

## **Airing Pain Programme 22: Pain support groups and facial expressions**

***What facial expressions in mice can tell us about pain, managing pain in dementia patients, and finding hope in a pain support group.***

*People with mental illness and chronic pain often find it difficult to access the treatment they need. Specialist nurse Valerie Conway talks about her work in providing carers with the skills to better look after people with Alzheimer's and dementia who have pain.*

*Measuring pain through facial expressions is one way in which health professionals can become more aware of the needs of those who are unable to verbalise their experience. Professor Jeffrey Mogil tells **Airing Pain** about his work measuring pain responses in the facial expressions of mice and how this could help in understanding human pain and in finding new drug treatments for pain.*

*We also hear from Sue Clayton about how sharing her experiences and getting pain management advice at a pioneering chronic pain support group in the eighties helped her put her life back together after post-surgical pain.*

**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](http://painconcern.org.uk).

**Sue Clayton:** I was being told by the medics that I was mad, bad and sad, basically – mainly mad. That I didn't have pain – it was all in my head – and it completely devastated my life. I couldn't work, look after family, I desperately needed someone else who understood me.

**Valerie Conway:** If English isn't their first language, it doesn't matter – it's about recognising a change in behaviours and being able to identify they might be in pain so what are we going to do about it?

**Professor Jeffrey Mogil:** If you put one of the mice in jail in pain and the other one isn't, and if all three mice are female and cage-mates, then the three female mice will spend more time with the mouse in pain than the mouse that isn't in pain.

**Evans:** [laughs] ...we will come back to the mice later. They could well be relevant to a pilot project being run by the Community Chronic Pain Services in East Kent, whose Lead Clinician is Consultant Nurse (Chronic Pain) Val Conway.

**Conway:** For patients with learning difficulties the challenges are that they cannot always express themselves in a way that is obvious that they are in pain. Other challenges are that some of the carers who are looking after them are inexperienced, may lack training and may not know what to look for as far as pain management is concerned. One of the areas that we're looking into is to develop a training package in order to help carers look after clients in their residences. We're currently looking at a tool called DisDAT (Disability Distress Assessment Tool), which is a pain tool specifically for people with either learning difficulties or dementia. Hopefully when this tool is rolled out it, it will improve pain management for this group.

**Evans:** You mentioned communication skills with people with learning disabilities, with dementia, but how do you deal with that, how does it show itself?

**Conway:** It's going back to the basics. What we're looking at is to see if we can get the carers to assess their client group when they come to the home and have a baseline of what is normal for that person. For instance, if it is normal for a person to rock in the chair or grimace, what happens when they are in pain is that behaviour will change. It is recognising the change from the normal for what is normal for that person. And that is what we find is missing, carers may not know the change in behaviour is something to look for that they are in pain.

**Evans:** How do you notice that?

**Conway:** This is what the education package is about. We are going to get the carers to come along and my experienced colleagues and myself are going to help them identify pain. We're going to do some role play; we're going to do some group work, so they can identify baselines for these people so they will notice the changes actually mean something. That way we hope that the communication between the carer and GPs/healthcare professional will be improved to get the right treatment for that client group.

**Evans:** Is there a lack of knowledge on pain management within the care system?

**Conway:** Yes, mainly because most of the care system is not within the NHS (National Health Service) umbrella, it has gone out to private care homes. And a lot of the staff are not trained nurses or physios. They go into the profession because they want to care for people but often the training is not available within the specialised areas.

**Evans:** My memory of my father in a nursing home was that most of his carers were from European countries, non-British countries – actually, they were very good indeed, but how would you train somebody in that position who spends more time with a patient than anybody else really, how would you train them?

**Conway:** Well this is what we looked at, when we were designing the education package. Certainly in Kent where I worked a lot of the carers were young and English is not their first language, therefore, the tools we need to design must be simple, but ones they recognise and understand. Again, if we are using the same tool day in day out repeating it, they will learn the different words and behaviours they are dealing with.

**Evans:** So in many ways you are picking up more on the body language than the spoken language?

**Conway:** Well yes... well it is looking at the baseline. Looking at what is normal – normal in inverted commas for that client group – and they can recognise that. It doesn't matter if English is not their [first] language it is about recognising a change in behaviours and being able to identify that this might be they are in pain and therefore what are we going to do about it.

**Evans:** Val Conway, Lead Clinician for Community Chronic Pain Services in east Kent. Now one obvious form of body language is of course facial expression. If you stamp on my toe, I will probably grimace. I know that is not earth shattering research, but Jeff Mogil who is the EP Taylor Professor of Pain Studies at the McGill University in Montreal, Canada is interested in how facial expression could be used as a measure of pain, but his subjects aren't people but mice.

**Mogil:** Facial expressions of all the emotions are rather stereotyped – people from different cultures and different ages reliably show the same movement of muscles in the face when they are angry, or happy, fearful or enraged or, as it turns out, in pain. However, this is not what I'm interested in. That has been going on a long time. I was interested to see if this works in animals, as well as people. And of course Darwin wrote an entire book on the subject in 1857, *The Expression of Emotion in Man and Animals*, where he argued that any emotional state that you can see through a facial expression in humans, you should be able

to see in all mammals and amazingly no one had ever tried that. No one had ever looked to see if there is a grimace simply put, in any other species other than people.

So we tried it in the mouse and recently we tried it in the rat and it works and of course they do grimace. Interestingly, it works sometimes and not other times, so generally speaking we find that pain that lasts anywhere from about 10 minutes to two days you will see a grimace in animals.

**Evans:** So, you being able to tell if a rat is in pain or happy or whatever, how is that going to affect me?

**Mogil:** Right, in the pain field there has been increasing frustration with what we call our poor record of translation. What that means is we have all this basic science knowledge, we know all these new molecules that are involved in pain and new brain areas and we really think we have a good handle of the physiology of pain.

The problem is, if you look in the clinic, and see 'well what's new?' You realise not much. You come to the conclusion that most of the drugs used to treat pain at the present time are either drugs that are very much like aspirin, which is from the willow bark ultimately. They knew about willow bark two thousand years ago. The drugs that are used for severe pain – the narcotics, the opioids are... well those are ultimately the same drug as opium. Again, the opium poppy was known two thousand years ago.

Really there is very little that is new in the treatment of pain. People have put these two facts together that we have all these new molecules, but none of them have led to anything new in the clinic. This has led some to believe that the problem might be that the animal models we are using to give ourselves confidence that these drugs would work in people just aren't doing the trick.

**Mogil:** There is a lot of current work on trying to make new animal models or refine the animal models so they will be more predictive, so if the drugs work against the model in the mouse or rat, we can have more confidence that if the same drug is given to people it would actually kill pain.

What can we do to make better animal models is being worked on, so we recently published we can use facial expression as a new measure in animal experiments. Before we would make some manipulation, a drug, say, then we would poke the animal's foot with thin nylon filaments and we would find that after the injury they would respond to thinner filaments, then

if you gave them a drug they would respond only to thicker filaments. Again we pretended that that was pain, but it isn't pain, it was a reflex withdrawal to stimulus.

And this is not what patients complain of – they do not say, 'I withdraw my hand from thinner filaments than before' or 'when I used to put my hand on a hot stove it hurt, but, boy, now after my injury it really hurts.' This is not what patients are presenting with at the doctor's this is not the clinical problem. The clinical problem is spontaneous pain – 'my arm hurts. You do not need to touch it, it just hurts.'

And our problem in rats and mice is that we have not had very many measures, if any at all, of spontaneous pain. We can poke the mouse or the rat, exert mechanical pressure, but we have a hard time knowing if an animal is in pain. This is where facial expression comes in as they are commonly used in nonverbal humans.

Obviously in normal adults, you do a pain study and you ask how much does it hurt and they will give you a number and you have your measure. In babies, for example, or in demented older adults you can't ask them and get any answer at all or get an answer you can trust; so, for ten or twenty years people have been using facial expression to come up with a number for how much pain that baby is in. We figured that measuring spontaneous pain you don't need to touch them, you just need to video their face and then find a way of scoring it. If it's good enough for babies, it's good enough for mice and we could see, if it works, we could use it as a measure of spontaneous pain that is different from the current measures. And so far it has been working out really nicely in fact.

**Evans:** In evolutionary terms is that the purpose of facial expression?

**Mogil:** That's a really interesting question. It's been argued in humans that the purpose of facial expression – actually, the person who argued this first, Amanda Williams, who was at this meeting I just came from – it's been argued in people that the purpose of the grimace is a communication strategy designed to solicit help or for sympathy. It may be the same in mice, but we are not sure.

We have one piece of evidence, that we find very interesting, that if you put two mice behind jail bars at the end of a corridor and then you have a third mouse that can go where it wants – it can stay away from both or go and visit one or go visit the other – and you put one of the mice in the jail in pain and the other one isn't. The purpose of the experiment is to see where the free mouse spends its time. We find that generally they do not care much. They generally spend a bit of time with one, a bit of time with the other, with one exception: if all three mice are female and if they are cage mates – if they all come from the same cage so

that they are familiar with each other – then the free female mouse will spend more time with the mouse in pain than the mouse that isn't in pain, suggesting that she was going over to try and help. But how did she know they were in pain?

We expect it's at least partially because of facial expression and this might be the operation of a communication strategy that's effective in the mouse. Then on the other hand, it has been argued as well that things are there and they are ultimately reflexes and through evolution primates and eventually humans will learn to use these reflexes for other purposes. It is possible that facial expression in animals has nothing to do with communication, but because it was there and we got smart enough we figured a way to use it for communication. So I am not sure yet, but that's actually a really good question.

**Evans:** I remember from my basic psychology days at university an experiment on classical conditioning. Half our class smiled and the other half of the class looked disinterested and grumpy and the teacher would automatically gravitate towards the smiling half is that the same sort of thing?

**Mogil:** Yes, it may very well be the same thing with one exception though: one can imagine that because of the experiment the professor is spending more of his or her attention on the smiling class because the smiling is more comforting perhaps and looking at smiling people increases his or her mood. But our mouse spending time with the mouse in pain is voluntarily approaching something that may very well even be dangerous. The mouse doesn't know whether what happened to the mouse in the jail could happen to the free mouse too. It doesn't know, so it could actually be doing something dangerous. So it is all the more impressive that it occurs at all.

**Evans:** Are you bringing altruism into the equation though and aren't humans supposed to be the only species to have altruism?

**Mogil:** They are and they are also the only species that are supposed to have empathy, but we actually showed in another series of experiments a few years ago, that mice are quite capable of at least the earliest forms of empathy as well. Do you want to hear about this?

**Evans:** I do. [laughs]

**Mogil:** Ah ok [laughs] ... So essentially what we found, is that compared to mice that were tested alone in a Plexiglas observation cylinder by themselves – which is how we and everyone else usually does it – if you now instead of testing one mouse per cylinder, test two

mice per cylinder and you compare the situation where one mouse is in pain and the other isn't to a situation where both mice are in pain.

Now remember, in the condition where both mice are in pain, not only are they in pain but both are also looking at another mouse in pain. And the question is, does that make any difference? It turns out that it does. That both mice will have more pain than if they are tested alone or tested in the presence of a mouse that wasn't in pain. But only, again, if they are cage-mates, if they are strangers there's no effect of this social observation. After about a year of controlled experiments that the reviewers made us do a year later we convinced ourselves and the reviewers that this represented empathy.

Now, your listeners may find that odd. That's because people's understanding of the word 'empathy' and the real definition of 'empathy' are not the same. When we say 'empathy' most people think of sympathy, but sympathy isn't empathy. In fact, empathy breaks down into four or five different things the bottom layer is something what we call 'emotional contagion'.

Emotional contagion is in fact something everyone is familiar with. The two great examples of that are one baby in a nursery crying and setting off all the others – that's emotional contagion. The other classic example is a contagious yawn. If someone yawns, it is more likely than chance that people near them will also yawn. They are not yawning because they are bored or tired, they are yawning because they saw the first person yawn. And that is, of course, empathy. Your state is being manipulated by the state of someone you are observing.

And so we think our demonstration of increased pain sensitivity while observing a cage-mate in pain fits exactly into this same category. Human empathy has been shown to modulate pain and also to lead to activation in the same brain regions that are activated when there is real pain, so observing pain in someone else will light up the areas of the brain as if you were getting the pain yourself.

**Evans:** I may be saying the unforgivable here, but it seems as if people with chronic pain shouldn't actually mix in crowds of other people experiencing chronic pain.

**Mogil:** Yes, you're right, the implication of this work is that pain in some sense is contagious. Now that is just a hypothesis and that would obviously need to be shown. I've been racking my brain trying to think of a way to prove that. I can only think of one experiment that would work, except I don't think it would be practical or that I would ever get permission to do it. But if you did an experiment where you looked at soldiers in basic training, who are living in a

barracks together and no-one isolated themselves from anyone else, I would be willing to bet that if someone there got a headache or migraine, that you would see others in 24 hours would get migraines over and above chance levels. But I think that's right, that's the implication but hasn't been proven yet.

**Evans:** So where do support groups fit into this?

**Mogil:** Well right, it suggests that support groups may be doing harm in addition to doing good. It's very important to point out that on balance I'm perfectly convinced that they do more good than harm.

**Evans:** And of course in support groups people aren't going just to be in pain. They aren't sitting down being miserable and moaning. They are going to give support to other people and to experience how to get on.

**Mogil:** Yes of course and one needs to remember that chronic pain patients aren't in pain constantly – they have attacks of pain and that happens at certain frequencies and the likelihood that during a support meeting that a whole bunch of people actively moaning about a pain crisis is pretty low.

**Evans:** Jeff Mogil of McGill University in Montreal, Canada.

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**Clayton:** I'm not suggesting that patients sit over long cups of coffee and switch horror stories. Sometimes that is therapeutic, but I think we can get much more out of our relationship with each other than that.

**Evans:** This is Sue Clayton who has had neuropathic pain following surgery to relieve her back pain in the early 1980s.

**Clayton:** I desperately needed someone else who understood me. I was being told by the medics that I was mad, bad and sad, basically – mainly mad. That I didn't have pain, it was all in my head. I was in my mid-thirties, had a young family, I had everything to live for, I did not need a chronic illness or condition. I didn't know anyone else who had a condition where they didn't get better, people usually have an acute condition and they're treated and the problem is solved. In your mid-thirties you don't tend to know people who have ongoing conditions. It completely devastated my life: I couldn't work; I couldn't look after my family; I worried my children would need to go into care because I was bedridden. But above all I was experiencing terrible pain, back pain.



I'd had surgery, I'd had a second surgery, been told 'yes, the operation was a success, so it is your fault you are not getting better'. Which is an incredibly damaging thing to do to somebody because you are left with no support, because what your, in my case, orthopaedic specialist tells your GP affects your GP's attitude. And presumably they were saying 'this lady has been operated on, problem solved. What is the problem?'

But I had unremitting pain, which absolutely destroyed me and I was being given nothing that even touched the pain and I was just consumed by it. I couldn't eat, sleep, I was depressed. I was worried silly. My poor husband had to take charge of looking after me and the family while trying to keep a roof over our heads by hanging on to his job which was quite high pressured.

So I felt totally isolated. And I really thought 'am I going mad?' But I knew I wasn't. I knew the pain was real, but I was being told otherwise, which destroys your whole central being, so I was desperate to find out what was going on. These were the days before the internet, so it was incredibly difficult to access medical literature, so it was really hard to try and research what was happening to me.

I happened to see an article in my local newspaper on a work-injured nurse who had damaged her back lifting a corpse at work. She stopped working as a result, couldn't get help because of her problems, so she ended up going to the Walton hospital in Liverpool, which then back in the 80s was the only pain management programme in the country. It helped her tremendously. She learnt a lot about managing her pain and she'd come back to Whitstable, which is quite nearby to where I lived in Canterbury. And she decided to start a self-help group to help others.

She held meetings to which I started going. So for the first time I met people who understood what I was going through – other patients. We shared stories and information. We gave each other support, we had speakers from the medical profession and allied professionals like medical herbalists, acupuncturists, Alexander technique, physiotherapists. It became a complete lifeline, so through her I learnt what pain management was about, what books I could read and how I could teach myself, so it grew very, very slowly from there.

**Evans:** So this is back in the 80s?

**Clayton:** Yes, this is back in the 80s, around 1985. So it was a lifeline. If I hadn't found that I really don't know what I would have done because my life had fallen apart and there was no support from the medical profession at that stage. I was so angry at what had happened to me. I thought it was disgraceful that people could be left in such a serious condition, with

their lives completely falling apart. The anger impelled me to get involved. I thought, 'this isn't right. Something's got to change. We need to support these patients. We need to build links with the medical profession. We've got to make things better.'

**Evans:** You were instrumental in starting Pain Concern which was then called Self-Help in Pain. I am certainly grateful to Pain Concern for the management of my condition. How do you think people should use self-help groups like this?

**Clayton:** I think it's given people somewhere they can go to be understood and receive support and information. For many patients, it has given them contact with other patients who have chronic pain conditions themselves – maybe different conditions – but there is an affinity there which patients respond to amazingly which I certainly found valuable.

Pain Concern has done a fantastic job over the years to build relationships with the medical profession, because I think the way forward is for us to work together. Some clinicians have been fantastic and have seen the value and wanted to be part of patient groups. They have wanted to make that partnership much easier and that can only be good for other patients.

Originally SHiP and then Pain Concern just issued information about chronic pain which is usually what people want most of all, but of course the helpline has issued support and information to people for many years to people who have nowhere else to go, couldn't find anyone else who understood them, nowhere to get advice. Pain clinics were perhaps few and far between. Pain Concern has been able to put people in touch with pain clinics and tell people what pain clinics can offer. I think it's just been a rallying point, really as much as anything, to give a voice to patients who otherwise wouldn't get heard at all.

**Evans:** So Pain Concern is here to help all of us, so don't forget you can put a question to our panel of experts or a comment to our blog, message board, Facebook, Twitter, via email or of course pen and paper, all contact details you need and a link to download ***Airing Pain*** are on our website and that's at [painconcern.org.uk](http://painconcern.org.uk).

Now, before we go I will just remind you that while we believe 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 knows the appropriate action to take on your behalf.

Now returning to Sue Clayton to end this edition of ***Airing Pain*** – she may have different conditions to you me or any of the 7.8 million of us in the UK who live with chronic pain, but her experiences in dealing with it will be familiar to all of us:

**Clayton:** Absolutely, that's why we understand each other. And that's why there is this affinity, it's impossible to have that with someone else who doesn't have chronic pain. It's a bonding experience which has given us strength above all else to feel we can change things and make a difference. Services will be improved and we hope that policy makers will understand the scale of the problem and the difficulty in addressing the problem.

And I think what needs to happen now is through political pressure where the patient support groups are working with clinicians to present a united voice to policy makers, perhaps we can develop much better integrated, comprehensive services staffed by clinicians who have got adequate training and clear pathways, so patients understand what will happen when they are referred, what it will mean, who will see them, why they will see them and what support is ongoing.

I think patients need both good official medical services and they also need the opportunity to meet with other patients if possible or at least to communicate with other patients. This of course has changed enormously with the internet, patient forums, email has completely revolutionised the way patients can cooperate and talk to each other which is a huge bonus. And I think actually this has the potential to take a great load of the health service. Patients can raise the profile and make a difference to the way the services are provided so they are suitable for the people who are going to be using them.

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