

Airing Pain Programme 33: Gender and Communication

How gender can influence experiences of pain, and living with cluster headaches.

We hear about orofacial pain (pain of the face and mouth) from Dr Barry Sessle, a professor in the Faculty of Dentistry at the University of Toronto in Canada. Dr Sessle also explains why some types of chronic pain are more common in women than men. Continuing with this topic, clinical psychologist Dr Amanda Williams talks about pelvic pain and the difficulties men in particular have in coming forward to seek treatment.

The International Association for the Study of Pain designated 2012 as the Global Year Against Headache. We speak with a husband and wife on how they manage as a couple to live with husband Phil's debilitating cluster headaches.

Paul Evans: Hello, I'm Paul Evans and welcome to **Airing Pain** -- the 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 has been enabled by an educational grant from Pfizer Limited.

Phil O'Brian: Before I was diagnosed the pain is so bad that you automatically think that you've got something in your head, a growth in your head or whatever, and everything flashes through your mind. Nothing can hurt that much, it cannot be normal that you can have that much pain and you're going to live.

Sue O'Brian: Phil would pace up and down and be out in the garden at 3, 4 in the morning, and he'd be really irritable so I would sort of stay away from him. I didn't know whether to help him or to stay back.

Evans: The International Association for the Study of Pain designated 2012 as Global Year Against Headache; headaches being among the most frequent of medical complaints seen in General Practice. And they take on many forms: from tension type headaches, migraine, to rarer conditions such as trigeminal neuralgia, all of which we've featured on **Airing Pain**.

Later in the programme I'll be talking to a husband and wife, and how they manage as a couple to live with husband Phil's debilitating cluster headaches. But I want to start with

Doctor Barry Sessle. He's a professor in the Faculty of Dentistry at the University of Toronto in Canada and he specialises in orofacial pain. That is pain of the face and mouth.

Dr Barry Sessle: Some of the most common pain conditions in the body, whether they're acute or chronic, occur in this region. And particularly for the chronic pain conditions in the orofacial region, the face, the jaws, the mouth, like many chronic pains elsewhere in the body, we don't know very much about their etiology, what their cause is, and how they progress. And so that makes diagnosis and especially management problematic, when you don't know exactly what are the underlying mechanisms. And so I've spent the last 40-45 years trying to work out these mechanisms, particularly using animal models of acute and chronic orofacial pain.

Evans: What are the other problems with facial pain?

Sessle: One of the most common – other than toothache, which is probably one of the most common pains in the body – there's also headaches of course, different types of headaches, and some of them can actually get expressed, or be spread to or referred to, parts of the mouth or parts of the jaw. And also another very common condition is called temporomandibular disorders, where there's pain in and around the jaw joints or in the associated muscles. And basically 5-10% of the population have temporomandibular disorders and there's a female predominance. There's in fact a female predominance in most chronic pain conditions, not all, but most. And so clearly gender plays a factor in a number of these chronic pain conditions in the orofacial area, as well as elsewhere in the body.

Evans: Do you know why that is?

Sessle: There're genetic factors involved in the manifestation of the pain, and part of that is related to sex differences. Some of our own research has shown that, firstly in animal models, the responsiveness of the nerve fibres supplying parts of the face and mouth and jaws and the jaw joint, there's a sex difference in how they respond. So in animals for example, you give a chemical agent to activate these nerve endings in the joint or muscle, the jaw muscle, and with this particular chemical activation the female rats, for example, those afferent fibres, sensory fibres in female rats were much more responsive than those in male rats. And likewise if you inject this chemical into awake humans, into their jaw muscle for example, again young women are much more sensitive, give much higher pain ratings, much more spread of the pain that they indicated, compared with young men.

This is important because it means that there's physiologically based sex differences in these peripheral pain mechanisms. Not even talking about the brain and possible differences in how males and females may differ in their neurochemistry and neurocircuitry related to pain within their brain, but even in just the sensory nerve fibres outside the brain, there's these physiologically based sex differences.

Evans: Put simply, does that mean that women *hurt* more?

Sessle: Yes, there's actually been documented in women, humans – and again I'm generalising, it can vary from one country to another or from different racial and cultural groups – that females, for example, have lower pain thresholds, they have greater pain sensitivity at threshold, but they also have lower pain tolerance, they can tolerate pain.

There are these tests one can carry out in a controlled environment to measure pain threshold or pain tolerance or ratings of pain between those two extremes and it's very clear that in a number of these racial, cultural groups that there are these sex differences. And of course one of the questions as well, is that psychologically based, is it physiologically based and is it centrally based – in other words is it within the brain that's causing this, or is related to this sex difference? Or is it the nerve fibres themselves?

As I said, we have established that it seems that at least the peripheral nerve fibres, there's some differences in how they respond to some painful stimuli. Doesn't mean that's how they respond to all painful stimuli, it just happens to be the ones that we were testing. But also you have to take into account that of course there'd be differences within the brain. There are differences between males and females in the neural circuits in the brain and the neurochemicals that are used in those circuits.

Evans: So, taking that back to facial pain then, dentists and clinicians should be aware that men and women are feeling different pain?

Sessle: That they *could* be, yes, they could be, yeah. It's important to establish that there are these physiologically-based differences because many times in the past, and maybe still happening in some isolated cases, that women complaining of orofacial pain, or pain elsewhere in the body, had been sort of sloughed off by the clinician, and saying, 'this is just a female thing, it's being, they're just exaggerating, being, you know, too emotional about it' and so on. And they've attributed it to that and really haven't managed the pain properly, just sloughing it off as a female thing that'll eventually work out. But there are these physiologically based differences, well established, both in the peripheral nervous system and in the central nervous system, sex differences.

Evans: Doctor Barry Sessle, from the faculty of Dentistry at the University of Toronto in Canada.

And we'll stay with gender differences for the moment because one area where men and women most definitely differ is of course the pelvic region. Physical differences aside, men and women have different attitudes towards pelvic pain and many men put this in the category of 'women's problems.' And the reticence to discuss their own pelvic pain can, and does, put their lives at risk. Doctor Amanda Williams is an academic and clinical psychologist and she works mainly at University College London.

Dr Amanda Williams: It's a particularly difficult pain for people to talk about, to disclose to those around them. So particularly men, we've found, tend to make up a cover story which then isn't very consistent, because that's not where they feel pain and they don't behave in a way that shows they have pain in whatever they said... their knees. It is a difficult problem to disclose, people may laugh rather than sympathise, as they might over another pain.

People worry about something being wrong, with all visceral pains, sort of pains inside the body cavity, they can be quite diffuse, they may be quite sharp, but they may be quite diffuse and hard to locate. Many people aren't quite sure what's inside them and of course they start to worry about things like cancer or tissues torn or damaged in some way, something horrible going on, and find it hard to get the information that'll reassure them.

Evans: Well, you've just confirmed what happened before we switched this recorder on. I had a little giggle about urogenital pain, because I assumed that's women's problems.

Williams: That's very interesting isn't it? Because you're absolutely right, lots of the websites which say 'chronic pelvic pain' only refer to women. Even scientific papers which are titled 'Chronic Pelvic Pain' only refer to women. But men can also get pelvic pain, sometimes for the same reasons, to do with muscular pelvic floor. And then of course men and women do have different organs and they'll have different pathologies and problems that affect those organs. But it is seen as a woman's problem and I think that, again, makes it hard for men to talk about it.

Evans: So what problems do men get?

Williams: They may be very specifically located in the genitals, they may be much more generally in the pelvic cavity, they may affect their bowels – it often happens with irritable bowel syndrome. Men may have problems in particular activities or positions, so very keen cyclists are a bit over represented. And certainly in the cycling literature there's a lot of discussion about how to make saddles more comfortable and padded clothing to help. So it's

clearly a problem that then just goes over the top in some people. So really a great variety of things, which again makes it hard for men to find information easily, that they feel refers to them.

Evans: Why do you think men have a problem in discussing this?

Williams: They find it harder anyway to talk about emotionally laden issues, things that worry them. They tend to look more for information and hard facts, perhaps, rather than reassurance as well. Women might go for both. We know that in all sorts of health areas people talk to friends, family members, many times before they reach a doctor, unless it's something very urgent. Women do that far more than men and they'll get a range of opinions among which may be, 'oh yes, I know somebody who had that' or 'I had that and, yes, I went to my doctor and I was given this.'

So you start to get an idea of the possibilities if you talk about it to other people. If you have something fairly rare and you don't talk about it, you're never going to get any of that reassurance that it might be treatable, that a doctor will understand and take it seriously and so on. And of course some of the men we've seen have said that they've felt the female doctor wasn't terribly sympathetic, although others have found them fine.

Evans: One thing that people have told me is very effective is when a, say, high profile sports star comes out. I mean it's happened recently that John Hartson had testicular cancer. And he was very, very open about just leaving it to go and go and go and he's survived it. But it could have been very different. Now I actually know people who've been worrying about the same thing for years and just one trip to the doctor, just one 10 minute appointment, makes them sleep at night again.

Williams: Exactly, or else get directed to further investigation treatment. Now I think it's really admirable when people do do that. I don't know about that particular sportsman but I do know that with Kylie Minogue talked about her breast cancer, it's lead to a really significant increase in young women going to doctors either with worries about breast lumps or going to mastectomies or just taking it more seriously and not seeing to something that only affects other people.

Evans: So men must not be bashful.

Williams: A doctoral clinical psychology trainee of mine did two very nice bits of research: one was literature review but the literature was what was available on websites. So she used typical web-surfing behaviour to look at what would be available to men who looked up

urogenital pain, chronic pelvic pain on the web. And actually, of course, many sites were for women only.

But when she found the sites she looked firstly at whether they gave good information on the causes of pain, which can be helpful information for men and often reassuring and the second was whether they gave any reference to psychology, psychological consequences, difficulties, distress and so on. And she found it was really quite hard to obtain both those bits of information. Only three websites that she found had good psychological information, quite a lot more had information about cause but some of it was seriously out of date or misleading.

The second bit of work she did was talking to men about what they thought was wrong with them before and after their first consultation at the pain clinic when they were coming for urogenital pain. And men were very keen to have a mechanical explanation that made sense to them, for which of course some needed some extra background information about how the mechanics works anyway.

We were expecting more cancer fears and we actually saw rather few. What was nice to see was that when men felt they'd been investigated for cancer often at an early stage via the GP and it was ruled out and it stayed ruled out, they didn't come back to that worry later. And that's very good to see because in some groups you see people keep on coming back to the cancer worry, you know, six months after the scan was done they think, well, perhaps it's developed recently. So that was good to see.

But they were often very bewildered about the possible cause. And because pain is a problem within the nervous system about it functioning differently, it doesn't fit very well into a mechanical explanation and you can develop analogies about computers or phones and so on but none of them is really convincing. So it's quite hard to get a convincing explanation of pain in the urogenital area for men and I know quite a lot of the doctors use a lot of diagrams to convey that. But again, with static diagrams you can't show how messages instead of going along the nerves occasionally are firing off all the time and then the brain of course experiences pain.

Evans: When I was worried about testicular cancer, not seriously worried about it but I had a pain in my testicles, something you don't really talk about, I didn't make an appointment with my female GP, I made an appointment with a male GP and he felt my testicles and then he said, 'I'm just going to stick my finger up your bottom.' Had I known that was going to happen [**Williams:** ...you wouldn't have gone...], I would not have gone – but I'm very grateful that I did go and everything was ruled out.

Williams: Exactly, and as you say, then you can sleep at night.

Evans: I know. But I wouldn't have gone if I'd found a website that said your doctor was going to do something like that...

Williams: Yes, that's a very good point because it does put people off, although one can with that information say, 'this is perfectly normal, the doctor does this many times for investigations and is completely unbothered by it.' So you just have to think of yourself as, for instance, another person in a long row of people having that investigation. But I agree, it does put people off. And what came out of this research project was very often that men haven't found anything that made a huge difference to their pain but what they had done was resolve those worries enough. They felt that really horrible things had been ruled out; they knew they weren't going to steadily get worse and that was enough for them to feel, 'Okay, now I know where I stand, I can start to think about what I need to do differently', and so on.

And there's some good evidence for physiotherapy helping some of those pains, whereas before they wouldn't have considered physiotherapy, now it makes sense to them to try that and so on. So it was kind of opening some good doors and closing some bad ones that she had heard over and over again from men who had had their consultation and felt better for it.

Evans: Well, I can confirm that it's exactly as you say it is. [Laughs]

Williams: That's great to hear!

Evans: Clinical psychologist, Dr Amanda Williams. Now at this point I'll just say our usual words of caution, that whilst we believe the information and opinions on *Airing Pain* are accurate and sound, based on the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

As you heard earlier in the programme, 2012 is the International Association for the Study of Pain's Global Year Against Headache. Now cluster headaches are excruciating. They're more painful than migraines or any other type of headache. In fact they're so severe that they're often described as 'suicidal headaches'.

Phil O'Brien: My name's Phil O'Brien and I suffer from cluster headaches.

Sue O'Brien: I'm Sue O'Brien, I'm married to Phil and I also suffer when he suffers with cluster headaches. [Laughs]

P O'Brien: True, true.

Sue O'Brien: I do.

P O'Brien: I've had them for six years and it took us two years to find out what it was, which apparently is quite quick. Most people don't find out, they're not diagnosed with clusters for four, five, six years. And I've just been told there have been people who haven't been told, not known, what they've been suffering from for 10 years plus. So we found out quite quick, really.

Evans: Just tell me what a cluster headache is.

P O'Brien: A cluster headache's not like a migraine; you've got a nerve in your head and basically it send out two bigger signals. So most people's nerve is sending out little signals, making things work in your head and making things happen, and mine sends out – when I'm having a cluster headache – there's something in the brain stem, isn't there? [**S O'Brien:** Uh, huh...] becomes active and my nerve sends out massive signals. So I get pain in the ear, in the eye, in the teeth and in one side of the head, it's only ever one side. So mine's on the left side. So when I first got 'em and we didn't know how to treat them I could be in absolute agony. I liken it to someone parked a lorry on your head, the pain, and that could go on for 4 or 5 hours.

S O'Brien: Whereas obviously in a migraine people like the quiet and you get sort of get agitated, and you pace up and down a lot, don't you. So the symptoms are totally different to a migraine.

P O'Brien: So we read articles where they say it's a migraine times 10 on the pain factor but I don't know because I've never had a migraine.

Evans: Somebody called it a suicide headache?

S O'Brien: Yes.

P O'Brien: Yeah, we was just talking to the specialist just now and he's known of people committing suicide whilst having a headache. It is a severe pain. You can't describe to someone what it's like...

S O'Brien: You say it's like a clamp, don't you? ...and it just keeps tightening, and tightening until you can't take it anymore.

P O'Brien: It's as if someone's putting your head in a vice and they're tightening the vice until you really can't take any more pain and then they give it another half a turn. And they

won't release it and you could have that for two hours. It's not a throbbing, it's constant pain. You just can't describe it.

S O'Brien: So in the beginning we didn't know what it was did we?

P O'Brien: I used to head-butt the wall, didn't I? And bash myself in the head. And so I can quite believe that people could give up on it, if you like, you know, give up on it.

S O'Brien: You used to hit yourself didn't you? Saved me doing it I suppose! [Laughter] You did get quite agitated. But we've learnt now the best thing for Phil is I would leave him alone and let him deal with it. I'm always in the background, and if he wants anything he'll tell me.

P O'Brien: When I get a cluster now...

S O'Brien: We've got a routine haven't we?

P O'Brien: Yeah, because it's been diagnosed and we've got various treatments, so we can take an injection which gets rid of it quite quickly. If it's not too bad a headache then I can take some painkillers and then we have to wait for it to go but the side – mine's is on the left side of the head – and I'm burning up... so Sue knows that we've got two flannels and she gets really cold water and she keeps swapping the flannels for me and she knows that I like...

S O'Brien: ...they come off actually really hot, so he's actually burning up and we change the flannels, like, every 30 seconds....just constantly changing them.

P O'Brien: And then Sue knows that I like to have a cup of tea, so in the early days I used to get agitated. I used to say, 'get this, get that, leave me alone.' And that's not in my nature normally. But when I was in the middle of a cluster headache, I become bossy... [**S O'Brien:** Irritable...] and sometimes I just needed her to go away and leave me alone.

S O'Brien: But now we don't really talk to each other much. So I just get on with what I'm doing, we've got a little routine going...

P O'Brien: Yeah, we've got a lovely system going where we deal with it together, don't we?

S O'Brien: And there was a stage when I used to wake up before Phil would have a cluster, because I knew he was going to get one. So I'd wake him up and he'd wake up and say, 'Yeah, I've got a headache coming.' But I was aware that he'd be scratching his head in his sleep. So I'd wake him up and say to him, 'you gonna get a headache?' [**P O'Brien:** And I did.] And he did.

Evans: How did you know then?

S O'Brien: We found out that in the beginning, Phil's headaches were just at night-time; they were one hour after we went to bed, regardless of what time we went to bed. We used to set the alarm for 45 minutes after we'd been to bed to try and wake up before, but my subconscious always used to wake me up when he started sort of fidgeting in bed so I wouldn't particularly sleep quite deep. And sometimes it might go past the hour and I'd wake up and think, 'oh he hasn't had a headache yet.' I'd get back to sleep and then he'd wake up with one so...

P O'Brien: There's a weird thing where, as Sue just said, if we went to bed at 11 o'clock at night, the headache was exactly 12 o'clock. If we went to bed at 10 to 1 in the morning the headache was at 10 to 2. And it's almost like your brain has become this... [**S O'Brien:** 'You could set your clock by it.'] You'd lay down and you go to sleep and you'd become into a relaxed state and once your brain, say, after an hour's sleep, your brain must switch off or whatever or do whatever it does. And my brain thought, 'ahh, now's a good time' and it used to fire off these signals which would create this headache.

We could deal with that. When it was every night, or every other night and it was just at night, we could deal with that because we used to get out of the bed, get rid of the headache and go back to bed. That wasn't a problem. For the last two years they've started coming during the day. So now you're driving along, all of a sudden you're aware you're gonna get a headache, you've got to pull up wherever you are, you can't drive, you can't concentrate, you can't really talk to anyone. So now, it's sort of affecting our lives quite badly.

S O'Brien: Yes because the other week he was on three or four a day; so every time we get him doing something we'd have to stop.

P O'Brien: So hence we're now back at the migraine and head clinic and they're now looking at other methods because the treatment I was on, it basically isn't working any more. It used to work but my headaches have actually got worse and worse. So we're now in the throes of having other treatments, aren't we?

Evans: So what treatment is that?

P O'Brien: Well I used to be on large amounts of Verapamil which is like a blood pressure, a heart pill, I believe, and it also helps with cluster headaches. So we're now going on to a treatment which is quite specialised in that it's small doses of Lithium, which frightened the life out of me because it was used to treat depression and things like that.

However, we've been told by our specialist that, you know, Lithium does all sorts of things for different people, so I had the impression it was going to play with my mind and things like that because it's linked to depression and it's nothing like that at all. It basically helps how active the brain is at certain times so for people with cluster headaches a little bit of Lithium can do some good but then I have to go and have blood tests and things like that; it's a treatment that has to be closely monitored. And then because I've had cluster headaches for so long, to give these other treatments an opportunity to work, we need to try and switch them off for four or five weeks because my body's got in the habit of having a headache. So we're trying to switch them off for 4 or 5 weeks.

Evans: Switch off the medication.

P O'Brien: Switch off the pain, switch off the cluster headache.

S O'Brien: So today...

P O'Brien: So today I've had an injection in the back of the head...

S O'Brien: ...a nerve blocker...

P O'Brien: ...which is a nerve blocker. So I've had that today and now we've got to wait and see what effect that has. So we're hoping that this nerve blocker injection...

S O'Brien: ...changes the signals in his head...

P O'Brien: ...is going to calm everything down rather than change them, I believe, it's gonna calm it all down. So hopefully I'm going to get five or six or even eight weeks off from having a cluster headache, which will hopefully give the new treatment an opportunity to get a hold and work.

Evans: You were saying that it's become unmanageable over the last couple of months. How does that impact on you?

P O'Brien: Well I've got a business, so I'm better off than some, I suppose, in terms of I'm my own time manager. So it's good in that respect. But the biggest difference for me is that when I used to just get them at night, nobody knew I had them. We didn't tell anyone because it wasn't important. It was just something between us at home who knew that I...

S O'Brien: You don't like the fuss, do you? You don't want people coming up to you...

P O'Brien: No, I don't want people feeling sorry for me and asking me if I'm alright, I just want to... I'll get cluster headaches but I just want to get on with me life. I still just wanna be me; I don't want everybody asking me how I'm getting on.

S O'Brien: But people who are aware of it are constantly going, 'Oh, are you alright?'

P O'Brien: Because I don't think of it that I'm ill – because I'm not ill, I just suffer from cluster headaches. Now in fact, if somebody's ill, then you want... maybe they want sympathy, and people keep going, 'oh, how do you feel now' and people like that. And it's reassuring; it's almost a pat on the back. But suffering from cluster headaches – I can only speak for myself – I don't want people's sympathy. I don't want to talk about it. Because it's not an illness that's going to kill me or anything, it's just an unpleasant thing that happens to me. So I like the idea of people not knowing, really. It's better because they don't keep asking questions.

S O'Brien: You've got a quick treatment now as well. You have an injection, so when he gets a headache he injects himself and the headache's gone, normally within 10 minutes, which is really good. So we just carry medication around with us wherever we go, don't we? If ever we go out you've got some and I've got some. And then if Phil does get a really bad headache he'll just go off and inject himself and within 10 minutes it's gone.

P O'Brien: Yeah, so this new treatment is good. I'm saying new treatment – this is a treatment that was offered to me three or four years ago, and I didn't like the idea of injecting myself, because – this sounds weird – what happens is, I was told that I could have these injections and they gave me some. And I went home pleased as punch, 'I've got these new injections, I can't wait for my next headache to see how good it is.' And it becomes a little bit like that, y'know, you almost want try it out. And I got a headache which made me flustered and agitated, so then I didn't want to inject myself. I took the lid off and I'm, 'oh I can't, I can't do that' and so that went across the room because I'm agitated, [laughs] big handfuls of painkillers and it went on. So I had these injections that I didn't want to take... [**S O'Brien:** They're brilliant.] So, and now eventually I've seen someone here and they said, 'You've really got to try these things. You've got to... you've got to cope with it, you've just got to have this injection.' And now I have the injections and they're brilliant, aren't they, they're a lifesaver.

Evans: Phil and Sue O'Brien who I met at the National Migraine Centre in London. We'll come back to them to end this edition of *Airing Pain* in a moment. But let me just remind you that if you'd 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, e-mail, Facebook, Twitter and of course pen and paper. All the contact details are at our website,

which is Pain Concern, one word, painconcern.org.uk. And you can download all the editions of *Airing Pain* from there too.

P O'Brien: We deal with it as a pair, as a couple, really.

S O'Brien: In the beginning I felt really useless because we didn't know what it was, and Phil would pace up and down and be out in the garden at three, four in the morning and he'd be really irritable. So I'd sort of stay away from him. I didn't know whether to help him or to stay back. But now we've just got an understanding. I do what I do and you do what you do and if anything changes he'll let me know if he wants anything else.

P O'Brien: The way I've been told today that after a period of time it can just go away. And I await that day. [Laughs]

S O'Brien: Definitely.

P O'Brien: Really.

Contributors

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