

Airing Pain Programme 56: Images and perceptions

Artist's impressions of pain in the clinic, and – clubbing or model railways? – why living a good life with pain is in the eye of the beholder.

If only pain were visible... Deborah Padfield talks to Presenter Paul Evans about her project collaborating with people with pain to produce works of art that represent their experiences. Her photographs are co-creations, using objects and ideas brought to the studio by the orofacial pain patients from University College Hospitals, London.

The art produced not only provides a voice for individuals who may have felt their experiences marginalised by the medical establishment and wider society, but is also part of a study aimed at finding better ways for people to communicate their pain. Images created by Padfield – from a clenched fist to flying sparks – are now being trialled by patients not part of the project as visual prompts in ordinary medical consultations.

'Pain is a memory', says Dr Rajesh Munglani, explaining how the way we feel pain is affected by past experiences and our emotions. From the phantom limb pain of a soldier wounded in action to an injured motorist caught up in a bitter legal struggle for compensation, the context of chronic pain can be crucial in helping or hindering people from moving on. The different ways people perceive their pain also means, Dr Munglani argues, that perhaps pacing is not right for everyone, all of the time – a big night out might mean a few days in bed for a teenager with pain, but provide an important boost to their confidence.

Paul Evans: Hello, and welcome to another edition of **Airing Pain**, a programme brought to you by Pain Concern, a UK-based charity working to help, support and inform people living with pain, and healthcare professionals. This edition's been funded by a grant from the Scottish Government.

Pain is invisible and it's subjective, so trying to express or quantify it can be difficult. Have you underplayed it? Have you overplayed it? And do people believe you? Yes, there are well-established numerical scales by which medical professionals can chart your progress, but could there be a better way for you, the patient, to convey exactly how you feel? If only pain were visible. Well, pain may not be, but the arts, so they say,

can convey emotions much better than words. Music can have a valuable therapeutic role, but what about the visual arts?

Deborah Padfield is a visual artist working mostly with photography. She's collaborated in a project with facial pain specialist Professor Joanna Zakrzewska and her team at University College of London Hospitals.

Deborah Padfield: The project has a lot of different strands, but the first strand is co-creating images with – in the present project – with facial pain patients. And I've been really lucky. I've got a wonderful group of patients I've been working with, who are phenomenally creative and bring all sorts of ideas and objects to those sessions, and I work individually with them to make the photographs. So I'm taking the photographs, but using their metaphors, some of their ideas – we discuss the ideas together, so they really are co-creations and they bring in all sorts of objects.

And the reason I want them to be co-creations is I think by the time someone's got to a pain clinic, they've been investigated so many times, they've been on the receiving end of the medical gaze so frequently – I think it's quite important to reverse that, and that people need to be in control of how their pain is seen, how it's understood by others. It's not appropriate or inappropriate; it's not adaptive or mal-adaptive; it's what they're experiencing. And to put it in a shareable space, so it's not trapped within the body and hidden and private, but it's out in a collective, shareable, visible place.

We've taken a selection of the images and we've made them into the pain cards that you see here. At the moment, it's a collection of 54 cards and we're still evolving which images we select, so we're in a study, we're recording which images get selected most often by patients. And these cards are actually being used *not* by the patients who have contributed by co-creating them; they're used by patients who've never seen them or been part of the project. They're coming to normal consultations.

We're doing a study with, I think it's 10 different clinicians in different specialties within pain medicine at UCLH, and in the facial pain team and pain management teams – and we've done a study group not using images and recording it. We've got use of a wonderful... it's an artificial hospital at UCLH, so the cameras are terribly discreet and hidden. And we're recording a baseline group not using them and now we're recording a study group where patients are given the images about 20 minutes before the consultation and then they're asked if any of the images mean anything to them or resonate for them in some way, or even if they can say that's *not* like my pain – my

pain is hotter or my pain is like this; it's not like that – if in some way they mean something to them.

They take those images in, and what we're seeing is can that change the type of conversation that clinician and patient have? Can it allow other aspects to enter the dialogue? There are so many aspects that I think get missed out if you're measuring it from 1 to 10 – it's not broad enough as a sentiment. And when you think the pain is intensified by so many aspects of our lives, if those aspects are not brought into the consulting room and discussed, and the impact pain has on people's lives, you're limiting the exchange that can take place. So it's not trying to say it'll be alright if the patient talks forever and tells their story forever, but it's trying to equalise that space, so that the exchange that happens between patient and clinician is useful and is shared. And my observation, which follows my hopes for it, really, was that when you have an image between two people, you have to negotiate.

We all interpret images differently, for instance, we had a session yesterday when we were talking about some of the images and there was an image with a lot of hands around a figure, and some people interpreted that as someone being very supplicant and asking for help from all these hands around. Someone else interpreted it as being actually some figure of authority or some clinical figure and there are all these hands trying to get help – so a complete reversal. But it means that what that image triggers in you is what's relevant. It doesn't matter how anyone else sees it. If it can reveal something useful, that you need to bring to that consultation and open up that dialogue. And it doesn't have to stay connected to the image. It's just a trigger.

Evans: Let me just try some of these images on myself. [**Padfield:** Uh-hum] Let me just look through some of them, describe them, and see what they say to me, and perhaps they say something completely different to you. Well, they *will* say something...

Padfield: They probably will.

Evans: They *will* say something completely different to you. I'm going through these cards. There's one here of a fist, a black and white image, a fist clenched, thumb under the forefinger. Now that says to me tension and a gripping pain – almost cramp.

Padfield: That is probably actually pretty close to the experience of the person who I made that with. I think there was a certain amount of anger, but there was the gripping and the sense of tension within it. Some of the images are more literal, and some are

more ambiguous, in the hope that you can project more of your own experience onto them. Joanna Zakrzewska is trialing them in her own routine clinics now, which has been really fascinating.

Sometimes she uses the images of the sparks, which are more literally a neuropathic pain or more likely to be a TN pain, but I know that she's also been discovering that what has been interesting is not always the cards patients select, but also the ones they don't select, or when they say 'it's *not* like that, it's not sparks'. And it's been particularly helpful with people where English isn't their first language.

Evans: I've just picked up this one [with the] sparks. It's three electrical wires and a firework coming out of it and I've just been talking to a lady with TN – trigeminal neuralgia – and that's exactly what she was talking about. If I'd gone to my GP and said, look, that's how I feel, I would like to think that my GP would say, 'I know what he's feeling', or 'there's something to start a conversation here'.

Padfield: I think there are two things that... The starting a conversation, that's what I hope is important – it's not an endpoint; it's the start and it's having permission to say it's like that and see wherever that conversation goes. But I think also, the other thing is you're saying you'll say it to your GP. If, hopefully, you said that 'my pain is like that' to your GP, hopefully they'll recognise it's TN. You would then be referred correctly and speedily, because I think what happens with a lot of people with facial pain and particularly trigeminal neuralgia – they wait an incredibly long time before they actually get the right referral to a facial pain clinic which deals with trigeminal neuralgia.

Evans: I know that images are used by psychologists to express emotion and things like that – and I'm thinking of a very famous image, Munch's *Scream*, which is so evocative of pain: sharp pain and anguish, and people might recognise that – but these are slightly different. Some of them come straight out, but there's an image here of an empty hospital bed with some words: 'invisible', 'confusion', 'not asked' and 'why'. Let me ignore the words – it says to me immediately not panic, but worry.

Padfield: Yeah, there's an anxiety.

Evans: I don't know what's going on.

Padfield: I think there's confusion, anxiety and some of the letters of the words are spelt back to front. I think I was making that with one of the patients from Bradford, and one of them was describing the sense of confusion around and hearing the voices and things talking about you on the bed and around it and it actually not making sense. I

don't think I totally understood that at the time and now I do because I actually *have* occasions where I will look at letters on the Underground and, I know the words, I can see them, there's no problem with sight, I can't make the letters mean anything.

But again, this one you've picked out, which isn't necessarily the most successful image in the aesthetic sense, in the gallery context, but in the clinic context, Joanna Zakrzewska was using this in one of the consultations – I think it might even have been one of our recorded ones – and the person who'd chosen several of the images actually held onto this until fairly late in the consultation. And then Joanna asked her why she'd chosen this particular image and she said she was actually worried about the anaesthetic and that's why she was terrified of surgery, so that then elicited a whole conversation about the reason she hadn't wanted to have surgery, which then managed to be turned around.

So I think if you can elicit things which maybe are difficult to say, the hope is that an image can give you permission to say it. And that maybe the image can give a feeling of rapport between clinician and patient, or the clinician can have a way of accessing and understanding it and hopefully that both speakers can shift their position a little. I think communication is successful when there's movement and there's a chance for *both* speakers to shift their understanding, and if that works in medicine, that's great, you can work together and both go forward to hopefully a successful treatment and management. I think when you've got an impasse, as so often you have, it's very difficult to effect that sense of movement and trust.

Evans: Now there's another image here of cogs and gears and spanners. My first impression when I first picked it up was – 'I have fibromyalgia – this describes what my brain does when I'm going through what I call an attack of fizzing and not being able to turn down, constantly bouncing from one side of my head to the other'. I've taken a second look at it – [pause] no, I've still got that same image. Now, I may not be able to describe that to a doctor, but talking about the image makes it so much easier for me to describe what's going on in my head.

Padfield: What were you going to say when you stopped, you looked, and you said, when I looked at it again, and then you said 'no'?

Evans: When I looked at it again, I saw a spanner and I thought, 'this is a broken body; this is a broken me. It's not my brain at all because I interpreted the cogs and gears as the working of a watch, whirring around all the time'. Now, I've seen the spanner, and I imagine it as the workings of a car and the car being broken. So that's two separate

images, but just by you *asking* me what did I not see, or what was I about to see, has brought the second image up.

Padfield: I think it's really interesting. You've picked up on lots of things that are within that image: it actually is a broken – literally, it's a broken clock – and I made it with someone who was very, very keen and knowledgeable about clocks. And he'd had a period where he died and was resuscitated. And when he was resuscitated, he started working with clocks, and clocks suddenly became terribly important – he started taking them apart and putting them back together again. So I think maybe there's a sense of this being, as you say, the body or the mind actually falling apart, and maybe there's a spanner in the works somewhere, if you take a very literal metaphor, but also maybe there's the hope that there's all this spiralling everywhere, maybe those cogs can be put back together.

And maybe the question is, who does that? Who puts this body, this mind, back together? Is it us as patients? Do we expect it all from a clinician, or can somehow we recognise that together, and actually both effect that movement forward? Because I don't think you can do one without the other; maybe we have to do more of it as patients.

Evans: Well, I was sceptical. Firstly, I work in radio, doing anything on art on the radio can be a [Padfield laughs] little bit of a nightmare, however, I'm incredibly impressed that I could carry one of your works of art, a photograph, a creation, around with me and hold it up to somebody when I've been trying to explain what my condition feels like, where I can hold a photograph up and say, that's how my brain works. That's how my arm feels. This is the pain I have in my head. It's so much easier than words.

Padfield: And how does that make you feel? If you can actually say, this is what it feels like, what change does that effect?

Evans: Well, it would make me feel a lot better about myself, less guilty about not looking ill. It would save an awful lot of explanation. What I and many people say when they say, 'gosh you're looking well'. I say 'Yeah, I'm fine'. Whereas, actually what you want to say is 'I feel total rubbish. This is how I feel: here's a picture of it.'

Padfield: Yeah. It's changing the expectation from the other person as well, isn't it?

Evans: That was Deborah Padfield.

Now, the feelings or emotion conjured up from seeing or hearing a work of art depend on so many stimuli, past and present, all retained in memory. So does memory have a similar role when it comes to the way we experience pain? Dr Rajesh Munglani is a consultant in pain medicine and lead clinician in pain services at the West Suffolk Hospital, Bury St Edmunds. Previously, as a lecturer in the University of Cambridge, he ran a research lab looking at the mechanisms of pain.

Munglani: I actually got into my research looking at memory formation and my initial question about that many years ago was ‘can you remember under anaesthesia? If you’re having an operation, can you form memories?’ And what we showed is that in fact, you can, in certain situations, form memories, despite the fact that you’re not aware of what is going on. That is called ‘implicit memory formation’.

Now, the interesting thing is, as soon as I started doing the research, I realised that *pain* is a memory. And it’s the same sort of thing that if you, for example, have a really nice meal at a hotel, and you [take in] the smell of the restaurant, you find that, to re-experience that rather nice event, say, a few months later, all you need is one smell, the smell of the food and that will re-evolve the whole atmosphere.

In the same way, chronic pain is a memory. It’s a circuit that’s been set up and it doesn’t take much to keep it going. You don’t have to have the initial trauma – say, it was an accident or an operation – you can have just very light touches that set the whole thing off or a certain movement, or a certain unpleasant experience that you experienced emotionally, and it will set off the whole pain experience.

If you say, ‘does that mean it’s not real?’ The answer is no, it’s actually very real, because everything in our brain is related to memory. That’s our identity. I don’t know if you remember seeing *Bladerunner* and the guy realises that the robots all have memories and they don’t know they’re robots, because the memories have been implanted and then he has to think about his own. He’s sitting there playing the piano and looking at all the photographs and it is really quite an important concept that what we’re dealing with and what we try and disrupt, if we need to, is that circuit, and there are lots of different ways of disrupting that circuit.

Evans: So I could go to a concert and I could experience the wonderful violinist on the stage and there could be somebody coughing next to me or somebody smelly next to me and I could go home and listen to the CD of that, and I’d have a completely different experience. Or, perhaps whenever I listen to that music again, I would have the smelly, noisy experience [**Munglani:** yes], not the full emotional...

Munglani: Absolutely. It's been modified, and you *can* modify it. And that's actually a very interesting way... you may have listened to that symphony in the past and you may have a really nice attachment to it, but then subsequently it's modified. One of the ways of an unpleasant memory being tackled is through the psychological approaches and what you attach to that memory subsequently and lots of different techniques are called for. And some psychologists will be able to talk about this in a better way than I, but, for example, reframing: you put different contexts around different meaning to that memory. It's very clever. It works for some people and it doesn't work at all for others. [For] other people, you have to just modify with drugs, trying to get rid of the circuit and other people of course...

What I do is spend my time finding the triggers, like we talked about the smell that evokes the restaurant. There are sometimes, *in the body*, little triggers that set off the central pain state and they're called 'peripheral triggers' or 'peripheral maintenance of central sensitisation'. Something from the periphery feeds in, keeping the whole thing going, and so what we can do as well as working on the central memory and modifying it through, say, psychology, through drugs, you can do something about the peripheral trigger. You can, for example, kill it off, numb it, as I do sometimes, Botox it, take away the muscle spasm, and we know that that is not the whole pain, but that's all you need is to take down the evoking of that memory.

Evans: Lots of people give the example – and you may have given it as well – that if I stamp on your toe and tell you, 'oh, by the way, somebody's stolen all your money and your bank has gone bust', you will feel quite a lot of pain, but if I stamp on your toe and I say, 'oh, you won the lottery too', the pain might not be so severe. So the pain isn't finite – it's the surrounding, it's everything else that feeds into it.

Munglani: Absolutely. The context of pain, the context of suffering, is very important. If you have a memory of a pain and it's associated with, for example, deeds of valour, and you came out of it well... I mean, when I treat military guys – this is interesting – the way they stand up to certain pains because of the context of the pain meant there was meaning to what they did, meaning to the outcome. Doesn't always work, but this is... It's not meant to sound condemnatory to anybody else, but if you have had that experience [of getting] your leg blown off; I've seen people who, for example, stepped on mines, had an amputation and still have severe phantom limb pain, but they're now riding horses, running event companies. They have got back to normal life.

You see others who have lost their leg in a road traffic accident – deep anger at the drunk driver involved, who caused this to happen. And the focus for them very much

becomes the court case, the anger at the driver being allowed to go off with a relatively little fine, which often happens and they've got the pain in the leg still. So you have this awful situation of trying to help them move on from that experience and, of course, that is where reframing that whole experience – trying to get them to come to terms with the pain, is part of the healing process in letting them move on, and people *do* move on.

But sometimes you get stuck. You can get stuck physically because the pain is just too severe to deal with. One of the issues is if the pain is that severe, your brain cannot move on because the trigger, say, the stump is painful – every time the stump hurts, it triggers the whole phantom limb experience; it triggers the memory of the accident and you can't get them to move on and they can't do it for themselves. So this is where lots of interventions [are necessary]: do you numb the end, do you kill off some nerves, do you put a pump in their back? As well as helping them move on with, say, the court case, the medical-legal process. All of that needs to end to help them move on with their lives, otherwise, they're trapped. They're in a prison.

Evans: The examples you've given give fairly clear reasons why the pain has started in the first place, but I know you've written a paper on diagnosis and the effects of diagnosis on people with chronic pain.

Munglani: The issue about diagnosis has to be seen in two or three different ways. And the first way to say is that a lot of people wander around in pain and they have no idea what's causing it and most doctors don't understand what's causing it. To give those people the dignity of a diagnosis, I think, is terribly important because it validates the pain and the suffering they're going through and that's important.

But pain isn't the same thing as disability. What we know for *some* people is that when you give them a diagnosis, they look it up on the internet and they think, 'oh my goodness! This is how I'm going to end up'. And the worry and the fear actually promotes disability.

So there is a distinction between a diagnosis and a disability. The two aren't the same at all. In fact, if you look in scientific terms at what is known as a correlation coefficient, i.e. how likely is it with a certain diagnosis, you'll have a certain level of disability, there is virtually no correlation. And that is quite important because what it says is believing people, giving validation to their pain experience by giving them a diagnosis, the dignity of a diagnosis is important. *But* you can use that moment then to help them move on and reduce the disability.

The unfortunate option is that people can get stuck looking on the Internet and looking at what horrendous things may happen, and they become fearful. And I think Job said in the Bible: 'that which I greatly feared has come upon me'. And it is amazing how we are sometimes trapped by our fears. But it also gives us a way forward; that's important.

There's no judgment here, and I emphasise that again – there is no judgment. If you look at all pain mechanisms, we are dealing with *such* a complex issue. An important thing to understand is you *can* move on from these situations, if there's a willingness there to move on. Sometimes it's incredibly difficult and this is why pain therapies sometimes take a long time; you have to go through various trials to find what is the right approach because there's such different ways of maintaining that pain and the disability that comes along with it.

So, for example, the medical-legal situation is one I'm very aware of because I do so much medical-legal work, is that people get trapped because fundamentally, the money you will get at the end of a court case has to be based on how much disability you've demonstrated – not just simply on the diagnosis. [For] the diagnosis there are certain amounts of money you will get for, say, chronic lower back pain or injury or even spinal trauma, *but* what actually makes the difference and where the big money is, literally, is in whether you can work in the future and what your care costs are – that is where the big money is. So, what is related to not working and how much care you need? Disability.

So the disabling effect of a medical-legal process is profound. And we know for some people, the only way to get them to move on is to end that process as soon as it is humanly possible. For me, then we've seen cases where once the court case ends, the people can move on. In fact, one or two people improved so much once the case had ended that the insurers in one case went back and asked for their money back because this guy got out of the wheelchair. It was a big, big case. And the interesting thing is, the court refused because what they said was no, we decided this is how disabled he's going to be and we said that there was always a possibility he might improve with treatment, and there we are, but he's improved, so there we are, but the money that we've set aside is there for him.

And it was almost a relief to some people because what it meant was that if you had finished a court case and you then got a bit better, would you always be fearful that the compensation you got was going to be taken away from you? Because if it was, think how disabling that would be: it would mean you'd be trapped into a cycle of

appearing disabled or *being* disabled for the rest of your life, so that people would still believe that you were injured in an accident. And so it was quite an important case.

Evans: It's incredibly important because anybody who's been through this – through tribunals or whatever – will tell you how stressful it is going through it. It's box-ticking: you feel you're box-ticking. 'Can I walk? Oh no, I can't walk. But what if I walk tomorrow?' 'Don't even go there. Don't even get out of your wheelchair.' And it is enormously stressful.

Munglani: Absolutely. The assessments that a lot of people are going through at the moment through the disability assessment forms from the government – because there, as you know, there is a very strong political drive to get people off disability benefits and back to some sort of work. And in one sense, I applaud that.

The issue is, with pain, I cannot feel your pain; you can't feel mine. And the actual presentation of disability is dependent on so many factors and, as you say, it's not whether you can walk, but how far you can walk. So I would say there are two things: there's capacity – whether you are able to do something at all – and endurance – how long you can do it for – and that, unfortunately, is not really taken into account.

The fact that you can probably pick up a heavy weight two or three times in a day is fine, but you couldn't do it thirty times seems to be lost on a lot [of people], or certainly they choose to ignore that fact, that most people can do something, but they may not be able to do it for very long. You can do a bit of gardening but you can't garden all day long and end up with backache.

This is one of the big issues we have in [the] medical-legal process: how much you can do and for how long you can do it. Simply being able to walk doesn't mean you're going to be able to work again.

Evans: And for many people – 'yes, I can do it all today and I may be able to do it tomorrow, but I can't tell you about Wednesday. And if I do it today, I can tell you categorically that I will be in bed next week.'

Munglani: Yes, yes. And as you know, this leads... Jumping to the solution of what's known as 'pacing'. And rather than having the up-down, yes, you do a dramatic amount when you're feeling a lot better, and then you collapse in bed for two or three days. And then this undulation between the stop/start and you try and regularise that...

I'm not sure, actually – I'm probably going against the grain a bit here – I almost feel it's very good for the person to have that day of absolutely doing... I mean, I have patients, for example, who are young and in chronic pain and they go clubbing on a weekend, but it does mean that for the next three or four days, they can do virtually nothing. But on the day they went clubbing, they felt alive, they felt normal. And it was terribly important for them to do so. They don't want to live in the mediocrity of pacing, they went to go to the dizzy heights of dancing for an hour or so and then they know that for the next few days, they're not going to be able to do anything.

But the interesting thing is, say they were on disability benefits and somebody caught them in a club dancing – and that has happened – there's cases where, for example, people have been claiming disability benefits and they've been caught dancing at a wedding.

Now, does that mean they weren't disabled? And the answer is, I don't think so. It's not as simple as that. Sure, there are cases where there is fraud, but actually, many times, it's because it's their daughter getting married or their son getting married and they want to celebrate at that point, *knowing* there is going to be a cost for them to do that, say, for the next few days, they'll be in bed. But I think it was important for them to dance at their son or their daughter's wedding, so whatever for that individual gives them a quality of life, that's important. But you have to have an understanding society around you and I think that is being lost at the moment.

Evans: Dr Rajesh Munglani.

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I'll leave the last words on the changing relationship between patient and doctor to Dr Rajesh Munglani:

Munglani: The patient has to be part of the solution and this is where, in pain particularly, the previous paradigms of what is a doctor-patient relationship... As a consultant, I know when I first started, what I said basically went. We would say, 'this is the solution for your problem' and you'd do this. In chronic pain, you can't do that; you have to be far more flexible. This is why I very much support, for example, the Expert Patient Programme – enablement; empowering patients to help be part of the solution. And it's not in a sort of fuzzy-wuzzy, sort of well, let's all just hug and hold each other's hands – it's actually a very fundamental difference of how we manage a condition which we know, unfortunately for many, has no cure.

So we have to find a way forward that gives you a quality of life. And sure we can modify the pain by injections, drugs, psychotherapy, etcetera, but in the end, the final common outcome that we all want is a quality of life for that person. So we have to say, what gives you pleasure in life? And what gives you pleasure may be completely different... If looking at model railways is what turns you on, great, but if it's going clubbing, then fine and you're going to have very different solutions for that process. So [it's about] deciding what is good for you.

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