

Airing Pain Programme 25: A heads up on migraines

How to manage migraines: patients and experts share their thoughts.

Nine out of ten people report a lifetime history of head pain and 2012 has been designated the Global Year Against Headache by the International Association for the Study of Pain.

Evans finds out more about migraines from Dr Giles Elrington of the National Migraine Centre in London.

We also hear from people who live with chronic migraine about their experiences, what triggers their episodes and the treatments they've tried, and Heather Sim tells us the steps to take to get referred to a migraine clinic.

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 who live with pain. This edition is made possible by Pain Concern's supporters and friends. More information on fundraising efforts is available on our Just Giving page, and that's at painconcern.org.uk.

Keri Bucholz: I get very sensitive to smell and to lights. I get a pain behind the nose and behind the eyes...

Dr Giles Elrington: Is it a disorder of the mood, of the psyche? No.

Bucholz: And I get really tired...

Elrington: Is it a disorder of the neck? No.

Bucholz: After that, I usually get really nauseated. Then the headache will hit, and the pain that will come with it.

Elrington: Is it a disorder of the sinuses, of allergy, of the heart, the blood vessels? No, it's a disorder of the brain.

Evans: Now this year, 2012, has been designated Global Year Against Headache by the International Association for the Study of Pain, working with the International Headache Society. And that's quite appropriate because one in every two of us will have some form of headache during the year and a staggering nine out of ten will report a lifetime history of head pain, with the most severely disabled three per cent of those having chronic migraine

and chronic tension-type headaches at least 15 days per month. And that makes it the most common of all neurological conditions and among the most frequent of complaints seen by GPs.

Chris Whitehouse: They go in phases and when they're worse, they're typically every other weekend or every weekend, occasionally. I'll get up on a Saturday morning and I'll fairly soon have a pretty bad headache which will mostly render me pretty incapable for the rest of the weekend and then it'll clear up on the Sunday night and I'll be up back off to work again. There's also a stomach element – that I could feel a bit nauseous – and again if I think about that it's not particularly extreme, mostly, although sometimes it causes me to throw up. I also sometimes feel very cold, so I'll put on lots of clothes and sit leaning against the radiator. So the overall thing is that I feel completely drained of energy and I have no ability to actually get up and do something.

Evans: Now I was brought up to believe that a *headache* is just something we have to grin and bear, but a *migraine*, as described there by Chris Whitehouse, is something on an entirely different plane. So a few weeks ago I visited the National Migraine Centre in London, where I met its Medical Director, neurologist Dr Giles Elrington

Elrington: Headache is a symptom and I think that people go to doctors or pharmacists with a symptom, not with a diagnosis. Generally speaking, when things aren't going right, the first thing you want to do is to go back to the start and rethink the diagnosis. So one of my big issues is to be symptom-focused, not diagnosis-focused. Having said that, almost all headache is migraine. There is an exception: there are a group of headaches called trigeminal autonomic cephalgias, like cluster headache and I think most experts in the field think that that's a separate disorder, but there is a maverick view, that might be right, that says it's all on a continuum.

But if we set that aside, then there are basically two types of pain in the head. And if we just get this out of the way early on – doctors who practise in head pain call any feeling you don't like above the shoulders 'headache'. Not all patients like that: 'It's not a headache, doctor, it's a pain in the head.' It's actually really unhelpful to get bogged down in words, so we call it all 'headache', whether it's a sharp pain in the lip, or a compressing feeling all around the cranium, it's all 'headache'. Pain in the neck is a headache.

So, there are two types of headache: primary headache and secondary headache and, using a computing analogy, primary headache is a software problem and secondary headache is a hardware problem. So in primary headache, the disease is a change in the pain pathways, the electric activity of the pain nerves is switched on when there is no good

reason for it to do so. It's rather like the oil light in your car coming on when the sump is full, or the fire alarm going off when there's no fire. So it's giving you a message as if something is happening, but the problem is the message, not the thing it appears to be telling you.

Now, people worry when they have pain in the head, when they have headache, that there is a brain tumour or a trapped nerve or 'Is it my neck, doctor? Is it my sinuses, is there some structural underlying cause?' And the answer is 'hardly ever'. And so the longer you have pain in the head, the less likely there is to be something else wrong, for there to be a hardware problem, something bust.

Another way of looking at it – with the secondary headache, you could make the diagnosis without talking to the patient if you did the right test. So you could see the sinusitis on a scan or an x-ray, with an endoscope, you could identify the trapped nerve with an electrical test or an MRI or something like that. But only a tiny minority of headache is the secondary headache, or a hardware problem, and the simple rule is that if you have a secondary headache, other stuff goes wrong apart from the pain. So if you have a brain tumour, which is often the big concern, the main symptom is epilepsy – hard to overlook. And then the other big group of symptoms with brain tumours is a progressive loss of function.

But if we then come back to what I largely practise in, which is primary headache, that is, an error in the way the brain deals with pain, migraine is the big group. Now you can use the word migraine in, really, two different ways. The old-fashioned way is to use migraine to describe the nature of the attack. But you can use the word also to describe the underlying condition, the tendency to migraine. So it's a bit like having acne – you have a spot, a zit. But there are times when people with acne don't have spots and zits, briefly – I remember well.

So you can use the word in different ways, and in many ways it doesn't matter how you use the words, as long as we all stick to the same definition. But almost all recurring, chronic, disabling, troublesome headache is migraine. And most headache experts these days are not very keen on the old idea of so-called tension headache or tension-type headache as it became known and we see tension or tension-type headache as being a relatively featureless form of migraine.

Now there's a lot that we can do to help migraine. Journalists often say, 'Have you got a cure?' I don't think doctors cure very much. OK, I'm a neurologist and we have that reputation, but think about it, what can doctors cure? We can control a lot, and we can make an awful lot of things easier to bear.

Evans: OK, so I'm not going to ask you what the cure is.

Elrington: Thank you.

Evans: What is the management?

Elrington: OK, so the management of the migraine begins with the diagnosis.

Evans: Dr Giles Elrington, Medical Director of the National Migraine Centre in London. Chris Whitehouse again:

Whitehouse: I saw a doctor here, and he asked me a lot of questions about how it occurred and if I could think of things that caused it. He then explained in quite detail how migraines work and how triggers work and how you can help by learning your own triggers, which was really helpful. And he gave me some information sheets that I took away.

Evans: You said that you've been told to learn to recognise your triggers.

Whitehouse: Yes.

Evans: What were your triggers, how was that helpful?

Whitehouse: My main trigger is to do with sleep. And I'm not actually working now. But when I was working, typically I'd go to bed a little bit too late all through the week, so by Friday I was a bit tired and on the Saturday I'd have a bit of a major sleep-in. And it seemed to be weeks where I'd lived like that, followed by a particularly heavy sort of sleep, that would be then followed by the migraine. So that's my main trigger. I also think that I have to be careful about eating sugar and actually certain types of cakes – I don't know what ingredient it is, but there seem to be certain types of cake which seem to trigger it. It's particularly the sleep thing that really triggers it, but I think I get more sensitive to them if I've been eating sweet things, so if I eat a lot of jam, or chocolate or something.

Elrington: Once you've made the diagnosis, the first step is lifestyle matters. Now what migraine likes is for the brain to be knowing what's coming. It likes regularity, it likes rhythm, it doesn't like surprises. So, people with... who are prone to migraine, need to have three meals, at least, every day. The one that many people skip is breakfast. Big mistake! 'Oh I never skip breakfast, I have it after I get off the commuter train.' Wrong! You must have a fibre-containing breakfast every day without fail before you leave home for work and you have something for lunch – just a sandwich or a roll is fine – and you have a meal in the evening. Snacks in between, terrific, but many of us struggle a little bit with our weight, so it's important to keep that snacking down, keep it natural, keep to wholefoods, keep the fibre level up. Why fibre? Because you need to maintain a smooth blood sugar profile, rather than having big ups and downs through the day.

So the first thing in migraine is regularity, first think about the diet, then think about your sleeping pattern. So migraine is worsened by too much or too little sleep. Ideally, you need to leave the alarm clock on seven days a week, so every day is the same. My patients with migraine who suffer at weekends, as many of them do particularly, leave the alarm clock on, get out of bed at the same time, get shaved, get washed, get dressed, be at breakfast at the same time, maybe even at the time that you're sitting at your desk, 9 o' clock, possibly 8:30, at work, that's the time you're doing the crossword and you've got to finish it in 15 minutes, so you keep the stress levels the same.

Migraine is actually more often worsened by the let-down from stress than by the time the stress is on. Keep it level, don't change it. And if you go, 'Oof, it's the weekend, I can lie in, I can take it easy,' that's when the migraine come and hits your head.

The next thing is what treatment do you take as and when you have an attack? The simple treatments for migraine are either aspirin in a large dose, 900mg, or ibuprofen in a large dose, 600mg, preferably dissolved in water – and there are preparations of both which will do that – accompanied by an anti-sickness drug called domperidone. Not Dom Pérignon, which is French champagne, but it sounds almost the same and you can buy it over the counter and you can get a little packet of those. And you take two of those with either the aspirin or the domperidone [sic. editor's note: ibuprofen]

'Oh, but I don't feel very sick.' Just take the domperidone; the reason being to promote the brisk absorption of the drug because with gastric status in migraines, the drugs don't get through. Add the domperidone, and if you do vomit you can have the domperidone as a suppository. Get the domperidone in and the aspirin and the ibuprofen. If that's disappointing, there's a class of drugs called triptans, there's seven of them they're all much of a muchness, different patients suit different ones, and you need to take them when you have the headache, and you take that once at the start. If it works well, fantastic. If the migraine creeps back after it's worked you can take a second dose but you should not repeat the dose if the first dose hasn't worked well.

The difficulty with acute treatment of migraine is the more you take a short term treatment, the more the migraine bounces back. So if you find that you're having to take a short-term treatment to abort migraine twice a week or more, you should rethink your strategy and go for a preventative.

Always a good idea to keep a record, keep a diary of the migraines before you go on to preventative treatment and if you look on the Migraine Clinic website you will find lots of diaries you can download. But you can do it on an Excel spread sheet, or a piece of paper,

but keep a diary or you won't know if it's changed, but it's a medium-term strategy for at least three months, possibly a year. But you wouldn't pack in preventative treatment before three months or you haven't given it a chance.

There are many different drugs to try. You can try some nutraceuticals from the health food store, you can take drugs from the pharmacist, many of them and often they can work very well indeed. So where we're going in the future is to treat the head, and the big interest in putting injections in and around the head – Botox, occipital nerve blocks, nerve-stimulating devices, possibly even magnetic or electrical stimulating devices – very experimental, but there's an awful lot happening and we hope very much to have migraine a more treatable disease in the future than it is now.

Evans: Giles Elrington, Medical Director of the National Migraine Centre. He mentioned the word 'nutraceutical' – well that's just two words put into one, from 'nutrition' and 'pharmaceutical', in other words, food products that reportedly provide health and medical benefits.

And now's a good time for me to remind you that whilst we believe that 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, Emma Williams is a patient at the National Migraine Centre. She had her first migraine at around the age of 13:

Emma Williams: I thought I was, like, dying of a brain tumour and nobody really understood. My mother didn't really, she thought I was making it up, because my brother and sister don't have them, they'd never seen anything like it, so it took her a while to actually take me to the GP. She thought I was using it as an excuse to kind of get out of things and that's when I would go and lie down and be knocked out for hours because I'd have a horrible headache, and the visual impairment aura just really terrified me.

Evans: Can you just explain to me what the disorder is?

Williams: For me, I kind of, sometimes I draw them so I remember, or if I think there's something specific to remember. It's kind of like your vision is... if you think of it as a clock face, it's like zig-zaggy lines, it's almost like you've got water in your eye or something, or if you're a lady, if you've worn, like, sparkly mascara, and then you've got a bit stuck on the inside of your eye, or if you've ever stood on the stage and had really bright light and it

catches the edge of your contact lenses or something like that. It's like that, it's like you're like, 'Oh is something...?' It can be really beautiful actually, rainbow colours, for me, and it's zigzag lines from the centre of, as it were, a clock face, and then it travels around clockwise.

So it sort of goes – sometimes it goes from light – and it can be left-hand side or right-hand side, so the doctor wanted to know exactly which, sort of, hemispheres it's coming from. Is it left, is it right, does it move between the eyes? And then it can feel more, like, watery, like a sort of aqueous solution's in your eye, and you can kind of, I don't know, I feel slight pressure in my eye, not any pain. And then it moves around and then it fades away.

Giles Elrington: Aura is a very interesting part of migraine. And I think it's aura that allows us first to realise that migraine is a disorder of the brain. But not everyone with migraine gets aura. The public often think that you have to have flashing lights, for example, for it to be a migraine and this is incorrect. Depending on how you divide your patients up, among people who have migraine, only about one in three, one in ten have aura.

You can get really bogged down in the argument whether migraine with aura and migraine without aura are the same or different diseases. It's the same disease, I think, it's just a question of how much bolt-on stuff there is. The odd thing is that we find changes on functional brain scans that are identical to what happen in aura, in people who don't have aura. I think it's all the same illness but I accept a range of opinion on that.

Now, migraine changes over time and one of the few advantages of getting older is you tend to get less headache with migraines. So migraine, migraine headache, all forms of migraine are less common in older than in younger people. Many people who start off having migraine with a visual aura, which is the commonest aura we recognise, will, over time retain the aura and lose the headache.

Williams: It's like I can't really see out of one eye properly, so I get that, and then if I lie down then I'll get a headache, and a really bad one. But I learnt when I was about 21 that if I don't lie down, I don't get the headache, so I have an odd, medium half-migraine kind of thing. But they can happen really suddenly, and they can knock me out for about an hour of visual disturbance and then I feel a bit, sort of, groggy afterwards.

You do just want to go and lie down, because it just makes you feel really tired. But I'm learning that – especially recently, I'm sort of playing music when I get the visual disturbances if I can, and I learn to go into just a snooze, but not lie down. I prop myself up with beanbags, and I play very delicate music, sort of, really testing it, and I drift off, and I don't get the headache, and then I wake up feeling quite refreshed in a way. I just think if I

try and battle them, with the visual impairment I've never actually walked into a wall or anything but my sight is depleted, so might as well still down and deal with it, rather than get annoyed, as I maybe used to. And I think that's more positive, because it's almost like time out, it's good, it's like decompress. Why not, it's happening so might as well make the most of it. And I get creative ideas as well when they happen so that's good.

Evans: So you actually use the migraines for positive purposes?

Williams: I'm starting to now, yeah, I think. That doesn't mean I want lots of them, but if your brain is doing something that's physically making you feel so tired, but that can still be interpreted as a peaceful time, yeah.

Bucholz: My name is Keri Bucholz. I am a wife and a mother of two daughters, and a stay-at-home mum. I suffer from hemicrania-continua and migraine with or without aura.

Evans: Tell me something more about the hemicrania-continua.

Bucholz: I just recently found out about hemicrania-continua this year, coming to the clinic. My doctors back in the States have never even heard of it. I thought it was migraine on my left side, under my cheeks and sinus area and behind the eye. It would get bigger and more painful and then it would just go away, where it would just be a little bit of pain behind there, no big deal. It was just a constant pain behind the eye. The hemicrania-continua is under control now, I get migraines at least twice every couple of weeks.

Evans: And how long do they last?

Bucholz: They can last about two to three days. The worst of it is only about a day.

Evans: So, what we're talking about, you get one of these once a week that lasts for three days.

Bucholz: Yes.

Evans: Well I don't have to be a brilliant mathematician but it leaves four days per week where you feel well.

Bucholz :Yes, yes.

Evans: Now, how do you bring up two children and run a home, with only four days out of seven?

Bucholz: It has a big effect on the family. The unpredictability, I think, has been the hardest for my girls. Whether they have an activity and Mom's planning on taking them, or Mom's

planning on being there, and then Mom can't be there, that's pretty tough on them. I think that's the hardest part.

Evans: How do they cope with that?

Bucholz: I think the most important thing is talking so they're not afraid when they see that Mom's not feeling well. And then when I am feeling well, we enjoy going over...watching a video of what they've accomplished that I've missed, or things like that.

Evans: So, they absorb it into their lives and keep you up to date with what's been going on these three days a week when you haven't been able to cope.

Bucholz: Yes.

Evans: Explain to me how you got them to do that and what they do and what they tell you.

Bucholz: It started out chronologically keeping track of what they were doing at what age. There's a programme called Hallmarks Mile Box. It's easy for any age to turn in videos and things and turn it into a little programme that not only they can enjoy forever, but you can enjoy.

Evans: But it embraces the whole family, it's the children being involved in your illness

Bucholz: Yes.

Evans: And contributing to the management of your illness.

Bucholz: Yes, I think there's less tension, and less fear, and less worry when you can be in control of a little of something in life. And especially children need to be able to have that in their lives, to say, 'OK, maybe this isn't normal for everyone but at least I know I can do this.'

Evans: Keri Bucholz.

Now, you'll remember that Giles Elrington made a distinction between primary and secondary headaches. He used a computing analogy to describe primary headaches as a malfunction of the brain's software and secondary as problems with the hardware.

Elrington: Let's say that you have pain due to a toothache, so the tooth is doing something bad, that sends a message in the trigeminal nerve into the brain stem – the stalk of the cauliflower which is the brain, the trigeminal nucleus. The nerve relays there and passes on a slightly different message up a pathway in the brain stem and that goes to the thalamus which is, coming back to the cauliflower – it's where you cut off the florets off the stalk – and then it goes on from thalamus up to the cortex, which is the white bit of the cauliflower and of

the brain. What's happening in migraine is it cuts out the first part, so there is no bad message coming in the trigeminal nerve, but there is a spontaneous generation of pain in the trigeminal nucleus.

Now, around that area there's other stuff happening and as well as the generation of pain, there is the recruitment of messages to the stomach that make the stomach say, 'Let's empty upwards rather than downwards today.' It's called vomiting, or nausea, so that's recruited as well. Also you turn up the gain on messages from the ears and from the eyes, and from the balance mechanism, so movement makes you feel giddy and sick, vision is painful, lights hurt, noises hurt. It works on smell as well, so smell becomes unpleasant, the smell of cooking makes you want to vomit and the smell of chemicals makes the pain worse. So you can model migraine as an amplification disease, but also as the spontaneous generation of abnormal messages.

Now, that also projects up to the cortex of the brain, which is the most complex part, the bit that makes us different from all other animals. And there is a suppression of cortical activity which moves across the cortex in a wave, like a tsunami coming across, and that's what gives you your visual aura, sometimes paralysis, speech difficulty, memory difficulty, stuff like that. So it's in peril within the nervous system, but it is an important matter, this is where we're at with understanding migraine. Is it a disorder of the mood, of the psyche? No. Is it a disorder of the neck? No. Is it a disorder of the sinuses, of allergy, of the heart, of the blood vessels? No, it's a disorder of the brain. I'm a neurologist, am I biased? Possibly.

Evans: Giles Elrington, Medical Director of the National Migraine Centre, which is a charity to treat people with headache, but also to carry out research and to provide education to health care professionals. It used to be known as the City of London Migraine Clinic. The name changed to emphasise its national status. So how does one get referred to the National Migraine Centre? Heather Sim is its chief executive.

Heather Sim: The majority of people actually self-refer. Some of them who come through as 'self-referred', in inverted commas, are actually referred by the GP but the GP shows them our website and tells them about us and then they ring up themselves which saves the GP writing a letter. All the patients that come and see us have a full report written that's sent to the GP and a copy given to the patient. And the GPs like the service because they get a lot of information back and some of them have reported that they've learnt a lot about managing headache from the reports we send back with the patients.

Evans: How much does a referral cost?

Sim: We're a charity, so we don't actually charge patients as such. We do have private patients and there is a private patient fee which at the moment is £250 for a first appointment and £175 for a follow-on. We also, if people have private health insurance, they can be seen through their private health insurance. But they have to ring up and get the agreement from the private health insurance first and they pay the money to us and then they reclaim it.

The majority of patients are seen through the charitable route which, because we nearly closed two years ago through lack of funds, we share with the patients when they book that the cost to deliver the service to them is in the region of £208 for the first appointment and £104 for the follow-on. We say, if you can cover the core costs, that's fantastic, however, if not we have a suggested minimum donation of £100 each time people come. But if people are on low income or unemployed, that they can just come along and give what they can and remember us when they get a job.

Elrington: If I have a criticism of my colleagues, I think there's an over-concern about secondary headache. So there's a great tendency when you go to a neurologist with headache to acknowledge this and say 'take this very seriously'. And you do a brain scan and the patient's frightfully pleased it's being taken seriously at last. And so off they go and have their scan and they come back, 'What does the scan show, doctor?' 'I'm very pleased to say the scan's normal'. And the patient's so relieved, they're out of the room before they think of the proper question: 'OK, so what are you going to do about the headache?'

So where we are, in this clinic particularly, is in symptom control. And I think it's very important to say to the patient, 'What's your main symptom?' Sometimes people say, understandably, 'I just want to feel well', and then you have to dig into that and say, 'Well, of all the symptoms you have, which is the one, if I could make that go away, it would have the biggest impact on your life?'

And often it's not just the pain – often it's the fear of attacks, and many of the patients with migraine – which is in most people an episodic disorder, the minority is chronic and persistent but mostly it's episodic – a lot of my patients have simply stopped agreeing to do things in their life because they're fed up of having to cancel and they live a very sheltered and rather boring life. So the fear of attacks is very important.

I have a big problem with patients who are so devoted to their work that they will bang on taking short-term treatments that will actually make things worse in the long-term because they can't bear to take the time off work. For heaven's sake, take some time off, get it sorted, then go back to work when you're better.

Evans: Giles Elrington, Medical Director of the National Migraine Centre. And their web address for further information is NationalMigraineCentre.org.uk, that's NationalMigraineCentre – no gaps – NationalMigraineCentre.org.uk.

Now before we end this edition of ***Airing Pain*** don't forget that if you'd like to put a question to Pain Concern's panel of experts or make a comment about these programmes, then please do via our blog, message board, email, Facebook, Twitter or even pen and paper. All the contact details are at our website which is painconcern.org.uk and from there you can also download this and all previous editions of ***Airing Pain***. I'll end this edition with Keri Bucholz and Emma Williams.

Williams: Just because you have migraine, don't think it can control your life because it can really feel like it does, and I know mine are mild but even for me I would notice such a difference in self-esteem. If you feel that someone has heard you and understood, and just chatting to other people that have had it, and they don't think that when you're having aura you're, sort of, drunk or... because sometimes it can come across as that, or you're being really odd or quiet, because I go very quiet when I have one. Many just sit and suffer in silence. Don't do that, please come and find more information, it's really important.

Evans: What advice would you give people like you, young mothers who have migraines, trying to bring up families, trying to keep a home together?

Bucholz: Go easy on yourself. I mean, be gentle with yourself, don't get overly frustrated with the things you can't do. Enjoy the things that you can do. And it takes times to figure out what's going on when you have any pain disorder, it takes a lot of time so don't get discouraged, and enjoy those relationships with your family, and communicate and talk to others about it, because you'll find that you're not the only one out there that has migraines and also you'll find it'll help ease a lot of things in your family.

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