

Airing Pain Programme 46: Post-herpetic Neuralgia and Migraine

Busting some myths about shingles and post-herpetic neuralgia, and the dos and don'ts of managing migraines.

Migraine is not 'just a headache' – it's a disabling condition that can cause major disruption to work and personal life. So says David Watson, a GP who specialises in treating patients with chronic headaches. He explains that the 'migraine brain' is extra sensitive to changes in the environment, how small changes in lifestyle can help people minimise episodes and how to avoid the pitfall of medication overuse. Dr Watson also gives helpful advice on how patients with migraine can best prepare for a visit to their GP.

Post-herpetic neuralgia is another frequently misunderstood condition with myths about its contagiousness and relationship to chickenpox and shingles causing confusion. Marian Nicholson of the Shingles Support Society clears up these misunderstandings and emphasises the importance of preventative treatments. We also hear about a new vaccine which should help to protect older people who are most at risk of developing post-herpetic neuralgia after shingles.

Paul Evans: I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain. This edition has been funded by a grant from The Scottish Government.

David Watson: If you look at population studies of people with chronic headache, anything up to 20–30% of patients are overusing painkillers and if you look at specific clinic based studies of patients who have been referred by a GP to a specialist, anything up to 70% of those patients overuse medication.

Marion Nicholson: The nerve that the virus used to travel to the skin surface by, has been damaged by the virus travelling along the nerve and it carries on sending these pain messages to your brain and that's what people talk about when they say they've got shingles months later, it's not shingles – it's now called post-herpetic neuralgia.

Evans: In this edition of **Airing Pain** we're looking at two conditions that can have a major bearing on how we live our lives. One deriving from a virus that nearly all of us have carried since childhood and the other is headache. David Watson is a GP in Aberdeen with a longstanding interest in headache as well as his general practice; he jointly runs a headache clinic in the Department of Neurology, Aberdeen Royal Infirmary. He was also involved in developing headache guidelines and standards at a national level in Scotland. Now we all get headaches, so shouldn't we just put up with them?

Watson: Tension headaches are probably the commonest headaches that anyone can get but tension headaches are non-disabling headaches, if you've had a bad day at work or you're a bit tired and you should probably go out and get some fresh air or go for a walk, maybe take a paracetamol, but migraine on the other hand is a disabling headache. It probably affects up to 6 or 7 million people in the UK and migraine by definition is a

headache that is worse with activity. If you say to someone who gets migraine 'what do you do when you have a migraine?' very often they feel they need to stop activities. Interestingly, the World Health Organisation would put migraine in its top 20 disabling conditions and in fact, in women, in its top 12 disabling conditions. If you can imagine that migraines are moderate to severe headaches that are made worse by movement, some people feel squeamish or sick with it and other people find that they are very sensitive to the room, whether it be noise or light or smells, and if you get one of those very bad migraine episodes then probably you're going to be sitting in a dark room or even lying down, and because of that you are not able to do activities. So I think we need to take migraine very seriously cause it's probably one of the commonest causes, for example, of short-term sickness absences in the UK and they reckon it probably costs a couple of billion pounds a year in lost revenues to the economy, and for the sufferer it's very difficult. A lot of people get migraine very often and live in fear of their next migraine. It's a bit like the weather and weddings: it's not in any way planned and people live in fear and dread about having to cancel activities like meeting a friend, going to the cinema, going out with their partner. Interestingly, if you speak to the partners of people with migraine, they've had situations where it's them that have gone to the party and partners have been left at home, for example.

Evans: I can vouch for that!

Watson: I have been in that situation as well, my wife, my mother-in-law and my daughter all get migraine and I'm very lucky, I probably only get about four migraines a year and it's my way of the body just saying slow down and you've got to get some proper rest. I remember before I got mine, meeting my wife in Amsterdam and it was all commotion and song, a lost weekend in a hotel in Amsterdam with my poor wife lying there with her migraine and I was thinking 'do I sit in the hotel room all weekend with her or do I go out and see all the sites of Amsterdam' [laughs] so yes it *is* incredibly disabling, not just for the patient, but for family members as well.

Evans: We're laughing about it now but it really is a serious problem for people.

Watson: I think the single biggest difficulty for people with migraine is people who don't get migraine calling it just a headache. I think for someone who gets disabling migraine, you know for example, they phone in to the boss in the morning and say 'I'm very sorry I have a bad migraine today' there is a bit of 'what do you mean you can't come in! It's *only* a headache!' and this poor person is lying in a dark room with a sick bucket by their bed, daring not to move because the pain is so severe. So, yes, I laugh about being in that situation, a headache doctor with my wife having migraine, but it is incredibly disabling.

Evans: You say you get a couple of migraines a year, do you know what causes those?

Watson: We don't know what causes migraine. So when I see patients and they say 'can I have a cure' and I have to explain that we don't know the cause so we can't give a cure. But what we know that the migraine brain is sensitive to the environment whether it is to our internal environment or external environment. It's almost like there's a switch in the bottom of the brain and when it gets switched on you get this wave of energy going across the brain setting off the chemical changes that then result in all the migraine symptoms. In a sense, how often you get your migraine is set by how sensitive the genes you have inherited have

set that switch. So I'm lucky that it takes quite a lot to set me over that threshold and the migraine brain likes regularity, you know, it likes regular meals, regular sleep, regular exercise. It's much more common in ladies because of hormonal changes, that's why three times more ladies get migraines. So that's a sort of internal environment. Then there's the external environment, some patients will have specific foods or smells. A colleague, for example, for who a particular perfume will set him off – he remembers being in a lift to a meeting once and getting a migraine after standing close to a couple of ladies who had this particular perfume on that set him off. Some migraine sufferers, for example, can predict weather changes, they feel that atmospheric pressure change. I know in my case it's burning the candle at both ends, trying to do too much, maybe rushing around at work and not drinking enough fluids during the day, missing lunch because I've had to go to a meeting or whatever it might be, and it's almost like the brains getting wound up and wound up and wound up and then you get that release of pain. I'm probably quite lucky that my headaches aren't extremely painful but I get all the non-recognised symptoms, I'm a bit clumsy, my speech isn't quite as clear, my brain goes into this like fog and I know that I probably need two or three nights of proper sleep and eating at the right time, drinking plenty of fluids. So we know for patients that a combination of these factors will bring on a migraine for them. We see a lot of patients at the clinic who have what we call chronic migraine. Now chronic in headache terms simply means headache for 15 or more days a month. So, most patients with migraine will get one or two migraines a month that might last a day or two days, fairly disabling for that patient. But there are patients that get headaches a lot of the time, certainly more than half the month and if eight of those days are migraines then we call that chronic migraine. It's inevitable that most of the people I see at the clinic with chronic migraine are ladies in their late 30s, into their 40s and they are very likely starting to become slightly perimenopausal so hormonal levels are just starting to go up and down. But they tend to be busy people, they're working full time, they've got children, they're running a household, they are part of the parents association, they are helping out with Scouts on the weekends or at the church or whatever, and very often not getting proper regular sleep. They're not getting any time to themselves and really in a sense their brain is never getting a chance to switch off. I very often say to these ladies 'well we can try you with some medicine or a tablet but I'm going to give you some homework and that homework is that I want you to find a time each day that is your time to try and switch the brain off'. Now I can't tell you how to switch your brain off, for some people it may be to shut the bathroom door, a hot bath and a book, for others it might be going out for a walk, but it's important for migraine sufferers to give their brain some down time just to give it this kind of unwind time to relax it.

Evans: And this isn't a self-inflicted thing, it's a *genuine* illness, it is not something that you're putting on yourself.

Watson: Absolutely not! People with migraine have the genes that make them more sensitive to what happens either inside the body or outside the body. Someone who doesn't have migraine will do the same and not get headaches. Unfortunately for the patient who gets migraine the brain needs that kind of switch off time. And I think it's for people to try and recognise that in themselves. I've seen patients that have come back to me and have said they have managed to get regular sleep and [are] making sure they don't miss breakfast and are better at drinking fluids and [they] do as [I] told [them] and [they] get migraine now and then but [they are] not getting so many. I saw a lady in the clinic the other day who works in the bakery at Tesco, I said 'it's a hot place, do you drink any fluid?' 'Oh no, I don't drink at all

when I'm at work' and I said 'what about at lunch?' 'Oh well I cut my lunch short and get away early so I can pick the children up from school' and when I saw her again she was much, much better and probably the medicine helped a bit, but she said 'I actually go out of Tesco and go for a 20 minute walk at lunch time and I make sure I'm drinking plenty' and it's nice to think that a small change for some people can make a difference.

Evans: It's interesting that what to many people sounds like common sense: that if you do work through your lunch, if you don't drink all day, well you would think that it would have an effect on you, but to be told that by a doctor then it's OK.

Watson: I think sometimes, with my GP hat on, a lot of what I do sometimes is to try and put things into perspective for people or even kind of normalise things a little bit. Don't get me wrong, for a lot of people, looking at lifestyle isn't the whole answer for migraine and they've got this condition and they need medication as well. But I think sometimes people kind of get onto the hamster wheel a little bit and kind of need permission to get off that hamster wheel now and then.

Evans: You mentioned earlier that most patient's experiences with dealing with their headaches is by going to the pharmacist and getting paracetamol and whatever else is on the shelf, is this a good practice?

Watson: Patients who get a bad headache or a migraine every now and then, I think it's absolutely fine to self-manage, in fact a lot of the guidelines say that taking aspirin or ibuprofen is as good as the more specific migraine tablets. The difficulty is for patients who start to get more frequent migraine and we know that if you start having to take painkillers on a more regular basis, for some patients, painkillers will actually cause headache and we would probably say that patients would need to restrict painkillers to no more than two days a week, and unfortunately medicines with codeine in them tend to be the biggest culprits for headache caused by painkillers and that's in things like Solpadeine and Migralve and Co-codamal and Co-dydramol, you know very common painkillers.

Evans: So you're saying that overuse of these can actually cause the headaches?

Watson: Absolutely! Absolutely! So if you look at people who transform from an episodic migraine, now and then, to this chronic headache over half the month, a large factor in that for some patients is the overuse of painkillers. Now, the difficulty is that when you stop the painkillers not everyone gets better, but certainly in our clinic in Aberdeen probably in 10 patients overusing painkillers and you stop those painkillers, within about 4 weeks probably 6 out of 10 patients will be a lot better, not cured of migraine, they would still get their headache but it would be back to every now and then. But the four patients, where stopping the medicines didn't help in terms of headache frequency, what we do know is that the prevented treatments will work better if the overused medicine is not there. And if you look at population studies of people with chronic headache, anything up to 20 or 30% of patients are overusing painkillers and if you look at specific clinic based studies of patients who have been referred by GP to a specialist, anything up to 70% of those patients overuse medication. It's a perfectly understandable thing, if you've got pain you take a painkiller and you have patients who say 'well I have to take something when I wake up to get me through the day'. I think it's difficult for these people because when you stop a painkiller the

headache will get worse for the first week to 10 days whilst the medicine's coming out of the system and that's why it's really important to have a partnership with the patient.

Evans: What would your advice be to somebody who is suffering headaches? How should they talk to a health professional?

Watson: That's a good question. I think a lot of patients find it difficult to express the disability they get with especially migraine and they sometimes find it difficult to express the other symptoms that they get. It never surprises me that headache doctors have a smile when patients come to see us and they've been referred, for example, with a headache that they've had for 2–3 months. I will say to them that 'we need to talk about that headache' but I need to know about other headaches you've had in the past and they say 'Oh, I just get normal headaches' and we smile because most peoples' normal headaches are migraine and I say 'can you explain what you mean by normal headache?' they say 'Oh well, you know, I get this headache and feel quite sick and have to go and lie down' you then might explore that more with them and ladies will say 'Oh yes, it's a headache I got with my period' and when you say to the patient 'well that's actually migraine' and they say 'Oh, no one's ever told me that I have migraine.' So patients may naturally play symptoms down and I think that's difficult for patients to try to understand, but you can't expect patients to know how to make a diagnosis. What will be useful for patients is to think of all the ways that headache affects them because what I say to GPs is that if you've got someone that comes in with a headache that's episodic, in other words they get a headache for a day or two and then they're better for a couple of weeks and then they get a headache for a day or two and that headache is associated with some disability so the patients maybe want to stop activities and they maybe feel a bit sick and they don't like light, then those are kind of the trigger to say this is going to be migraine.

Most people try and keep going so they don't think of themselves as being disabled and again when I teach the medical students I say, if you say to a mum with three kids under five and she gets migraine 'Do you go and lie down?' She's going to look at you as if to say 'Well of course I don't go and lie down' or someone who's got a difficult job and the boss is a bit difficult and you say 'Do you go home when you get a migraine?' They say 'Well no, I just keep going'. So you have to phrase the question for example, 'If your husband is home on the weekend and you got a migraine what would you do?' 'Oh, I'll go and lie down'. So I think what's good for patients is before they see a doctor about headache is to think about how that headache impacts on their life and if they think that this headache is stopping [them] doing things or its preventing [them] doing things properly, in other words, [they] keep going but it's a struggle. Then it [can be difficult] to try and talk to the GP about that because what very often doctors focus on, if they don't really understand migraine, is where is the pain, which bit of your head and is it sharp pain or a throbbing pain or a dull pain and so patients get sidetracked describing the pain. Whereas migraine can be any kind of headache, anywhere on the head and the key is really more to what the other symptoms are. We have developed, in Aberdeen, a questionnaire that goes in a booklet out to patients just to say to patients 'These are the sort of questions that a doctor's going to ask you, just have a wee think before you come to the clinic about how the headache affects you'.

Thinking about it, if you come to the GP for example, and most patients with migraine will never see a specialist, it will probably be only 1 in 100 patients with migraine will ever get referred to see a specialist. So if you're going to a doctor because you are getting bad

headaches, don't go in and talk about your child's chickenpox or your gran's dementia or problems you get with your flat feet or whatever, go in and make a headache consultation so the GP has time just to talk about headache and go in thinking about how does this headache affect me and how does it impact on my life and in that way you're kind of prompting the doctor to ask you the right questions.

Evans: I'll just remind you that whilst we at Pain Concern believe the information and the 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 about 1 in 5 of us will have shingles in our life, most likely after we've past our 50th birthday. Marion Nicholson is the director of the Shingles Support Society.

Nicholson: Shingles is the name we give to a repeat appearance of the chickenpox virus. So what happens is everyone gets chickenpox as a kid or nearly everyone in this country, it's about 95%. Then at some point in the future, chickenpox virus can reappear, instead of coming out over your whole body what it does this time is just come out in a line perhaps around your ribs or side of your face, it's always one side of the body only and it usually starts with a nasty pain which often the patient doesn't recognise, that's one of the tricky things. They will say I thought I had pulled a muscle or I thought I was allergic to something I used or I thought I had been bitten by an insect. And then after that pain, usually after a couple of days, and that's when it gets diagnosed. When the doctor can actually see the spots, because before then the doctor will probably agree that, yes, you have probably pulled a muscle. That's a bother because the treatment for shingles needs to be started within 3 days, there's a 72-hour window. Because, although the treatment could be given after that time, it really won't have much effect. Shingles needs to be treated early with the antiviral drugs.

Evans: Well I've known people who've had shingles, my own grandmother included, who you say the treatment has to be started within the 3 days, she must have had it for months and months and months.

Nicholson: Right now you see that is no longer shingles. Shingles really is the name that we give to the blisters that happen and clear up usually within 2 weeks, in the case of my nephew who's 13 they cleared up in 3 days. Now what can happen in older people particularly, or in some very unlucky younger ones, is that after the shingles blisters go away the nerve that the virus used to travel to the skin surface by has been damaged by the virus travelling along the nerve and it carries on sending these pain messages to your brain, and that's what people talk about when they say they've got shingles months later. It's not shingles, it's now called post-herpetic neuralgia. Neuralgia meaning, it's a pain created in the nerve. I often tell people that it's a sort of *ghost* pain – in that, although the arm or the rib feels painful, there is actually nothing wrong with that arm or that leg. It really is that the nerve is sending a false message to the brain just as people who have had an amputated hand report that they still feel pain in that hand although that hand is no longer there. So it's the nerve itself which is creating this pain message and it's very tricky to treat.

Evans: How do you stop the shingles becoming post-herpetic pain?

Nicholson: We don't have any way of stopping shingles becoming post-herpetic neuralgia. Although one expert pain doctor does suggest that anyone who is 50 or older who develops shingles, should immediately be started on one of the two main drugs that are used to control this kind of pain. One is a tri-cyclic antidepressant, the other is an antiepileptic drug, originally, both of these drugs are used now, mainly to treat this kind of pain, neuralgia. His suggestion is that if you're 50 when you develop shingles, the rash, you should immediately be started on this tri-cyclic antidepressant because these two drugs, they are really interesting, you know, they are not actually pain relief in that they don't actually stop pain right away, the way aspirin or morphine would, what they do is slowly over time they build up a pain block, so day after day that you're taking these two drugs another brick is added to the wall of blockage and eventually after 3 weeks, or in some people 6 weeks, and with the dose increasing regularly, every 10 days you would need to put the dose up again, your pain wall is high enough that the pain message no longer reaches the brain and once that's in place you can start reducing the dosage of the tri-cyclic antidepressant or the anti-epileptic drug and the pain block will hold even though you're now reducing the dosage.

Evans: You've just mentioned the illness, chickenpox; many people won't associate the condition, shingles, with chickenpox.

Nicholson: That's right and one of the main concerns is when they phone the helpline of the Shingles Support Society is 'how have I caught this or who can I go visit, who can catch what from me?' So, you start off by catching chickenpox as a kid, it remains in your neural ganglions those are nerve junction boxes beside every spinal vertebrae in your body and then when it reactivates it is called shingles. Now you can *only* have shingles if you've had chickenpox, *nobody* can catch shingles, it is always something that just develops because you have had chickenpox in the past, and shingles is *only* transmitted to another person if they actually rub against the shingle sores. So a person with shingles, if they feel well enough, can continue normal social or work life, they don't have to stay at home. However, if someone who has never had chickenpox rubs against the shingle sores then they would catch chickenpox from the shingles outbreak. You have to think of chickenpox as the first thing and shingles is just the repeat outbreak. Interestingly, chickenpox itself is easily transmitted, you only have to be in a room with somebody with chicken pox for 15 minutes and you are expected to have caught chickenpox. So chickenpox is in the air whereas shingles is not in the air, it is just transmitted by touch to somebody who has never had chickenpox.

Evans: For those who have had chickenpox, which is probably most of us – is there any way of not having shingles?

Nicholson: Shingles gets triggered by all sorts of different things, sometimes nothing at all except getting older, but often it's after an operation or a fall. There is now a vaccine to prevent shingles from developing and it will be very cost effective to vaccinate people because although not everyone develops post-herpetic neuralgia following shingles, basically, the older you are the more likely it is that that is going to happen to you and if you're unlucky and that shingles pain drags on, and it does for about 1 in 5, it can really change your manner of living. You might need Social Service support to do your shopping or one lady told me that she didn't dare drive anymore because the shingles pain for her was a stabbing sensation that hit her across her forehead from time to time. She said 'if I was driving a car at that time, I would be unsafe on the road so I just don't dare drive anymore'.

Another lady was telling me that her husband couldn't bear wearing clothes because the shingles pain, in his case, was a super sensitivity of the area around his left ribs and just the brushing of his shirt across his ribs felt to be such an excruciating pain that he just didn't want to wear a shirt.

Evans: I remember my grandmother, her face looked as if she had been burnt in a fire, she could not touch it.

Nicholson: Interesting that you say that it looked like it because quite often the problem is that it feels like that to the patient, a burning sensation is another one of the range of sensations. You see because the nerve has been damaged, the pain can be felt in a myriad of different ways. Any message that the nerve has at any time sent is what your shingles pain can be. So it could be a sensation of burning, itching, intolerable itching that keeps people awake at night, stabbing, aching, like a bruised sensation, and if people have had it like your Nan on their face, they may have unnecessary dental work done because they think the problem lies in their teeth, that deep ache. So all those sorts of different sensations can be a result of the damage caused by the virus in the nerve. Which is why, quite frankly, I am having the vaccination myself (laughs).

Evans: That was Marion Nicholson, Director of the Shingles Support Society, and their website is shinglessupport.org. Don't forget that you can download all the previous editions of *Airing Pain* or obtain CD copies direct from Pain Concern. If you would like to put a question to Pain Concern's panel of experts or just make a comment about these programmes then please do so via our blog, message board, email, Facebook, Twitter or pen and paper. All the contact details are on our website which is painconcern.org.uk. Now NHS information on that shingles vaccine says that it is licensed for use in people aged 50 and over. Although it can be used off label for people younger if a doctor feels it is suitable and if a GP decides vaccination is appropriate it can be prescribed on the NHS. In other cases the vaccine will need to be given at a private clinic. But from September 2013 people aged 70 will routinely be offered the shingles vaccine on the NHS with a catch-up programme for people aged 71–79.

Here is a final thought on shingles, I've had three children and I have got three grandchildren now and I seem to remember this chickenpox from my children isn't going to be pleasant but let's get it over with, let's go to a chickenpox party or something. Now you seem to be saying that perhaps as a parent we should've avoided that.

Nicholson: On the contrary chickenpox caught at a young age, usually early childhood, primary school age, is as you say a very mild disease. In some countries they do vaccinate their children against chickenpox, but it's done for commercial reasons rather than health reasons in that when the child has chickenpox the parents have to take a week off work. So in some countries it is actually done for that reason, and the interesting thing is, for the adult, the more times you have nursed someone with chickenpox the less likely you are to have shingles because each time you meet the chickenpox virus you're actually developing more anti-bodies, you're giving yourself a booster against having shingles.

Contributors

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