator is a machine that is a bit like a pacemaker which delivers an electrical current to the back of the spinal cord. You've probably heard of a TENS machine which is an electrical stimulator, where you stick pads on the skin over the painful areas, sometimes your back or your shoulder or your knee, and it interferes with the pain transmission by activating the pain gate. That means it's using the same nerves, sending messages in and mucking up the pain transmission at the spinal cord level, so that you feel less pain.

The spinal cord stimulator works in a slightly different way – we are not really exactly sure what the underlying mechanism is – but we have found that, by delivering a low current to the back of the spinal cord, which is where the nerves all come down inside your spine (so it has to be inserted through a needle or a small operation into that area) – it can give you pins

and needles or a numb sensation in the area where you would feel the pain. It doesn't make the feeling go back to normal, it replaces the painful sensation with the pins and needles or this, what we call, 'para-seizure sensation'.

It has been found to be really helpful for some people with persistent nerve pain and some people also with complex regional pain syndrome, which is where everything becomes very sensitive in a hand or a foot. It's also been found to be helpful for some conditions, such as angina, where you have pain coming from the blood vessels around your heart, but they can't do an operation that can improve the blood supply. And the interesting thing about the spinal cord stimulator is that actually it does increase the supply of blood and oxygen delivery into the tissues.

Now, spinal cord stimulators are only done in specialist centres and so you have to ask your doctor can I be referred for assessment for a spinal cord stimulator. Often the doctor you will see, even if they are in a specialist pain clinic, might not have experience themselves of spinal cord stimulators and might not know whether it's exactly the right thing for you. This is possible on the NHS and it is a slightly complicated route that you have to go through to get the funding for it. Now the spinal cord stimulation is really quite an expensive treatment but I don't think that this should necessarily stop us exploring this as an avenue of treatment if it's going to significantly improve your pain and quality of life. But I've got to emphasise that there are only a few people that will actually benefit from a spinal cord stimulator.

Evans: Dr Steve Gilbert of Queen Margaret Hospital in Fife.

And please do send us your questions via any of the usual routes which you can find at our website which is painconcern.org.uk. But let me just remind you 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.

Dr Steve Gilbert mentioned complex regional pain syndrome – now this is a condition that we know very little about and seem to be poor at diagnosing. But we do know what improves the symptoms and what makes them worse. Candy McCabe is Professor in Nursing and Pain Sciences at the University of West England. She's also a consultant nurse.

Candy McCabe: The most common way that people are first aware of complex regional pain syndrome is if they have a fairly simple fracture, like a fracture of a wrist, and the first thing that they tend to be aware of is that the pain is utterly different to any sort of pain that they

have ever had before. It seems more than you would expect for a fracture, even though you've never had a fracture, people commonly report that they're very surprised by the level of pain.

The other first common presentation is that if they're wearing a plaster cast for that fracture, they feel as if that plaster cast is far too tight and they're constantly going back to the doctor saying, 'My arm is swollen. The cast is too tight. I need the cast changing.' And, in fact, when it's looked at by the doctor, by the plaster technician, they can see that it's a perfect fit and there's no problem with it.

Then, six weeks later when the plaster cast is removed patients may be shocked to find that they have a very discoloured looking limb. Now it's common after a plaster cast coming off that the limb looks a bit different, but with CRPS people find that the limb may look very blue or red; they may feel like it's very hot or intensely cold; they may find that the skin is very shiny, sweaty and there could be a dramatic increase in the hair growth that's on that limb so they may find actually that they've got very *thick black* hair growing on that limb and their nails have grown phenomenally. The limb is commonly swollen and, again, it's the pain that is the biggest problem to people with this condition. They don't want to touch the limb, they don't want anybody else to touch it and quite quickly they feel that the limb doesn't belong to them and commonly, within a matter of days or even weeks, they feel like they would like that limb cut off. It feels alien to them – they don't wish to be connected to that limb any longer.

We don't really know what causes it, but most commonly people will present following a fracture or a number of repeat surgical interventions into a limb. The other thing that can trigger it is prolonged casting, so if people have had complex surgery that's required them to be in a cast for a number of months, then that can be a risk factor for developing CRPS. But also you can just wake up in the morning and have spontaneous onset symptoms in the limb which is even more confusing because you're desperately trying to think of what caused it, how did it happen and there may be no obvious trigger at all. But the most common things are trauma, surgery and prolonged plaster casting.

There are three approaches to the treatment. The first is to deal somehow with that pain, so you would be given a range of different medications to help relieve that pain. And that may range from very simple painkillers up to more complex pain relievers depending on your level of pain. The next arm in these three treatments is to have some psychological support, because it's very distressing. Pain of any sort can impact on your life, it affects your family, your job, so some psychological support is really important.

But the primary treatment and the one that is there that is supported by these other two is physical rehabilitation. And that is the most important thing to start as early as possible. So patients should use that limb as much as they can despite the fact that they don't want to. Despite the fact they feel the pain is so great that they need to protect it. Actually, what they need to do is use it little and often. Touch it a lot – get the brain to recognise that limb again as their own.

Evans: Now, a brain that does not recognise a limb of its own is a strange concept to grasp. But some amputees experience a similar but opposite feeling of a limb that was there but is no longer, the so called 'phantom limb'. A treatment to correct this involves the use of mirrors and Candy McCabe has been experimenting with a similar technique for the treatment of complex regional pain syndrome.

McCabe: It sounds very strange to talk about mirrors in relation to a pain that is so great that it can't be relieved by some traditional painkillers and that seems somewhat bizarre and wacky. But actually mirrors have been shown to be very useful in relieving amputee phantom limb pain by tricking the brain into apparently seeing that the patient has got their limb back again. And we think what happens in phantom limb pain is that the mechanism that drives the pain is a mismatch between what the brain is expecting to see in that limb and the information that its getting back from the limb. So by giving somebody a mirror to look in where they are tricked into seeing two normal limbs again – it gives the brain back what it wants to see.

And with complex regional pain syndrome we think a very similar mechanism is happening – that because you have reduced or changed information coming back from the painful limb, the brain doesn't recognise it as it should do; it struggles to plan movements through that limb and, because there's a mismatch between what the brain expects to see and the information coming back, it has to develop some sensations to tell you that there's a problem. The sensations that it develops is this unpleasant pain, these sensory changes.

So the mirror is there to give good sensory feedback – good information back to the brain about what that limb actually looks like, the fact that that limb can move. So patients will position a limb on the centre of their bodies so they are able to look at a reflected image of the unaffected limb – look in the mirror and low and behold they have two normal looking limbs just by looking at the reflection of the unaffected limb. And then you would be asked to move both limbs simultaneously while looking at this reflected image that is superimposed on the area of your affected limb. And by doing this little and often we can start to reprogram the brain so that it recognises a more normal limb and therefore no longer has to send out

these alert mechanisms to tell you that there is a painful limb and your pain improves, movement improves and the condition starts to resolve.

But what I would stress is that this isn't a cure in its own right – it's very important that you use the three treatment paradigms in CRPS, so you have medication, psychological support, and physical rehabilitation. The mirror is another tool in the trick box – it's another tool in your armoury to help correct the brain pathways, correct the messages and so we would never use a mirror all on its own without these other treatments but what we have found is that people with very early symptoms – it can provide instant pain relief as they look in the mirror – you remove the mirror and the pain returns. So we ask people to do it little and often – five or six times a day – no more than five minutes at a time so that they can concentrate.

For those people further down in the treatment who may have had this condition for one year, three years – we find that it's perhaps not as effective but this varies between individuals. It's also really important that you're assessed first of all by somebody who has been trained in this technique, because it can increase your pain if not used correctly. Training more people into mirror image feedback would be very helpful but I think much more importantly is training people in recognising the early symptoms of complex regional pain syndrome. If people understand better the mechanisms that drive this condition, identify it more quickly, we can treat people more quickly and therefore we would have fewer people going on to get the chronic symptoms.

Evans: Candy McCabe, Professor in Nursing and Pain Sciences at the University of West England. This is *Airing Pain* with me, Paul Evans.

Now, poor ineffectual sleep and chronic pain go hand in hand. Yet sleep is one of our basic needs. So what is sleep? Mark Blagrove is Professor of Psychology at Swansea University.

Mark Blagrove: Sleep is a period when you are usually very still during the night and for mammals, including humans, it is made up of different stages: light sleep, which is stages 1 and 2 and then deep sleep which is stage 3 and then there is also a rapid eye movement sleep which occurs every 90 minutes. We are not sure why there are these different stages and in fact they are quite intricately arranged so that you alternate between deep sleep and REM sleep throughout the night with deep sleep predominating in the first half of the night. REM sleep predominating in the second half of the night and having light sleep between each instance of deep and REM sleep, so it's actually very complicated.

Evans: What do you mean by REM sleep?

Blagrove: REM sleep is Rapid Eye Movement sleep in which the brain looks like, has many of the characteristics of being awake and has as many brainwaves that look as if you are awake but you are in fact completely asleep and your eyes are moving backwards and forwards quite frequently.

Evans: Do the different stages of sleep, do they have different functions throughout the night?

Blagrove: They might do – no one's quite sure yet, deep sleep may be involved in maintaining our warm bloodedness. Deep sleep and stage 2 sleep and REM sleep may all be involved in consolidating different types of memory and there's the possibility that we have other hormone or neurotransmitter functions going on – resetting them, for example, which are tied to different parts of the night. So it could be a whole lot of different functions for the different stages.

Evans: Is there a relationship between sleep and pain disorders?

Blagrove: There is a relationship between sleep and some pain disorders. What can happen is that they can both interact with each other, so obviously the pain can cause people to have a worse sleep. So especially the deep sleep and the REM sleep can become diminished and you will be left with light sleep which is less recuperative and so the pain can affect your sleep. There is the possibility also of sleep affecting pain. One possibility is that people seem to be more sensitive to pain if they have not had enough sleep and so you can do standard pain tests on people, for example, by putting their hands in very cold ice water, which is absolutely terrible, and if people have been deprived of sleep, then the pain feels far worse. So that's one way in which sleep can affect pain.

Evans: Let me just describe the sleep I had last night and I have most nights and which many people get. I feel that I've been awake in the night, I've obviously had a full night's sleep because my wife has told me that I've been snoring, but I've woken up and I don't feel rested or healed in any way.

Blagrove: Yes, it is starting to be realised that insomnia can have, not just have the inability to fall asleep but the possibility of being asleep but what is called 'NRS' or 'non-recuperative sleep'. So people can be asleep but it not do them very much good. Now one possibility there is if you've had the lightest stages of sleep and just those and you haven't gone into deep and REM sleep, you may have well have been asleep all night and you may just wake up and feel extremely fatigued because the sleep has just been of the light type.

Now, although we are not quite sure about what it is that light sleep and what it is that deep sleep and REM sleep all do for us, it does seem to be that if you have a night full of light sleep, then people feel much worse than if they had the other two types of sleep with it. So, although we don't know what deep sleep and REM sleep do for us, if we lack them and just have light sleep, people can feel the difference.

Evans: That's Mark Blagrove, Professor of Psychology at Swansea University. So what proportion of people with chronic pain do experience sleep problems. Dr Nicole Tang is a research fellow at the Institute of Psychiatry.

Nicole Tang: Usually you will hear percentages, like 90% of the people who go to a pain clinic to seek help they will report some kind of sleep problem. One of my studies... we have used a standardised insomnia scale to check the prevalence and severity of clinical insomnia in that population. We found that actually, more than half the people going to a pain clinic will suffer from some kind of clinical insomnia of either moderate or severe level.

When you have insomnia and chronic pain, it really messes up the problem quite a lot because when you have the pain, the first thing that you want to do is to perhaps not think about the pain and when you been having it all day, you really just want to have a time when you don't feel the pain, when you're not conscious of the pain, so that you can have a respite. So for a lot of people with chronic pain will sometimes use sleep as an escape, but when they're so desperate to get an escape they actually spend a lot of time in bed and that is not the way to regulate the sleep. So when you're trying so hard to get to sleep, forget the pain, you're actually violating some very essential rules – how to get a good night's sleep – because by extending your time in bed, you're just increasing your frustration that you are not going to get some sleep because you can't expect your body to sleep, let's say, 12 hours a day.

Evans: Now, Nichole Tang uses a number of cognitive behavioural processes in helping people with their sleep problems. You may remember that cognitive behavioural therapy, CBT, helps manage our problems by changing how we think and how we act.

Tang: Sometimes people think that the more sleep I get, the better it will be for my pain. That's actually not the case. When we've been looking into the research findings or the treatment findings, when people are saying, 'I'm now feeling better', it's not necessarily because they're getting more sleep, but potentially because they're getting a higher quality of sleep within a shorter period of time.

And the aim of using CBT a lot of the time is not about controlling sleep or controlling pain, it is more about helping people to understand how pain and sleep work and then so that they can find a different perspective of what is going on with them. Because a lot of the time when they have psychological problems it's mainly stemming from the frustration of not knowing how to control the problem. So to control they'll use their own strategy. But a lot of the time those strategies are not very well thought out and it is based on a lot of limitations.

So what we help them to do is to take a step back to reconsider their situation so that they can have a broader view to see what the options are. And then when they take a step back being calmer knowing what are the options, then they can act accordingly in an informed way based on what we have been doing in science knowing what works for pain, what works for sleep and that they could try some different strategies. Because if you talk to pain patients or insomnia patients, they feel like they are stuck in a vicious circle. So they don't know how to get out so in therapy mainly what we do is just to pull them out a little bit and see what they are facing and what are their options for them in terms of treatment and then gently lead them to a way that will help them to maintain their sleep.

And usually the strategies that we suggest to them are very counter intuitive – let's say you want to have better sleep actually the best way is to not lie in bed for so long trying to get to sleep. When you're dying to get some sleep perhaps the best way to regulate your sleep, so that your sleep could be consolidated, you will be craving sleep at the right time so that you can control the timing of sleep and you don't have to wait for hours in bed, tossing and turning and yet sleep doesn't come.

Evans: So how difficult is it to persuade someone with chronic pain to change the way they think about their sleep. Nicole Tang again.

Tang: It is incredibly difficult to get people to do something that they think is not going to help with sleep. That is why in treatment I usually start with a session of sleep education. So it's not just about sleep hygiene – giving them the tips, what to do to get a good night's sleep – it's actually to help them understand how sleep works. People think that the longer they sleep the better they will feel the next day and in fact it's not necessarily the case. There is the concept that when we get sufficient sleep for the first few hours of your sleep cycle, it is sufficient to get you going for the next day.

Sleep in a way is like an appetite it's like eating chocolate, so if you eat too much chocolate there will be a point when you think that I don't need that much chocolate and it will be nicer if I eat less chocolate. So sleep is just the same. So we will have to get people to understand that sleep doesn't work in such a way that the more you get it the better you feel and to

understand that if you try too hard to go to sleep, sleep won't come. It's just like a butterfly – if you try to grab it, it will just fly away.

So we help them to do something new, to try something different. So apart from changing the way they think about sleep, we also help them regulate their sleep schedule. So let's say that the main problem is that they spend too much time in bed, we will help them to set up a new schedule of sleep, so that they will postpone their sleep time and then get up at the same time so that they will save up some of their sleep pressure, if I may say, for the next day. So that the next day by the time when they are about to get to bed they will feel sleepy enough and they will just plunge into sleep faster than they would if they go to bed early.

So we help them to use a new sleep schedule, use a new strategy to deal with midnight awakening because a lot of time when you wake up in the middle of the night because of the pain it could be very frustrating. So we have to help them to focus and thinking of a better way of reacting to these kind of pain related arousal. First of all by not being too frustrated by the fact that you wake up because actually if you look at normal people's sleep, even the best sleeper on earth, they will have a number of awakenings during the middle of the night. But why don't they complain about waking up in the middle of the night – is it because a lot of the time they don't remember they have been woken up for no particular reason? Because also they can fall back to sleep relatively quickly, so those awakenings will not be registered in the memory.

So we're using tricks like that to help them to perhaps go back to sleep quicker, be more accepting of them awakening – knowing that perhaps it could be a good thing for them, because if you wake up that could give you a chance to adjust your body position so that you can feel more comfortable in bed. So by considering all sorts of different issues surrounding the arousal with the new understanding: why people wake up; what are the consequences of waking up in the middle of the night? what are the consequences if I react badly or frustratingly to the awakening? what will I do next knowing all these consequences?

So we help them to perhaps think of a strategy to get out of the bedroom so they don't worry in bed and think, 'what should I do now that I can't sleep?' Go to another room, do something boring – knowing for sure that the boring task will help them to fall back to sleep. So that they feel much more in control of what they do with the insomnia and usually within two weeks using this schedule and some new method of helping with their sleep, the sleep will turn out to be quite beautiful and a lot of people that I've treated have shown significant improvement to the point that they sleep almost like normal sleepers.

Evans: Dr Nichole Tang of the Institute of Psychiatry. And I would just like to draw your attention to the British Pain Society's new Special Interest Group for Primary and Community Care. It's inaugural meeting is happening at BMA House in London on Saturday the 9th of April 2011 and it will be cheered by Dr Mark Porter M.B. and Chair of the British Pain Society, Professor Richard Langford. And you can get all the details from the British Pain Society website and *Airing Pain* is planning to feature it in a future edition.

As promised, we will end this session with Edith Mowatt's experience with living and coping with nerve root pain. But don't forget that you can still download all the past editions of *Airing Pain* from our website at painconcern.org.uk. And if you want to put a question to our panel of experts or just make a comment about our programme then please do so via our blog, message board, email, facebook, twitter. Here's Edith Mowatt:

Mowatt: Initially, it kind of colours your whole life, but you begin to learn to control it and not let it control you. I found that high power drugs like morphine, all they did was addle my brain and seemed to make the pain more acute – they seemed to sharpen it, if that makes any sense. But once you get onto a regime of painkillers that suit you, you begin to be able to control the rest of your life and control the pain with – how would I put it? Not meditation, but you learn to be in a quiet place away from the pain; you learn to put the pain somewhere else. I use a technique of visualisation, in that, I can, even as I speak to you now, that if the pain is really bad, I could take myself on a journey and put the pain somewhere else away from me.

Go to somebody else who is in pain and can help you and teach you the visualisation techniques, as I say – the way to be just in a quiet place and put the pain somewhere else, so as you can get on with your life. I admit that there are still days when the pain controls me and you really won't want to be around when that's happening. But the bad days are really vile and the good days are many more than they used to be – many more than they used to be. But you have to be positive; if you're negative all the time the pain will seem worse, much, much worse! You have to be positive and you have to focus on what you can do and what it's allowing you to do and go that step further every day. Just take it that step further. You can do it!

Contributors

- Edith Mowatt
- Steve Gilbert, Pain Specialist, Queen Margaret Hospital, Fife.
- Candy McCabe, Professor in Nursing and Pain Sciences, University of the West of England.
- Mark Blagrove, Professor of Psychology, Swansea University.
- Nicole Tang, Research Fellow, the Institute of Psychiatry

Contact

Pain Concern, Unit 1-3, 62-66 Newcraighall Road,
Edinburgh, EH15 3HS

Telephone: 0131 669 5951

Email: info@painconcern.org.uk

[Helpline](tel:03001230789): 0300 123 0789

Open from 10am-4pm on weekdays.

Email: helpline@painconcern.org.uk

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