

# Special Interest Group for Philosophy and Ethics

# The Power of the Mind in Pain

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## Introduction

## Peter Wemyss-Gorman

The impetus for the first meeting in 2001 of the group which later became the British Pain Society Special Interest Group (BPS SIG) for Philosophy and Ethics was the perception that pain medicine had become more and more dominated by the search for understanding of neurophysiological mechanisms which would lead to the perfection of pharmacological therapy, and the refinement of physical interventions in the hope that they could be relied upon to provide long-lasting relief of chronic pain. Despite many successes in these endeavours we still seemed to be spending more and more time in our clinics dealing with people with complex problems for whom all our therapeutic resources had been of little help. Pain management programmes had helped countless sufferers to enjoy lives less dominated by the tyranny of pain and to reverse the psychological and physical vicious circles that tended to perpetuate it, but the sum of our patients' suffering nevertheless seemed to be only a little diminished.

There has indeed been progress, notably in the field of neuromodulation, in the intervening years but the impression remains – indeed has grown stronger - that pain medicine is approaching an impasse, and that it is difficult to be optimistic that such progress will continue indefinitely. So it seems imperative to explore any new approach that holds even a glimmer of hope, or at least promises to point us in a new direction.

In this context, the astonishing power of the placebo response and the therapeutic value of hypnosis have long been recognised but there appears to be a far bigger untapped resource of power for healing, and dealing with pain and suffering, within our own minds than we have hitherto realised or even imagined. Our speakers this year set out to demonstrate this in one of the most fascinating meetings we have ever held, presenting evidence that the most hardened sceptic would find difficult to ignore, and leaving us with renewed optimism that even if we may still have a huge mountain to climb, we may have found one promising route.

What is more, it seems that this power to heal and transform is latent both in ourselves and in our patients, even those that most make our hearts sink – and can be manifest in the interaction between us in the therapeutic encounter. It even seems possible that it can operate at a distance!

## Transforming Suffering: The Movie of Pain in the Cinema of the Mind<sup>1</sup>

## David Reilly

I doubt if anything I have to say will be truly new to you. I think my job is to try to create a reflective space so that we can come afresh to our thinking and to our work, and to a dialogue together.

I imagine that we all accept the central importance of therapeutic encounter. While we may differ on the practical goals and methods we call on, we can find a unifying foundation emerges from the question: What is this meeting in the service of? All our efforts are in the service of the relief of human suffering, and beyond into flourishing. That is our business: working with human beings restricted in some way – wanting to be free, externally and physically whenever possible, but always at an inner level - at a spiritual, personal, emotional level.

Many of us have come from the business of pain management. I think we are collectively beginning to face up to the limits of the models we have been operating in, and the maps we have been navigating by. The call for us now is to become experts in suffering rather than in pain. But we were not trained in this, and we have been attempting to apply the model of pain to the domain of suffering. That would be something I would lay in front of us as we wander into the whole question of suffering and what suffering calls for. Suffering is a call: it is a call for change at any level of our being: culturally, systematically, in our teams or in our own lives and families.

For me suffering has ceased to be the enemy that needs to be eliminated. It has become the guiding call. You can't talk about suffering without speaking of change, and indeed *transformation*. Transformation is the theme that I would like to explore together.

The crucible of change is often relationship: relationship with yourself, and, critically, with a trusted other. This must become a safe relationship. Yet few would now disagree that this human side of care is under considerable and unacceptable levels of strain in today's care systems. When we think our job is about suffering, release and transformation - and so, humanity and relationship - and the very substrate of it is under unacceptable strain, we realise that we are already in a dense predicament. At the simplest level (I don't want at this stage to go into any lengthy dialogue) what do you see as the cause of this?

### [Participants comment]

The clash of managerialism and professionalism.

<sup>&</sup>lt;sup>1</sup> An adapted version drawn from this this presentation is published as: Reilly, D. (2016) 'Suffering as a guiding call towards transformative change: the movie of pain in the cinema of the mind', *Pain News* 14(4):164-70.

Managerialism is management without presence; management is about the present, leadership is about the future. When we sit with someone it's about an orientation - a pointing to the future and a hope that the future can be better than the present - that they can be released from this suffering. It's not just an embedded now; it's a meeting together within that framework of movement. That is going to imply continuity, safety and a whole range of other things.

A national health system which is not a care system.

Undervaluing the carers.

Measuring success by numbers.

We are all specialists and a person may have multiple people dealing with little bits of them who are not whole person centred and nobody holds it together.

What do you think are some of the deeper roots - does anyone want to take us back in time?

Back to Descartes?

Spiritual roles have been subsumed by medicine.

Yes - a general *collapse* of spiritual enquiry, at least in the structural sense.

Modern medicine does some things very well but some things terribly but we continue to pour huge resources into drugs and procedures and things that are done terribly.

This is our predicament: our desire to engage with others for the relief of suffering is itself embedded within a context which can be road-blocking or destroying of the very the work that we want to do.

What we are saying here? This is a call for fresh thinking and I am saying that suffering *is* the call for change, for growth, for fresh thinking and movement. And that is why people come and sit with us. We are change agents. Again we didn't think of ourselves in that way and we weren't trained in processes of change, and we find ourselves adrift in many ways.

Let me pick up some of those themes and go back to the cultural transitions that started with Descartes and the dawn of science in the 1700's, and the massive waves of change within our culture – waves that shape and respond to the nature of our personal and collective suffering. As our suffering changes, the nature of the necessary response changes. Let's go back: what would have been the epidemics of the day in the 18<sup>th</sup> century? Cholera, smallpox and all the infectious diseases would have been very dominant. There was periodic famine in the countryside, especially in Scotland accompanied by migration into the cities, with 14 or 15 people to a room, poverty, starvation and dung-heaps in the streets. Cholera was killing 4000 people a year as it swept through the cities of the UK.

How did change come? Someone dreamed and changed the world with imagination and vision. If we have lost the vision of the possibility of release we are road-blocked. (While I am speaking on large scale here, all the principles we are exploring apply in a single suffering person's life). People said of cholera: "it's just the way it is, an inevitable part of modern life; it's part of the human condition; it reflects the sort of person that lives in that squalid way". And then my city of Glasgow dreamed of a clean water supply to the city. How do you think this new idea was viewed? – This fresh idea that might release the culture from the epidemic it was in? Well, it took 25 years before the Loch Katrine water supply opened, because people blocked its progress saying it wasn't technically possible, it wouldn't work, it couldn't be afforded. The year after it opened cholera swept the UK and thousands died but in Glasgow the death toll was reduced to just double figures.

Transformation: that is what someone coming to sit with us is hoping for at some deep level; movement. But it will require a shift, a shift of 'map' (my wee term for a very rich field). Transformation and shift will need to be occurring before the evident movement. And so over recent centuries, we dreamed up waves of public health innovation: of public works and other fabulous inventions; dreams involving creativity and social dreaming like the NHS. We dreamed up professions. I have to remind myself of the fact that *it's all made up*. It feels as if it really exists but it's all made up - doctors nurses physios, the NHS - it's all made up. So we can make up different stuff. But the mind doesn't like that. The mind wants its 'realities', its concurrent map of the world. We try our best to respond but we are up against the restrictions of mind's design.

What are today's epidemics?

Depression.

One in four of us having some sort of mental health difficulty. Loneliness.

Obesity.

Two thirds of us overweight and a rising percentage formally obese.

Dementia.

One in three of us; some people calling it diabetes type 3.

Drug dependency.

Chronic inflammatory conditions; chronic fatigue, chronic pain.

For how many of these do you go to the health system and it does something and you are fixed?

[Laughter and silence]

We haven't woken up to this.

# Is the problem that we are too focussed on methods and mechanisms instead of compassionate care?

I put it to you that it's like Glasgow and the cholera epidemic ... there was a call for more palliative care, more resources, because we've got to help people who are

suffering, we've got to fish people out of the river, of course we do - but any amount of that hard work would not and will not transform the underlying epidemic.

### Waves

We can put it in the metaphor of great waves. There have been four to date: Wave one was that of great public works and municipalism in the 1800s. Then Wave two in the early 1900s accompanied the refinement of the scientific approach including the germ theory of disease and the growth of hospitals and the introduction of health visitors. Wave three around the 1950's saw the restructuring of institutions, welfare reforms, new housing, social security and the infancy of the NHS. This was followed by wave four with a focus on the risk theory of disease, lifestyle issues (smoking, diet and physical activity). Now, we are awaiting the next wave – the Fifth Wave – as its been dubbed, because the diminishing returns from the four waves in the face of the rising tide of the epidemics of modern life is a call for change. And that is correspondingly true of personal suffering. If we are still suffering, we need a new wave of approach.



(If you are interested in the origins of the ideas I am offering here you can download the Fifth Wave report from the Public Health Institute of Scotland from <u>http://www.davidreilly.net/HealingShift/The\_Fifth\_Wave.html</u>; as well as Davies *et al.* (2014) *For debate: a new wave in public health improvement,* Lancet 384, 9957: 1889–95, and the *2015 Review of Public Health in Scotland* pages 13-14.) Subjective Change Within The Inner World Of Consciousness

Where is suffering? If you ask people they will say they don't know, or it's in the world 'out there' in their situations and in events, or, it's in their body. That is typical of where the dialogue begins: the external versus the internal. It helps to get clear that suffering is very distinct from pain. Suffering is a mental state. Pain hurts, now add a story, a movie of the mind, and you have suffering. The key point is that mental states are always up for change – even if the pain isn't. To say that nothing can be done about human suffering is always nonsense, even if the pain itself cannot be modified. And our art form and science and skill, and our maturing as a practitioner, lies around this area.

[At this point the audience was shown the same identical video clip twice, of a taxi ride round New York. The first viewing accompanied by some fast discordant spiky jazz, and the second to pleasant classical music. The first induced a feeling of anxiety; the background and the people they passed somehow threatening. The same pictures the second time induced a feeling of calm and happiness and the people looked reassuringly friendly.]

So you have had a change in mental state - your inner world has just changed. After the first showing you wouldn't want to stray far from the safety of your cab and hotel, but after the second you might want to go for a walk and breathe in the humanity. We've just had a shift in the whole of you: your mental state, your experience, your emotion, your physiology, your perception, your processing, how you are going to perceive and engage with the world. Can you begin to link this to the question of suffering?

# I understand suffering as a combination of negative things...pain, tension, stress, relationships, financial issues; all of these things combine to create suffering.

There are situations/predicaments: 'New York'; and then there is our mental state. You list pain, money and relationship as the predicaments of someone's life, that's their reality in this moment – but then there is their tension, stress and suffering which I am saying are the reflex responses to the mind's soundtrack, its 'take' on the situation, its 'story' of the predicament. So, what is *your* soundtrack? What is then the movie like, playing in your head?

I often suggest to people that their view of the world is like putting a filter on a camera lens so certain things make you feel in a certain way because of the filter, so let's work to change the filter.

Yes, and who put the filter there? Not you. Did you *decide* to be tense in the first ride? If I say: 'Just think more positively ... use a bit of will-power and commitment ... take a more positive attitude to your life ... pick yourself up ...come ON!' - is that working?

And see that switch in you with the second movie: did you *decide* to switch at the second one? No, you had absolutely nothing to do with it.

#### ... you can decide not to switch ...

... can you? This is critical. Once you understand this mechanism and its automatic its given – nature we can then begin to wonder how best to interact with it. We can begin with stepping back, mindfully, beginning to seek understanding about our automatic perceptions and thinking, about our maps of the world, and from there begin the practice of questioning it. And that, of course, is very central to an individual starting a journey of change. But I think we have to have the humility to accept that that we have a mind at work and that it is reacting (and always negatively at first to what it does not like or want). But we are not our minds. Can we command this mind with its three and a half billion years of evolution behind it? This mind is stronger than us in that sense. And we have to get savvy about that in order to understand that, like King Canute, we cannot command the waves of the mind to not react. That doesn't work - (at least for us ordinary mortals that are not master practitioners). But we can grow our awareness of the fact that we are in a soundtrack. And this awareness is the foundation of the shift: "Oh my God - do you mean I'm living in a soundtrack?" Now the mind doesn't want you to get this - it would rather remain in charge as it sees it. The mind doesn't need you, it can react just fine without you. But fortunately, you are more than your mind.

You know that we've all got a voice in our heads – a running commentary. It's not only people that are psychotic that have voices in their heads! But who is listening to it? When we attempt to describe someone's direct experiences words will fall into inadequacy, but that's the way it is. This is why I am trying to route us into some direct shared experience lest we go more astray into some left-brain / right-brain analysis. So there is a voice in the head but a larger part listening that can even say "Excuse me – can I have a word?".

#### The first soundtrack was made 200 years ago ...

... or a million years ago? ... first aroused by the threat of predator? When that happens we know the amygdala activates linked systems, and one of the things that does is to shut down elements of the frontal cortex, like its saying "you leave this to me!" And that is one of the reasons why what you perceived in the two videos of New York was different, because automatic systems are deciding what is relevant to your safety in the face of the threat. And this is true of the person's consultation with you – or of your marriage. These are very powerful systems - but we don't just have to be their passive slaves. It's where the potential lies.

Where is the world? For you, it's internal. You know the universe only through the content and process of your own consciousness. You live in a representation of the world. Think about the physiology - think about the image on your retina and its transmission: this electrical and chemical stimulus and its reproduction and recreation of energies inside with the filters on. That is the world that you know. The only world that we experience, and the people we sit with, is this internal world. Subjectivity; the first person; witness. Something, I want to suggest, looking at that 400 year map, retrogressively was dropped out of the picture with the rise of science.

## Transformation and consciousness

We have just looked at transformative change in action. This is not some esoteric concept. Human beings have built on these capacities for unbelievable shifts. So when I sit with someone who comes in I tell them I have only one rule which is that anyone who kills themselves under my care will be discharged immediately! I only have that one rule because I *know* that that person in front of me has the capacity for transformation. The only clinical sign that I need is that their heart is beating. So the puzzle for me has become quite different from that mechanised medical model, although I value it and still employ it sometimes. Transformation of the inner world in which we have just had: two New Yorks.

What is consciousness? We don't have a clue.

Nobody has the slightest idea how anything material could be conscious. Nobody even knows what it would be like to have the slightest idea about how anything material could be conscious.

(Jerry Fodor, philosopher, 1992)

Consciousness manifest is, in the deepest sense, who we are - but when we try to explain or analyse it ... whoa! There are two models: The first, the emergent view, postulates that the brain produces consciousness as an epiphenomenon; it just sort of happens. This is a promissory hypothesis. There has always been an alternative model. One of the most shocking thing I have ever heard was at a world hypnosis conference in Glasgow where a member of the group introduced the idea that we think we can prove the origin of consciousness because if you cut here in the brain a function stops, and if you stimulate here a function happens. But say I take a television and there are things happening on the screen, and then I go in and cut some wires stuff will stop happening. Does that prove that the TV is the origin of the things occurring on it? Of course it doesn't. This other camp suggests that the biological apparatus could be in some way be a filter in itself; a mechanism for transmission of consciousness which is greater than that biologic apparatus. I'm not talking about an entity; words are useless here - more a sense that all living beings share consciousness of some nature. So we have this second model, the nonemergent view that the brain transmits consciousness – which is "latent in the deep structure of nature: before brain, mind was" (William James, 1898).

The Buddhists talk about monkey mind and Freud talks about the ego and the true self. Is the ego like the consciousness we are aware of and the true self the mind bit?

The ego – is the mechanism and result of the movie, the soundtrack, the story, the narrative: But - who would you be without your story?

Try this – try sitting here without your story - just for a moment. [Pause]

#### We're free!!

OK take your story back ... the 'what happened to me, what might happen to me.' Past and future are part of the egoic structure, the virtual mind. It needs identity, it needs story. This is a mechanism.

Try closing your eyes for a moment and completing this sentence: I am ...

Me.

My body.

Mother.

#### Wonderful!

Now close your eyes and try thinking of this: a two word sentence with a firm full stop at the end of it: I am ... Gently repeat it if need be. [Pause]

#### What happens?

Tuned into ... sensations in my body ...

My heartbeat slowed.

Relaxed.

Did any of you have a sense of peace or stillness? Was there any sense of a cessation of the voice in the head? ... Just for a moment? [*Agreement signalled*.] That's who you are. You don't have an identity in your true self. What you are is *alive*. All the rest is a story – sweet and sour, rich and poor and so on, but for God's sake don't think you are the story of yourself, your identity or the state of your mind or your body; or else, *welcome to suffering*. And what a relief to know: I am.

That stillness, was described in the western spiritual traditions as heaven, as the inner Kingdom – mind you, that was before the West got carried away with anthropomorphic tales of places in the sky. I consider that Wisdom traditions have been providing guidance into the nature of consciousness, and the evolution of our relationship with consciousness. Peace ... 'I am' ... that's what we are searching for. That's what everyone longs for. Contentment, deep happiness, peace, release. And that is why we run around like blue-arsed flies in New York in search of what was there all the time. But mind doesn't want you to find it, because that egoic structure, in that moment of I am, considers that as a moment of annihilation, like a death, and has to keep you in the story and has to keep the story alive.

You have to live in the inner world – your own; to quote a Wisdom tradition: to 'be in the world but not of it'; to know the mind and its business, its drives and needs, the things it calls success and achievement and satisfaction and safety ... and eventually to be able to say, as to a little child: "Sweetheart, come here!" – "but I'm no good, I'm a failure, I'm no use, terrible things are going to happen" – "Sweetheart, come here". This relationship with mind is so important in the journey out of suffering: we're going to have a mind that's going to behave like a mind, to react like it did in New York; it's going to crave, to fear, that's its nature ... "Come here sweetheart, let's sit down."

And so this inner world, which is the world where suffering and peace live, which we are all living in and want to find resolution and ease in; how much over the last 400 years have we been studying this inner world in our medical and healthcare system? Let me go back before Descartes to Galileo:

... if the perceiving creatures are removed, all of these qualities (tastes, odours, colours etc.) would be annihilated and abolished from existence. (Galileo, 1623)

See the 'I am' here? This is what the spiritual traditions would call emptiness. The ego is terrified of that. Then we have the perceiving creature. Galileo understood the centrality of including this. It is not the reductionist materialism that followed and came to dominate for 400 years – the active discarding of subjectivity. And do you see the continuity into our pain management, the world of pain and mechanism? ... Let me see this, treat this, block this.

Let me go back to the same century and another tradition: St Joseph of Copertino, offered the view that what counts is "the heaven of the interior life", not "external devotions". He said the important thing is learning "the spiritual philosophy. Others may study natural philosophy and learn to know the things of nature but do not learn to know themselves."

I have found these themes that we have been touching on to be utterly central in my patient work. I may not be using this vocabulary, this language, but this is the territory I am in when I am sitting with people. I worked for ten years at one stage in the pain relief clinic at the Royal Infirmary in Glasgow, and the deal was that I would see people if the clinic had failed to help them. That's where I really did my training. I would sit there with a person for whom the toolkit was bust. I'm not knocking the toolkit; I'm just saying that there are a lot of people, as you know, for whom it's not adequate and I had to start again. And it would be in these realms that I had to start re-training myself.

Henri Bergson, a French Nobel laureate philosopher, suggested this thought experiment:

Imagine... we had four hundred years of research on the inner world, the mysteries of mind, soul, and consciousness.... instead of researching the science of matter... (Henri Bergson, 1913)

Wow – wouldn't that be something - as if we could be sitting here in that culture. Note that it was a hundred years ago he said that. This is a very old story: that we will approach human suffering in a fix-it manner; this external objectification of it – fix-it is a wonderful thing in its place: I'm not saying either/or, and we shouldn't reject what we have learnt and valued over these 400 years.

fMRI scans of people first seeing and then imagining familial faces and places show that the same brain areas are activated by the world 'out there' and the world 'in here'. It seems in physiological terms that when and where the mind leads the body follows. Say you are out walking in long grass and you stand on a big snake. What happens? You stagger back and you look down and only then do you notice that it was a rope! How do you feel now? (Apart from stupid.) What has happened to your fear reaction? It dissipates. What caused it? Not the object on the ground but the movie, the soundtrack, the perception, the take. And whatever the take, the body and the mechanisms of the mind follow - it has to, it's not personal. We must be careful about some sort of false 'positive thinking' about *choosing* your reality; no, you are going to react. So what are the snakes in your life? You've all got them. What if they are all ropes? What does your mind say to you when I say that? It rejects it. It's got investments in the movie, in the story. If you think of all the movies in your mind, you are always central in them, either as hero or antihero, maybe as conqueror or victim, maybe as humble martyr or triumphant leader - but your ego is still in the middle. This is the world of the person sitting in front of you - the New York they are in. *Just like me*. I use that as a very important mantra in my work. I find that usefully humbling: Just like me. We've all got one mind. It's all the same biology. We all have the same instincts; we're all subject to the same reactions, the same fears. You may not be in the same movie that they are in - but can you just get out of the one you are in?

In a study by Derbyshire *et al.*<sup>2</sup> of 'hallucinated' pain suggested under hypnosis, all eight subjects reported heat and five reported pain, and showed brain activity on fMRI in the same areas as with physically induced pain. Additionally, in suggested pain, some areas of the primary somatosensory cortex were also activated. But when they were asked to just 'imagine' pain there was only minimal activation of the pain network. Compared to just trying to imagine, the researcher directed and wrote the score for a crafted soundtrack, and the subject trusted them enough to go along with it. The brain isn't the origin of the movie – it's just the cinema in which it is shown. We get shown brain scans by people who opine because an area is activated "that's why this person is have pain". But if I showed you a horror movie while you are in a scanner, a whole set of circuits will be lit up; are you scared because of those circuits?

Of course there is no such thing as imagined pain – we all know that - because pain is a subjective experience, if I'm feeling it, I'm feeling it. But we can be trapped within the movie. It is possible to experience pain in the absence of direct stimulation. And there is evidence of possible direct cortical involvement in some clinical functional pain disorders. But it is quite wrong to suggest that people suffering these are weak or manipulative or putting it on.

## Hypnosis

I spent three or four years using hypno-analysis with regression and image generation and drama and such stuff. I loved it and I learned a lot, but eventually a twenty-two year old patient called Andrea came to see me whose bladder had been erratically paralysed since she was seven. It "would not let go" then just erratically empty. They had done cystometrograms, putting the dye in and waiting for reflex contraction of the bladder - which it should at brain-stem level - but they abandoned these as the bladder wouldn't contract. So they repeated the study under general anaesthetic; I think they thought it was sort of 'psychological' and if they knocked out the higher brain functions it would be different but they got the same result: the bladder didn't contract. So when she came to me she had a card with her for her operation to remove her bladder. Our first consultation together generated a dream that night for her in which a memory returned of someone looking in toilet windows when she was seven. She was strongly convinced that this insight would cure her. It did not. Some months later at our second meeting I suggested hypnosis - suspecting the issue was stuck at a level beyond conscious access. She said "I don't do hypnosis". You know how when you study something it can first expand you, but then it traps you within its own limits and discipline, and you see everything through the

<sup>&</sup>lt;sup>2</sup> Derbyshire, S. W. G., Whalley, M. G., Stenger, V. A., Oakley, D. A. (2004). 'Cerebral activation during hypnotically induced and imagined pain', *NeuroImage* 27: 969-78.

same filter? So I just hit the wall and didn't know what to do. There's a wonderful moment when you're dealing with suffering and you don't know what to do, and you see a crack that lets the light through. So in that moment I asked her: do you ever daydream? She said "all the time" so I said let's just daydream then. So we sauntered off (the origin of this word is 'holy ground' – the pilgrim's travel) into I didn't know what: eyes open, just chatting... Memories were revisited, feelings acknowledged, words of safety spoken. The next day she had a massive evacuation of her bladder and from that moment she was cured – the problem never came back. Also, she had been told she could not hold a pregnancy because of the swollen bladder, but had been trying unsuccessfully for some time to get pregnant: she got pregnant at her next cycle after she had healed. That child has now gone on to study medicine, inspired by her mother's transformation<sup>3</sup>.

So what is hypnosis? When you watched that movie earlier - was that hypnosis? Yes, if you want to call it that. I began to realise that every word and phrase is a movie script to the mind. You tell someone they have arthritis: that's a movie script; maybe for them it's the auntie that died; the crumbling spine .... So hold respect for this and monitor the words being used by the other and by yourself. See how alert you were in the first New York? That's how the client's mind is - scanning. I have learnt so much from patient scenarios where I can't help as well as I should, but I sit with someone with both our eyes open, together, in the space, connected: an integrative space, larger than critical analysis.

I always believed that the key of healing is in the patient. I don't know where the key is and neither do they but you give them the opportunity to find it. You had this moment with this woman when perhaps you provided the right environment to go that little step that they were afraid of for whatever reason. It's a great moment. But it's difficult when you're sitting there trying to analyse it because that blocks everything.

Agreed. The essence for me is in the image of the seedling. We are grateful for the former models of the external expert coming up with a solution: the clean water supply, the cultural structures and so on, but as we have considered already, in the modern epidemics that's not working. The shift that I had to take was from being Descarte's watch repairer, to being a gardener of human potential – from just seeing the brokenness to also seeing the strength within the individual. I know it's there - but how can it be released? A gardener doesn't make a plant grow. I don't know what makes plants grow (I don't even know what life is) but we can be gardeners. We can begin to understand what makes life behave and the conditions that affect it. We can get quite expert at gardening, but that doesn't solve the mystery of what life is and why seeds germinate. A plant knows how to grow; this is fantastic and we don't have to know. The key thing for us is to set up the right conditions and then we see it unfold in front of us like a mystery. We will see things resolve themselves that we never touched on directly. I find this a very releasing image of what we are doing when we sit with that individual and drop that god complex - and also drop that sense of failure when we are hitting with our favourite hammer and the nail's not going in; we just let go.

It works both ways. You mentioned that awful word 'crumbling'. Telling someone their spine is crumbling doesn't help their pain and can ruin their lives.

<sup>&</sup>lt;sup>3</sup> This story is built on in my TEDx talk, Human Healing Unlocked <u>https://www.youtube.com/watch?v=LUFgxkBPh4Y</u>.

Agreed. Quite a number of people come to a pain clinic with direct iatrogenesis. You know, those, to us, 'throw away' remarks: "things are fine, just a wee line on your Xray, but that is likely of no consequence...": enter the first New York! And that is a biological mechanism triggered and it is not going to just come off. It's a safety issue to the mind. The person may be reluctant to acknowledge fear, emphasise that they are positive thinkers and don't dwell on things, but in the back of their mind a voice is saying "it's a snake ... it's snake." And unless that situation is touched on in a way that will help to unlock that, you will be wasting your time. And there are more extreme situations when you encounter what I have nicknamed 'sentinel side-effects'. where a person has an adverse reaction to everything you give them ("you almost killed me doctor"). I actually think that is the person innocently witnessing the real phenomenon in their mind-body that is rejecting your treatment, or any other attempt to turn off the fire alarm or cut the wire to it. The protective system is saying "you need this pain because it is your safety signal, because you are in danger; they've missed something, your spine is crumbling ...". We need to aim to understand the mind's childlike thinking in this dialogue, active in the presence of an otherwise adult person. That is a fascinating and delicate adventure.

## Change

It is impossible to create a world that differs from your (unquestioned) inner map of the world. You are up against evolution and biology. If you take New York to be the first New York you are going to be living in hell. You're going to work really hard and try this and that therapy – that's most of us most of the time. If the map of New York is of a place of threat, despite all your hard work to deal with it, for real change the map is going to have to change. So just reflect for a moment: could the 'snakes' of your life be ropes? But this invites the mind's response: "what does this man know about *my* life? In *my* case it's a *real* snake!" This is a belief – indeed almost a religion (in a mechanical sense). And to achieve transformation we have to get to some of these maps and mechanisms and be part of the processes that facilitate the shift.

I'll try to bring that to life with a wee bit of physiology. The first time you think a thought, as far as we know, you have to hard-wire it with neuronal connections; it becomes a physical object in that sense. In the cinema of the mind thoughts make wiring. But at first they are tiny tentative connections (but are stronger if much emotion is involved at their creation). The more you think that thought, believe this, act out that way, live that way, support cells start to lay down myelin wraps around the pathway, eventually up to 30 to 50 wraps; and when this is maximally myelinated as a path the signal is going to be transmitted thousands of times faster than when it was first formed. This is now *embodied*. It doesn't need you anymore; it is a habit or a reflex, or skill or a belief, or philosophy or whatever you like to call it. So when we are talking about change we have to be aware of this deep relationship: the physicality with the biology. And therefore we can know that the journey over time may be for some people quite long, difficult and relapsing, as the old well-grooved soundtracks keep reasserting themselves. And we work over time to try to remyelinate, to strengthen, to grow and to remodel our minds – remodel the brain ...

#### ... do you see that as part of neuroplasticity?

Yes, the brain is a dynamic living organ responding to how it is used and who is using it. You have the virtual self of the mind – the stories and movies that are using it all

the time; and then there is the question of the possibility of a deeper self that can look at this behaviour of oneself with gentleness and patience and kindness and understanding and courage and strength. Shouting at it won't change it. Sheer willpower won't remyelinate it or remodel it.

So as change-agents involved in the issue of suffering, we are involved in the question of the transformative journey (The Hero's Journey as Joseph Campbell called it). How long that may take, and what are its stages; how you support someone in the different points, relapses and crises - that's the raw materials for us.

Those who cannot change their mind cannot change anything.

(GB Shaw)

The teenage explosion of brain growth turns out to be not so much new growth as pruning: cutting back what hadn't been brought out. So in children that are not read to, or taken into imaginative story lines, or given visions of hope, these circuits will atrophy, and circuits associated with survival will be strengthened: attack reflexes, awareness of predators. So the brain is adapting to the sort of jungle it finds itself in. But it is plastic and that is the point; otherwise this would be a story of gloom. Redemption lies in the discovery of plasticity as we begin to live differently, by different values, by re-emphasising a fresh compass – so the system begins dynamically to follow.

### **Transformation**

A portent or miracle "does not occur contrary to nature, but contrary to what is known about nature".

(St Augustine's City of God 5th Century)

That swap in New York - that's a miracle: in an instant it became a new New York, with personally transformative shifts in experiences. I'd call that a miracle; a transformation. That, in the most beautiful sense of the word, is ordinary. That is what happened to Andrea.

I spent 20 years ploughing the field of study of one-to-one encounters and healing changes. I studied hundreds of instances of healing change, working with videos and transcription, reflecting, trying to learn patterns and nature of individual healing, and what it is that blocks or releases these capacities in an individual. And when I thought I had mapped it to some reasonable degree, in 2004 I pushed myself out of my comfort zone and explored if I could take the principles I had learned and apply them in a group setting, and I have been researching this approach since then. This wasn't 'let's have a self-help group', but a conscious question: could that intimacy and place of healing change created in one-to-one work be scaled up? This became the WEL programmes (wellness enhancement learning). The answer proved to be yes for a good number of people.

So let's hear from a participant from one of these groups who is describing something of a transformation. I'd ask you to become a student - as if for the first time - even with all the knowledge that you have; your job is to think afresh: what the hell is this healing capacity? When 'Carol' (a participant on a StaffWEL group) was interviewed by one of the researchers three months before entry to the WEL programme, she revealed that she had suffered bouts of depression every year for the last 36 years,

which were as troughs in an overall pretty miserable existence. She had used antidepressants on a seasonal basis for years. She had experienced periods when she was unable to leave the house for as much as nine months. She was anxious all the time, and 'fear' is a central theme in her life. She had suffered panic attacks which could involve urinary incontinence and vomiting. She was subject to paranoia and self-loathing. Not many people knew how much she had suffered as she could 'put on a face'.

So what was possible for this person? And of course practically we have to deal with the reality of her situation and support structures and so on. So let's see how she got on after the intervention which was once a week for four half days. When she was interviewed three months after the researcher noted; her manner and bearing was upbeat and she spoke of a deep transformation in herself as a person in the world. Her life had changed: her work and relationships with colleagues, her family life and her attitude towards food. She was off anti-depressants. But what was most keenly felt by the interviewer was her changed awareness and ways of being with herself. In her own words:

It's totally different. The whole way I look and see things and feel things... I keep pinching myself that I'm not dreaming all this... I'm not afraid anymore... this confidence is coming from inside it's not just a phase... I'm myself now, I'm quite happy with who I am.

She was followed up by questionnaire for a further nine months and on all five research measures she showed self-sustaining growth in wellbeing, quality of life, fatigue, main complaint, and – critical in the success – self-compassion. This is what we are looking for: an unfolding change, building on a person's own life's strength – bringing a growing sense of self-efficacy. Carol's own words again:

I'm healing, I see myself as healing. This is just a personal thing, I've seen myself with like an open wound that's never healing, and now I can see it's closing down, you know, it's like you know how if you've got a scar it's open, so now this is closing in, its healing, that's how I feel. It's not open anymore.

Note the language. The inner world works with image and metaphor. That's how and why art works – as a bridge to the unexpressed. She generated, from the depths of herself, this image of a wound that is closing, an image of healing. You need to be attuned to these languages to reach more effective communication

At her 12 month follow-up she told us that it had been the first year since she was 20 that she never had to take anti-depressants or St John's Wort or something like that for her mood swings, having suffered from depression all her adult life.

She's not living in hell any more. Most of our soundtracks are hell – hell is right here and right now for many of us a lot of the time ... trapped in our mind.

It's hard to understand mechanism here, and what is cause and what is effect. It's why I am trying to root myself in empiricism, working with phenomena and not getting too disconnected from this by any one theoretical model.

I have chosen to rehabilitate the word healing for myself. Not as some esoteric idea or the interesting debate over 'non-local' effects – but as a very robust innate resource: you cut yourself and it heals, you break your heart and it works towards healing. This is a profound capacity lying within each individual. What can it do and how can it be accessed?

My priority is to consider this approach as first line, using pharmacology as second line temporary support (and all the while monitoring if drugs or surgery are called for). Even if I'm bringing in pharmacology I would be giving a metaphor around it, because for every action it's not what *happens* to you it's the *meaning* of what happens to you that is important; so when you give me a prescription or an injection, what meaning has been perceived by me about that? Is it a brokenness that needs a medical model or a different thing? Look, we have learned here of the fantastic ability that people have over time to settle within themselves, allow their system to become calmer, and with it things to become more manageable and easy. So if we do use any tablets it would only be to give you a temporary support while we get on with the real work. I want to give each and every person access to deeper capacities, and self-activation before I reflexly bring in the offerings of 'the four waves'. Our professional training allows us that discernment to know if and when we might employ something, but what a relief to be released from the 'have to' or the primacy of it.

## States of Consciousness

You and I are phenomenologists and the way we see patients may be different to another practitioner who has a different approach. So I am wondering if you can teach these techniques to others who are not phenomenologists.

It is true that we must reach for seeing other than through left-brain mapping and mechanistic intervention pathways. Now, I like those pathways and they are very helpful for balancing my cheque-book or assembling IKEA furniture, and occasionally useful in our medical work. But they aren't adequate on their own for our work.

When Picasso viewed remarkable cave-paintings from 40,000 years BCE he emerged saying we have not learned anything beyond this – and in our field: have we learned nothing from a quarter of a million years of shamanism and its study of the inner world and transformation and movements. Carol showed us a remarkable shift but we are engaging with this with inadequate understanding, and vocabulary.

We can begin to think of states of consciousness beyond the ordinary states of waking, sleeping and daydreaming. One way to introduce people to other than a left brain pathway would be the boundless bliss, as experienced by Jill Taylor, professor of neuroanatomy, during her left hemisphere stroke at age 37; a state that has transformed her mind. Her TED talk on this is excellent. To help someone recover when their perceptual maps are myelinated both by culture and their individual circumstances - that is no easy task.

Other states of consciousness include near death experiences (described as super vivid experience with a flat EEG) and terminal lucidity - which can still happen with heavy sedation. The most vivid example I saw was a man in terminal illness whom I was caring for in the Centre for Integrative Care, a context which gave me cultural licence not to use heavy pharmacology as first line. He had been unconscious for

three days when suddenly he opened his eyes, sat up, looked in the eyes of his two daughters who were sitting either side of him, laid down and died.

# It has been reported that in patients with advanced dementia that immediately before death they suddenly become lucid.

Which might be more comprehensible in the second model of consciousness – the transmitted model. I don't understand it.

I've now moved the WEL principle into the StaffWEL: nearly 600 staff in groups of 20. I take them on a journey, as with the patients, beginning from where they are, how they view the world, what is important, what their values are, what their language is, and supportively help them to transition into a safe place of coming off the usual map. It can be done with all the delicacy of a therapeutic process, and it's safe.

## Conclusion

We started with the mysteries of inner life, of consciousness, of change and transformation, then we saw Carol. I find myself wondering if some of Carol's experiences and way of being correspond to the goal of many of the traditional spiritual paths, of finding peace. It's interesting that these altered states on hard won spiritual paths, such as St Catherine of Genoa's model of the soul, correspond to that state of being when functions like thinking, sensing, feeling and intuiting become 'unified', complementary, mutually enhancing; a movement towards psychosynthesis - this oneness of being - rooted in a state of consciousness which probably all of us are privileged to have in one or two moments in our lives. There are other ways to this without having a stroke or nearly dying or going into a monastery. This becomes more our everyday journey - for Carol and ourselves. There are other ways: of course you can dissolve the structures of the mind with drug effects but this doesn't substitute for myelination, maturity, insight and growth, and I actually think it is a false opening.

# We all have that phase between sleep and wakening ... the two selves that are in you are not battling at that moment. You are in that moment seeing clearly ...

As you leave one dream – this universe you are in exists, it's happening – you wake up and think you're in the real world but you're in another dream; you're in another set of representations and stories – another New York. 'Wake up and smell the coffee, the reality', says mind - the story of this movie. Transformative life-changing experiences can crack this dream open – for example, the moment of a terminal diagnosis. People have told us that their cancer diagnosis turned out to be the greatest gift they ever had, because it snapped them out of the egoic structure into the air and freedom and light outside of it; coming to re-value - to actually live our lives, instead of complaining about them. Art, creativity nature meditation, prayer are all part of the transformative process but from our point of view what can all this puzzle bring into the therapeutic state? This sitting with people? What is the job to be done? What am I doing here? How might we come together?

#### ... but the system doesn't allow this...

It emphasises what it calls 'efficiency'. Yet a system can be efficient but ineffective – hitting short-term targets but failing to bring about real change.

Speaking of the purpose and quality of our meetings: have you heard of the study that showed that if we are physically close, my ECG can be read in your EEG? We are radiating! What state are you in: doctor, nurse, therapist? Which movie do you live in as I sit with you? Because there is a lot of non-verbal exchange happening, with resonance and impact between the participants.

Have you heard about people having heart transplants who assume the personality of the donor?

Which is back into the virtual world of memory, myelination and story. They are not the mind, the memories or the stories, and neither are you

Let me finish by emphasising our results of the clear rise in the self-compassion scale which seem to be a key in activating self-sustaining self-care and so wellbeing.

## **David Reilly Session 2**

People have been asking: what did you do with Carol?

Here's a wee phrase from Jane Kelly, an artist I was privileged to work with: "First create the conditions to create, then create". So when we want the blossoming that Carol or Andrea (or Brenda who I am going to tell you about) showed - we can aim to construct the conditions for such change and healing to emerge, for example: create that feeling of safety, that connection, bring positive intentionality, effective listening, and that development of empathy as a stepping stone to the opening of compassion. That's empathy not sympathy. Sympathy is a husband having labour pains as his wife gives birth, which is of absolutely no use to her. Don't confuse empathy with your emotional responses. It is the deep listening and the attempt to understand, which is an active process. Imagine what it is like to sit in the field of presence with another individual of good and warm heart, who is genuinely trying to understand: that's the medicine. And that may be verbalised: "Are you saying it's like this? Or meaning this?" It doesn't matter if you are wrong, but it shows genuineness in that cycle of empathy building: "is it more like this?" ... "OK tell me about that ...". That to my understanding is what empathy is. These are the things that we have been building on with Carol, learned from the study of one-to-one encounter.

## Brenda

Brenda was referred to me in 2011 by the rheumatologists, absolutely in extremis with disabling back pain that has now had her off work for six months. She had had to spend four months of the last two years as an inpatient. She had been the subject of many multidisciplinary case conferences. Life was a disaster for her. Her MRI showed a bone fragment off her sacrum and they were wondering if they needed to remove it surgically. And like so many patients with one long-term condition, she had others with a complicated background history of skin problems, asthma, Churg–Strauss syndrome (aka eosinophilic granulomatosis with polyangiitis [EGPA] or allergic granulomatosis), renal stones and a stent.

So: *First create the conditions to create, then create*. First, a ninety minute meeting. What would you need to do to restructure your services to allow your meetings to

become effective (as opposed to hitting targets in an efficient but ineffective manner)? You will see that this appointment length was indeed cost effective. At her follow-up at one month she looked much better and reported that her first meeting had had:

... a massive effect. I left here feeling so good and changed, went home, went through all that we had gone through and began to review my life... how I had been behaving and how it wasn't helping me. I am seeing things clearer and more realistically ... I realise I have to bring some focus on self-care and not just on everybody else. I am more relaxed. I'm back at work. The pain is also slightly better ... I am moving better in the morning ... not using the crutches. I am noticing that I am thinking differently about everything.

That is typical. We all know this form of shift, when you sit with an individual you often feel it as if the atmosphere changes; you see movement and changes in the face, the energy in the space. These shifts are very tangible. Notice that when the plant of her recovery was growing we saw a whole unfolding of stuff that I didn't necessarily talk through with her - things you can give fancy labels to like 'mindfulness'. You see from her words ('seeing things clearer') a perceptual shift. We've managed to achieve a second 'New York' here, and in that second New York you know you are a different person; things are just going to be different for you and in the world. Note her realisation that she had to bring a focus on self-care.

What I have been doing over the years is acting as a reverse engineer: I begin from a result like that in Carol or Brenda, and I say OK, if I want to help other people to do what they have done, what have they taught me to bear in mind with others. For example, taking from their account: How can I help someone begin to trigger a focus on self-care? And to review how they are living? And how they are looking at their life? Here I stay locked into the phenomenology, the evidence of their direct experience, and I avoid not moving off into theory - because this is the real thing, this is the germinating plant. This is direct field-study. If I can only be with this deeply enough, and listen enough, and sweat enough over it, I can learn what it is trying to teach me. Thankfully, I have found that there is no single correct thing to do to hit the dominos so they all begin their fall down. If you bring these conditions we have been talking about: your intentionality, your authenticity, your presence, your focus, your caring, your listening, your building of the empathy between you and them and who you are and who they are, a domino will likely fall. All this is against a backdrop of holding and bringing to them the vision of their strength and capacities and potential. Beyond this, some of us may be more skilled in certain therapeutic dialogues, or better attuned to certain approaches or techniques - that's fine, there's no one correct way to do this. But the generic catalytic elements trump techniques.

So at 42 months follow-up where are we with Brenda? Her improvement has still been maintained and indeed advanced. She is still at work and has faced numerous challenges including an operation to remove a kidney, (her surgeon was astonished by the tranquillity with which she received the intimation of this, and lack of drama in her recovery), fractured ribs, moving house and her husband losing his job. She remarked: "People can't believe the way I was not worried". She is off opiates and anti-inflammatories, and only on low dose Pregabalin. She has been discharged from the pain clinic who were 'very surprised by her unexpected progress'. She gets occasional down days but she can use what she has learned to "pull myself back ... If I get uptight, I come to my breath, go through my thoughts and question them, and

settle myself". She reduced the drugs gradually herself. I don't make warfare over drugs, I just suggest that people can reduce them if they feel able – I feel that to kick away the support from under someone's feet is counterproductive.

[There followed a video of an interview with Brenda when she expanded on the above.]

So from this one case you have the ingredients for what we are trying to do: to help a person become skilled enough to notice when they have gone off track, to feel it, and to have sufficient skills and understanding to begin that journey of pulling themselves back round and making that course correction. I'm not just talking about insight, but the germination of the strength and skills they need.

I think it's really good to do that kind of scaling (measuring) question [scores out of 10 used by Brenda in the video dialogue] so the patient can write down what it is that is helping them at a particular point and what it is that is stopping them getting lower down their scale. That will give them their maintenance programme and something they can look back at when they have a bad day or spell.

One of the things that came out very strongly, and I find with my patients, is that they appreciate being listened to in that deep way you have been talking about. The long and short of it is that if they have chronic pain the sensation, the way their nervous system is working, is probably going to be stuck with them and the end result is that they are going to have to put up with it and get on with their lives. But until they feel that they are being listened to by someone who is really taking them seriously, as you are clearly doing, and taking the time to strengthen them, they won't accept that and start to move forward. And when I ask a patient who does really well, as some of them occasionally do, what was it that made the difference and usually they say it was because you listened.

That's part of the art of the practitioner, isn't it? If someone manages to make a creative shift, sit with them and listen: Can you teach me? ...Why do you think this happened? ... How quick was it? ...What was the first thing you noticed? ...Can you give me any feedback about something you found helpful? This is nothing to do with your ego, this is genuine field study, so picking up on that listening theme: the first key is studying this healing reaction and understanding shift. The second key is - *us*. That's what we have been talking about. TS Eliot said "some people imagine a system so perfect that no-one will have to be good".

Picking up on the research that Paul (Dieppe) mentioned: it is activated practitioners who activate. You don't need to have arrived, but you're on the road. You're not just bullshitting. The sad truth is that the public is coming to us as health care workers to ask: How may I flourish in the modern world? And *we don't know*. The staff I am working with are just as sick as the patients. So beginning this journey with yourself, the journey of getting back in love with life, and building our own self-respect and nurture and movement into a more nourishing way of living.

## Empathy

Brenda: I could be open and honest; I spoke to you about things I hadn't spoken to anyone about.

You recognise that situation? When you sit with someone and you are fully present and warm-hearted for sixty seconds and they start to tell you something they had never told anyone else. There is something about a recognition response of these right conditions within ourselves.

We took 200 people just after their first consultation, and before any of the guidance or treatments had been put into action, and they scored their experience of empathy (I felt safe, that I was listened to, that the person was trying to help...). We also took scores of enablement (the spark of a feeling that I can make a movement in my life, I can change). We found that although a good experience of empathy doesn't guarantee enablement - it was a prerequisite. In 200 cases we didn't find one of high enablement with a low empathy score. So if that experience of empathy is not present, forget it. You can have good procedures, information, leaflets, websites, referrals – but you have missed the mark. The satisfaction scores may even still be quite high, but they are being scored to a low expectation horizon. Stewart Mercer has confirmed this finding in over 8000 cases, and it is independent of deprivation index or morbidity/complexity. Another example: It has also been shown that control of diabetes is substantially better in patients of doctors whom they scored high for empathy. So this issue is critical also in acute care and areas where 'hard science' features.

There appears to be some hardening of the heart during medical school. When we enter medical school we score above the general population average for empathy and when we leave we are below average. There is something about the induction into the tribe and the collective maps and ways of thinking that is actually crushing these natural capacities. Is this a putative coping or survival mechanism where empathic feelings are suppressed? We have all felt loved or insecure or afraid and had feelings that extend to others; how may that play out into our work and use that natural talent as a resource - instead of telling people they you have got to learn communication skills as if from scratch? ("I'm the expert, and you are going to have to learn from me)".

That said, can you train in compassion? You can. There are fMRI studies involving playing audio recording of people with emotional pain to test volunteers. Comparing baseline to listening to the voice, there is not much difference in brain activity in novices. However, skilled meditators, who have been training themselves in compassion, show much more alive activation<sup>4</sup>. It's there already as a natural potential, and you can myelinate it and grow and develop it over time. I think we should burst the idea that some people are just born with it.

When I do workshops on creating therapeutic encounter (some downloads on this at <u>www.davidreilly.net</u>) I find it is helpful to cover areas like:

<sup>&</sup>lt;sup>4</sup> Lutz A., Brefczynski-Lewis J., Johnstone, T., Davidson, RJ. (2008) 'Regulation of the Neural Circuitry of Emotion by Compassion Meditation: Effects of Meditative Expertise', *PLoS ONE* 3(3):e1897. <u>http://dx.plos.org/10.1371%2Fjournal.pone.0001897</u>)



- Vision and purpose: the vision of what's possible as shown by what Brenda, Andrea and Carol had within them; this is knowledge that the practitioner needs to take into the space. Here the image of the strength lying within the person is a key.
- Conditions: the ideas we have already discussed around 'First create the conditions and then create'.
- Presence and beginnings: bringing yourself to the situation, progressively deepening your presence. Be alert to the impact of the opening seconds. People who have studied micro-facial gestures note that in a genuine meeting the eyebrows flash for about a fifth of a second, and you register this welcome signal subconsciously. Whereas with a 'professional' smile, which I call a 'horizontal' smile, the eyes don't do anything. In a study where practitioners were asked to actively suppress the eye flash at the point of meeting versus not, the patients reported a poor outcome in the former situation. So genuine warmth makes a difference.
- Join-up Partnership: these previous factors are heading towards creating the join-up that is critical. The term is taken from Monty Roberts implying a tangible connection between the partners.
- The Dance: people seeing a change like those in the patients we have discussed naturally ask: What did you do? What did you say? Well, while there is sometimes technique in the doing and the saying, actually it is much more attention to planting this vision of change and the journey towards joinup that are the 'active ingredients'. OK sometimes, there is its fancy footwork or metaphor and stuff, but an over-emphasis on this can disempower the participants, who need to know that a sincere meeting of their humanity can heal. Let's watch our words very carefully. Every single word counts. Words make movies in peoples' minds – even single words.
- Enablement: the seed germinating
- The Journey: support as the person's strengths emerge over time, and they learn to sail the storms of their life.

Let me expand a little on a few of these elements. The meeting begins before the meeting - sometimes long before it. The individuals are already involved in their movie, their narrative, with their hopes and fears and their stories. Have you been to a medical appointment for yourself or a loved one? You know the discussion and planning and nerves before. Sitting in the waiting room, and now walking down the corridor - hearts thumping, finger tips sweating, thinking 'What am I going to say', 'What will they find', 'Will I be humiliated', 'What's going to happen? Who then calls you into the room, and how? As you walk in your bullshit detectors are firmly focussed on the practitioner! We are glass houses, and you can't fool these biologically evolved safety mechanisms - smelling the air, scanning the microfacial and body gestures. No amount of professionalism and practiced tones of voice will fool this - forget it! Does this practitioner actually care a damn? What is this I have just walked into? What is the atmosphere in this space? The first evaluation takes around five seconds. As a practitioner, have you prepared yourself to let go what's just happened, to do whatever it takes for you (maybe a few breathes and moments of centring) to make ready for the person about to walk in. Brenda taught us one of the states of consciousness we are after: I feel I can trust you, I feel safe with you, I can relax. You know how when you are in the conversation of a lifetime with someone and the room disappears, as I call it? That's what you are after. And that's how you daily practice to enable yourself to learn to progressively come to presence. That skill base deepens with practice. There are neural correlates of this state with reduced brain activity in areas that normally assign emotional value and judgement; enter that space, and you may have shifted the situation already.

I mentioned a study this morning which showed that when two people touch or are in proximity, the electrocardiogram signal of one is registered in the other person's electroencephalogram. I am reminded of Monty Roberts, the horse whisperer, and I see the same thing with people ... join-up is a very tangible thing. It might happen at the first meeting, or after many, but it has a reality to it, and in general any new ideas, messages, metaphors leave them until *after* join-up — don't waste them earlier before they are going to be received and responded to. And that is why so much of the work goes into building the situation even while you are 'taking the history' as it used to be called in the authoritarian model of encounter.

Tich Naht Hahn gave his answer to the question: What is the difference between illness and wellness? In three letters and two words: I llness and WE llness.

### Self-care and meditation

Studies have shown that antidepressants activate the left pre-frontal – but so too does placebo antidepressant<sup>5</sup>. Mathieu Ricard, the author of the wonderful book *Happiness,* who was a scientist before becoming a Buddhist monk and a trained meditator, can wake up his left prefrontal cortex at will (as shown by quantitative EEG) by the meditation on compassion<sup>6</sup>. So this is the way for you to help your health in your client's time and get paid for it! As you deepen the state of compassion you are making *yourself* better. Allowing for the exigencies of actual exhaustion, if when

<sup>&</sup>lt;sup>5</sup> Leuchter, A.F., et al. (2002) 'Changes in brain function of depressed subjects during treatment with placebo', The American Journal of *Psychiatry* 159(1):122-9.
<sup>6</sup> Goleman, D. (2003) *Destructive Emotions: A Scientific Dialogue with the Dalai Lama*, Bantam, ISBN: 0553801716.

you walk out of work you are feeling strained and low – I'd say you've scope for shifting your soundtrack. Again I would emphasise the differences between sympathy, empathy and compassion. Building empathy gradually opens the heart of the practitioner. Compassion opens as a deepening state of being – words are inadequate for it, but it has a quality of mercy; you could call it prayer. What is opening in me is my hope for the best for you. I'm not taking your pain, I'm not imagining you shouldn't be in pain, I'm not suffering with you – what's the point of that - of having two people suffering?! If I'm getting into suffering I'm doing it to me – I'm getting my ego involved.

There are immediate physiological correlates to the healing shift as is seen in changes in heart rate variability.

So we're moving on, the group or the consultation is starting, the mechanics are going on, and the real stuff is building underneath. You are perhaps using something like the plant narrative as you hear and begin to understand the soundtrack she is in, picking up on her stories and images and begin to offer some possibility of movement and hope – that's just natural and happens without thinking about it. But she may trip up on her road out of suffering ... 'oh my God, I've lost it, I've lost my footing, what shall I do?'. And that's where this support and instruction becomes critical.

#### So you're pointing out to her what she's doing for herself?

Yes. In questions (You made a cup of tea for the first time in ages – how did you manage that?), little stories, images, condensed stuff. In TheWEL group; each member has videos and a manual with these support images to use at home. We reflect back the change process to the person, no matter how small ('You don't judge a seedling by its size'), using the skills we have been talking about, and remembering the importance of timing and of narrative and the clarity of what it is to be done here which is to help this individual to understand her inherent capacity; to be inspired; to be given self-awareness tools and practical support (she will be taught some compassion-based meditation). There will be the use of a lot of gradually built shared vocabulary and image - so there is a circle of people with a plant in the middle and at first people don't realise why the plant is there, so they laugh when they realise that they're 'on a gardening course', human gardening, and begin to understand what selfgardening would look like. And then I am providing some gardening tricks and tools for them. I'm not emphasising to you the particular gardening toolkit I'm using in my work, because the central issue is sparking them into wanting to self-garden. Then they will find their own tools in time.

We talk about identity: They fill in the sentence: 'I am... (fill in the blank)' versus what happens when we sit with the simple two word sentence with a firm full stop at the end: 'I am'. This can be a revolution for people. To experience themselves outside of thought or story. People can spend their whole lives thinking they *are* their mind; we actually think we are the thought stream and the voice going on in our head. And somehow because this thought stream thinks this, and want this, and hates that, we think that's *me*. And what a revelation to understand that you have your mind, but you are not your mind. Because who is it that is listening to the voice in your head? You will have your own terms for this consciousness. And this is the beginning of a fundamental shift in relationship to ourselves, and to being alive, and to having a mind and emotions and drives and stories and dramas and histories and brokenness - and to realise that we are not all this, we are not our brokenness, our diagnoses, our pain;

we're not our story. These aspects of our life are to be respected and worked with but we are more than that.

Something of this shift in relationship to our own 'story' is perhaps shown in a study in which patients with rheumatoid arthritis or asthma were randomised to write about the most stressful event of their lives, or to a controls group who wrote about emotionally neutral topics, 47 per cent of patients writing about stressful life experiences had clinically useful changes in health status at four months versus 25 per cent in the control group<sup>7</sup>. Writing things out can be a useful exteriorisation, allowing a more 'outside' view to develop.

It's important not to just emote and to further myelinate your story. This can be retraumatising. But it is important to honour the old story, and if they know you've *got it* in some way, then you don't need to know all the details. OK, so now it's been expressed, but now comes the journey into shift — the snake in the grass metaphor and the like; the two New Yorks.

## The creative relationship

To summarise the creative relationship: Do *you* have a vision of healing potential? Is life worth living? Can people recover their spirit? Can the experience of suffering shift? Or are we telling people with chronic pain you have to live with it and come to terms with it? We don't want to bullshit people, we don't want false hope, but I can say, hand on heart, that I know that people have a fantastic capacity. Can we join with them in the journey of the release of these capacities — fostered by an activation of their own self-care. In turn, the key to this activation is the release of the nurture response that follows an opening of compassion in the person towards their own life.

### Discussion

#### **The Wounded Healer**

The elephant in the room is the professional carer, the doctor or whoever it may be and of course we come to it with our own stories and difficulties. That must have such a huge bearing on the outcome for the patient we are trying to treat apart from the methods we are using. So ... if when we go to work we are not at our best and carrying a lot of difficulties, as most of us do from time to time, what should we do about it?

You know the old Irish joke about asking for directions to Dublin and the reply is "ah – I wouldn't start from here!"? Everybody does start from here and it's utterly legitimate to be carrying our wounds and baggage. What we may be asked of in any situation is simply that we are all on our own journey. That will do. It's not about having arrived or released. Our experience of suffering is our biggest teacher. If you are vulnerable or not right – know that, label it, own it – and put an amber or red flag for yourself to strive at least to do no harm. Perhaps today will be a day for just getting by, with as much respect and technical competence as we can. If need be, ground yourself.

<sup>&</sup>lt;sup>7</sup> Smyth, J.M., Stone, A.A., Hurewitz, A., Kaell, A. (1999) *JAMA* 281:1304-09.

... but if we are on our own journey to Dublin and we take the patient with us we might misdirect them.

Don't take on the patient's journey, or ask them to join you on yours, for God's sake. It's their journey. No matter what state you are in, you can mirror back to them, reflect through questioning how their 'sailing practice' is going. The metaphor here is that we cannot control life, the storms, the weather, the symptoms, the situations, but, we can get better at sailing through these rough times. As you enter that dialogue you will find it is privately helping you too (so long as a compassionate approach is being adopted) – but that is not their business.

#### Suffering – The Friend

A big release for me is the realisation that people are supposed to suffer. How do I know that? What's my proof? Everybody suffers! It's normal! It's normal to age, suffer, to get sick – to die. And nothing we can do will change that. When I sit with a person my image and compassion is the realisation that they suffer as I and others suffer. Let me be compassionate, let me be present with this individual, but not take on their suffering, and not take away their journey. Quite a lot of baggage will fall away and the state of unself begins to unfold, until the opening of the space – call it what you will, the healing space, the prayer, the meditation, the hope for what is best that might unfold, what might be germinated out of this. And our own lives – our own suffering – are our principal teachers – not books. I think it's very hard to be an effective therapist or doctor if you yourself have not been broken, suffered, or continue to suffer.

Is there some sense that society has changed; that we have lost the ability to recognise that suffering is part of life?

I think so – it has become the enemy. Yet actually it is the cry of a child in the dark asking you to come towards it. You can't ask someone to 'embrace their pain' – what are you talking about? But you can reach through the pain to embrace the part that is in pain. You are not comforting the tears of the child, but the distress they signal. People can get that; they get that the body is suffering *for* them, trying to do its best. I worked with a man with chronic desperate neuropathic pain and sequelae of old polio. There came a pivotal point in our conversation, timed after the creation of safety, join-up, space and so on – when I asked: "What do you feel about your leg?". He responded "I fucking hate it - I would cut it off!". So then I asked: "What does your leg think about that?" ... ! [Laughter].

Because of timing, this question was the trigger for 'the sound of one hand clapping' – falling off the map, a loss of the familiar reference points, and entry into creative space. Into that space I brought a narrative about his leg doing its best for him, despite the pain it was experiencing. He came back a few months later and described his transformation in his pain experience, function and wellbeing – similar to the healing response we saw earlier in the other patients: "I realised that I needed to start being kind to myself."

Suffering is not the enemy. It is the call for change.

That's what I was going to say: patients' understanding that suffering is normal ... how do you know about long-suffering if you don't know about suffering? It's one of the most important factors in the healing process.

#### The Meaning Map

I suppose that for many people the worst aspect of their suffering must be that it appears to be meaningless. Do you think one of our tasks is to help people find meaning in their suffering? I'm thinking of Victor Frankl here.

Yes. Experientially.

The common image we have of our illness is of an enemy that has invaded us, damaging us, destroying us. Think for a moment in that way about your distress, some suffering or struggle or difficulty you might have. When you view it as enemy notice what that raises in you: feel it. This is the first New York, the response to a predator.

Now swop the image. What if your suffering is a struggling plant with dropping leaves? What does that raise in you? You feel the power of it? The heart opening? This evokes the instinctive nurture response.

This is very much in the realm of meaning. When people discover that shift in perception and the mobilisation it brings effortlessly, things begin to change for them<sup>8</sup>.

#### The Plant and the Gardener

By the way, what is that plant of your life calling for? Take a silent moment with that question. And if the answer comes back as metaphor: water, sunshine - turn that poem back into what that may mean in my daily life and see what comes. Often a quite simple instinctive knowledge is released in this way.

Oh, and by the way, whose plant is it?

[Ours]

Who is the gardener?

[Ourselves]

Give yourself a score out of 10 for your self-gardening. Could it be better?

[Agreement]

So, when you improve that score - something is going to happen. I don't know what it is. And the fantastic thing is that it doesn't need a master plan. You bring the tenderness, the care, the respect, the nurture, and life starts to respond. If the experience is stuck as meaningless suffering, we are completely trapped. Somehow that movie needs to change, and into that at some point will come tenderness. We have followed up over one hundred people after attending TheWEL group and seen growing sustained changes in the majority on questionnaires, qualitative interviews

<sup>&</sup>lt;sup>8</sup> See for example, an interesting article on this by Thomas Egnew: <u>http://www.annfammed.org/cgi/content/abstract/7/2/170</u>

and objective measures (like fasting insulin) - some fantastic shifts. (See the results section on <u>www.thewel.org</u>.) Central to them all has been the sparking of self-compassion and the nurture response this releases. Not egoic self-care – me, me, what I want - it's something outside of that, that brings back a respect for life itself.

## To Heal or Not to Heal: the Hamlet Effect

## Sarah Goldingay

I was reminded of a performance scholar whose work I admired called Baz Kershaw who talks about the way theatre changes people, and how some theatre is better than others at making this change. He makes a distinction between what he calls 'transgressive' theatre and 'resistive' theatre. In my encounter with you today I hope is going to be more resistive than transgressive. What that says is that resistive theatre is a thing that makes you go "really?! – I hadn't thought about it like that .... I'm not sure ... I wonder ..." – the sort of thing that provoked you into re-imagining your film-script. Whereas transgressive theatre pushes you into a place that you don't want to go to, and rather than be a transformative moment it pushes you down and shuts you off. Because I am coming from outside your shared world – I know there is a huge amount of diversity of knowledge and wisdom and practical experience in this room – my experience of the world might be quite different from yours, so if I say something that seems quite outlandish to you please tell me so that we can learn from each other. This is not about me teaching you anything but hopefully helping you to re-imagine your world a little bit.

I want to start with two stories. The first is concerned with the content of this session and the second with the method. (Not about a methodological approach or research methodology, but the way I want to structure the session to get the most out of it.)

First story: I am in a GP surgery, and above the surgery there is a meeting room. I'm sitting in a meeting in a circle of about 12 people and looking across at a woman, probably in her fifties; we've gone through the usual thing of going round introducing ourselves and the panic because we can't remember names, and this lady called Nancy starts to tell the story of her chronic pain. It is the most captivating beautiful story you can imagine. It is long and exquisite and I wish I could share it all with you but I just want to tell you about one line from the beginning. She had terrible widespread pain which had completely changed her life, her relationship with her husband and her family, and her work – a very familiar story to you. She was sharing her experience of healthcare provision, and the experience of going to her first GP. At her third meeting with him "he just shouted at me."

The second story: I am artist in residence at a municipal gallery. I am in the portrait gallery and I am lying on the floor on my belly, and lying next to me is a four-year-old boy. He looks across at me with those very sincere eyes that only four-year-olds have and says "You like watching me draw".

These two stories only make sense in the context of this talk. Can you make a connection between them? Let your imagination take you somewhere ... The reason I am telling you the story about the little boy is because it changed our communication utterly. His name is Jake, and I was working for the gallery because, a bit like postcode lotteries in healthcare, there is a lottery in use of culture. The truth is that people who can least afford a ticket to the theatre, cinema or an art gallery are also the people who are least likely to use it when it is free. So I was trying to encourage groups who are hard to reach to come into the gallery, to take it over and to make it feel it was theirs. My particular job was to work with early years groups, mostly children under seven. They would come in with their teacher for half a day. I

was working with Barbara, a wonderful visual artist, who was helping them to draw and paint, and I would help them to build the world that they imagined. Quite often the kids would tell me that they couldn't draw – four-year olds saying this. I was quite surprised by this. But Jake was different. "You like watching me draw", he said. And in that moment I knew that I was completely insignificant in any kind of learning encounter. I was just providing a little space but the actual encounter was his in that moment. And now when I work I think it's about 25% me, 25% you, 25% your peers, and about 25% time. And this morning the way that you will learn, the way that you move, the way that you have experiences is 25% me and my facilitating, 25% because you are here, 25% your wonderful colleagues and 25% time. This is a precious moment because in a situation like this there is actually time to slow down, to think, to return to the conversation over dinner, to encounter that again tomorrow. So that's why I told you Jake's story, because Jake was so important in my life and changed the way that I try to do any kind of teaching or communication.

So, what about the other story, Nancy's story? I have to say that any healthcare professional, healer or therapist - anyone working in a caring profession - I have encountered seems to want to have absolute compassion and care. We have talked a little this morning about the developing nervous system and nurturing responses and the kind of stuff that we are hard-wired to respond to. But there is another thing that we are hard wired for and that is care. Just as we are hard-wired for the nurturing response we are hard wired to care for one another. And that is very helpful for me. It seems to me that much of the frustration that I hear about is actually because we are hard wired to care and to understand; at a fundamental level care really matters. What was interesting about Nancy was that when she told her story about her early encounter she felt she wasn't being cared for. There was frustration on both sides; she said, "oh, I felt just as bad as the doctor did; he was completely frustrated because he couldn't give me a diagnosis. And I couldn't give him the symptoms which would give me the diagnosis so I felt just as angry." This story is really important to me. Somewhere in Nancy's story there was a need for her to fulfil a predestined script. So, as a performance studies specialist, script is one of the things I work with. Script analysis is something that goes back more than 2000 years to Aristotle and Plato. There is a lot of literature and discourse and isms and origins and thinking around the subject of what is a script. So I want to bring some of those tools, that analytical method for unpacking script, to your encounters as healthcare specialists with patients, or as patients, or encounters with people who come to you in everyday life.

If we start with a play script; it's usually printed as a book. That is interesting culturally because we tend to think of books as objects of authority – they have a truth. It is little known fact that Shakespeare's plays weren't actually printed in his lifetime. He would write them in longhand; they would go to a scribe who would write a roll with only the words for one actor so you knew what your bit was but you didn't know anything about the rest of the play. Shakespeare pegs it and some of his mates thought aha - here's a way to turn a profit and join some of these rolls together to form plays. Some of them are a bit sketchy and some patched together with what people sort of remembered of the words. Hamlet is an interesting case in point.

There is a lovely line in Hamlet where he says, "Oh what a peasant slave am I". But in one of the other versions he says "Oh what a dumbkill idiot am I". So for me, scripts are not absolutes; they are stories. [Participants were invited at this point to think about an object that they encounter, on a computer screen or on paper, which is some sort of text or list of something that they have to adhere to: for instance like taking a patient history or a tick-box list; and to think of ways they might encounter a script in real life which they are obliged to follow.]

## Lack of empathy?

This is an interesting subject we will come back to ... can you teach empathy? There are empathy scripts; Paul [Dieppe] and I did a study a few years ago when we gave some medical students empathy scripts; we were really frustrated as here were these very bright, articulate, socially competent 19 year olds, but they were completely baffled by empathy scripts.

I think a lot of scripts save time as you don't have to start at base level or find your way from the beginning; you have guidelines and markers that you can use. In the same way we as humans learn what is dangerous when we are small and each time we encounter these things we don't have to re-learn that. The script I was thinking of was the Highway Code, something I use every day which has been developed over a long time. It may be a bit restrictive but it keeps me safe, and there are quite strong legal consequences if I don't stick to the script.

Sometimes when we talk about Shakespeare we talk about absolute, almost sacred texts that can't be changed, and we know that's not true. A script is a blueprint for a performance; there are words for the actors to say but actors being actors often don't say those words because they forget their lines or miss things, or you find yourself in completely the wrong scene, the plot is getting lost, but the actor you are on stage with has taken you to the scene before the interval and while you're continuing this dialogue which comes half an hour later in the play, you have somehow got to bring the play back, for the people sitting in the audience, to the real moment in time that is actually occurring in the play. So scripts are blueprints but they also offer some actions, people go on or off, but again it's a matter of interpretation; directors, costumiers, lighting designers make creative choices.

So thinking about the scripts you use at work with your encounters with patients, do you think people adhere to them absolutely or are they blueprints or interpretations?

[Partly inaudible] ... tick boxes ... you are expected to adhere to, scripts interfere with spontaneity in human communication ... because you are stopping to tick a box.

I was thinking along the lines of your four year-old who was able to use his intuition to feel what you were feeling. Whereas if the doctor follows a script which is restricting and he has to use it within a certain time-frame, then he doesn't have the space to develop that important intuitive stuff.

This topic of time keeps coming up.

Perhaps people who are learning need to keep to the script and not let go of it until ... perhaps one of the marks of being an expert is being able to improvise once you've got the script and accept the challenge ... to learn something completely freeform without the script.

There are some scripts that are evidence-based and some made up without any evidence.

A very good example is the 111 script. When you ring the 111 number you've got a completely untrained person on the line who just takes you through the algorithm, and people have died because they're not asking the right questions, they can't improvise and have no way of judging.

Speaking of improvising, the thing that keeps coming back to me is about music. You have a set of notes but what makes it as a piece of music is improvising if it's jazz or interpretation of classical music.

But what are the limits? If everybody goes off piste then what will happen?

The patient dies.

Going off piste can be dangerous in this litigious medicolegal world and that is why we are sometimes so rigid.

Some of the conversations I have had about this suggest that it does change behaviour and does in some way limit the wisdom of the practitioner in fully expressing the encounter. Is that relatively recent? Do you feel it more keenly? Is it a generational thing? Does each generation encounter this? It's a story that I hear quite often. If someone gets the script wrong in my world no-one is going to die but ...

It may actually do the reverse because when you are a student learning the script you aren't concerned with the patient, you're concerned with the script because you perceive that the examiner will penalise you every time you depart from it or haven't incorporated something. But with experience we leave the script and take bits and pieces of it that are useful at the time you see the patient. And that experience is a very different issue. If you are a student clerking a patient you may miss some very serious stuff, and like with the 111 telephone calls you may have the patient dying in front of you but you do not know because you are focussing solely on the script.

I have seen this with medical students interviewing patients in the mental health field. They feel compelled to fill in their log books at the end of the session, and totally devastate the patient's emotions by insisting on drilling down to the final ... and when I say that the patient is looking distressed and suggest they should back off a bit they say "we have to fill in our logbooks – we have to do this for our scores at the end of term."

#### Which brings us back to empathy.

You were asking: how long this has been around? I have seen correspondence from a Swiss doctor, dating from the 1750's, about 1500 patients which mentions complaints of not being listened to. This factory mentality, this fix-it algorithmic dominance has been around these past few hundred years. The system is probably making these weaknesses more self-evident in some way because there is less scope for practitioners to blunt the sharp edges ...

Are we less comfortable culturally with dealing with uncertainty? We assume that medicine will ultimately have the answer even if we don't know it yet. That whole

grasp of ... that's your script ... we are juggling the whole time with being comfortable with not knowing.

Culturally speaking one of the dominant stories we hear is about the need for certainty and absolutes. The wisdom of history is a very interesting one.

You can come out of a script if you want to but if you don't have interaction with the patient you will lose them in one second. I have a favourite saying: you never get a second chance to change your first opinion – it goes for stigmas and non-verbal signals, attitudes, your approach, everything. You have five minutes to make a solid construction with the patient so they trust you. Without that you never get what you want ... they just close down everything.

I want to bring another element to the conversation. Do you feel valued as experts – is your expertise valued? Do you feel that in some way scripts disempower your wisdom?

#### Patients value us but the system is another matter.

When you are doing an analysis of a play you always think about context. For me, in my system, reproducibility does not exist. The randomised controlled trial is hokum. So the idea that you can go from bench to bedside in the blink of an eye and expect to get the same outcomes does not hold water. If you think about a play like Hamlet: when you saw it on the stage or TV was it the same as the first Hamlet that Shakespeare wheeled out at the Globe? Same script, same blueprint, but the actual enactment is completely different. As a jobbing actor, what always intrigued me was that you do six or seven shows a week of the same play, same words, same costumes but different audiences, and an absolutely different encounter: different experiences, different meanings would come out of the way the stories were told. And yet, healthcare professionals are somehow supposed to get the same outcome with each patient like a sausage factory. Somehow human beings are supposed to be de-contextualised, and these scripts that are supposed to help you do this. But of course patients, like audience members, bring their own expectations and interpret the world in very particular ways. Have you ever been to a movie you thought was wonderful and your companion thought was dreadful? So it's unreasonable for you, or rather the system, to follow the rules of randomised clinical trials. They don't live outside context, they have multiple conditions; they might have just had a really steaming argument in the car-park; they might have a snotty kid at home; they might hate the receptionist, their sister might say "I wouldn't take that tablet – I had a terrible time with it". Now some of these forces are very potent and complex and changeable. And timing is so important in a performance. In the 1750's there was a whole raft of enlightenment theories about the way a perfect play should be written. and a whole set of rules about the way the action should go, covering 24 hours with three hours per scene and so on, and of course that was completely hopeless. Plays happen over time and they evolve over time. And talking of refashioning of the plastic brain and the way that neural pathways rebuild, change takes time, and this is different for everyone. So what I am trying to say is I wish someone would give you guys a break because you are doing such an amazing, wonderful job. And it makes me slightly sad to think that there was a story in the collective aether about the way that the system shapes things.

So I will just finish up with a bit of textual analysis. All theatre theorists are obsessed with projects. They're mostly Marxists on the quiet. Post-structuralism has been and
gone, post-modernity has kind of had its day, but actually post-Marxist theory is having a resurgence. So the expectance is that somebody writes the script, and that they are trying to convince the audience about a particular story. The audience may or may not go with that.

I want you to think about this idea of power in the way that scripts are written and enacted ... to think about who writes the scripts, how long they last for, and who taught you how to enact those scripts. Was this something brand new when you encountered it the first time, or, when you were a student did you sit in with someone and observe them taking a patient history? And are you still embodying that practice?

# New Perspectives on the Placebo Response

# Paul Dieppe

The title of the meeting is the power of the mind in pain and the title I was given was the power of placebo, but I wanted to change it to new perspectives. (I have talked about placebo at one of these meetings before but I'm sure you've forgotten most of it!) The other title I thought of was 'Why does doing nothing work so much better than doing nothing?', which is actually the real title of this talk.

Before I go any further I want to acknowledge the people who people who put up with me: I am long time expired and officially retired but the University of Exeter put up with me and give me a lot of support. I also have a scholarship from the Institute of Health in Baltimore which funds a research assistant.

I have been influenced quite a lot by my recent reading: the first this book Cure - a *journey into the science of mind over body* by Jo Marchant and the second is a very recent article *Telecebo: Beyond placebo to an expanded concept of healing* by Larry Dossey (Explore 2016)<sup>9</sup>. So as usual I am plagiarising a lot of other peoples' ideas and a lot of this comes from Larry Dossey's work.

We're going to start with a play wot I wrote. The scenario: it is 1969. I am 23 and a student at a London teaching hospital, and I'm fed up with medical education and wanting some different experiences before doing finals. So I go to a clinic to sit in with a doctor.

Me: Can I sit in on your clinic this morning Dr Barham?

Doctor: Oh bugger off, lad – I don't like students in clinics.

Me: But this is a teaching hospital and I have a right to attend if I want to!

Doctor: Oh well, just sit there but for God's sake don't say anything or get in the way. Right – Sister, let's see the first patient.

(Knocks) Come in Doris .... What have you done to your hair? It looks bloody awful.

Patient: Thank you Dr Barham - I had it done just for you.

Doctor: Your lads are still in prison I suppose?

Patient: Well, no, one of them's out now and he's got a job at the garage.

Doctor: With your old man I suppose?

Patient: Well, he's not so good – he's had a heart attack last week and ... (*wipes a tear*)

<sup>&</sup>lt;sup>9</sup> http://www.explorejournal.com/article/S1550-8307(15)00166-4/pdf

Doctor: I'm sorry Doris – that must have been very hard for you. Has it affected your arthritis?

Patient: Maybe, Dr Barham – just a little bit ...

Doctor: OK, let's have a look at your hands ... just hold them out ... turn them over ... My goodness, Doris, that's wonderful! Your arthritis is fine – you've done brilliantly! You must have really been looking after yourself.

Patient: Thank you Dr Barham.

Doctor: Well, that's fantastic. And as long as you go on looking after yourself as well as those layabout men in your life you'll be just great.

Patient: Thank you.

Doctor: Well, you can bugger off now Doris – you've had your time.

Patient: When can I come back Dr Barham?

Doctor: What's the point? I don't do anything for you - I don't give you any medicine ...

Patient: I need you, Dr Barham. You're my medicine.

Doctor: (gruffly) Oh all right Doris – come back in three months then.

(Exit Doris)

Doctor: That, lad, is the art of medicine!

That was a moment in my life that changed everything. It changed me from a cynical medical student who thought that psychiatry was the only way to go because everything else was so uncaring, which is nonsense, and led me into understanding that you could actually be a caring doctor in the environment of London medicine as it then was. That man became my mentor and I went to pay my respects to him at his grave in Swaledale on my way up here.

You could see a placebo response when Doris gets better as a result of his using his hands and his words.

## The placebo "effect"

The placebo effect is a completely artificial concept derived from the randomised trial paradigm and the use of dummy drugs. If we give a drug for anything we measure its effect in some artificial way; a predetermined way which means that we've decided what the effect is going to be and we have decided what to measure rather than seeing what really happens. And then, to see how much of it has anything to do with the drug, we give a dummy drug alongside and assess the response. The only bit that really interests the medical profession and pharmaceutical companies is the

difference between this and the drug response, which in general is about 25%. We tinker endlessly with drugs and fiddle this and that to try to enhance that 25% and completely ignore the other 75%, or regard it as a nuisance; and until relatively recently it was dismissed by most of the big players in evidence-based medicine as just regression to the mean and something we don't have to worry about. But it isn't regression to the mean, because if you put in a third group of people that you just observe and do nothing with at all you do see some effect of natural change, but it's much smaller than what you get with your dummy pill. So that is the placebo effect and I think that is a 'wow!' factor, and it beats me as to why it isn't taken more seriously and given more attention. It does mean that giving nothing can be a very effective intervention, and as I will try to explain I think it's the *giving* of nothing that is the point.

So just to give you a reminder of how big this is with pain and depression: there have been a number of studies where people have looked at the data, where there is enough from control groups of people who have had just observation, dummy and real interventions to give a reasonable estimate of effect size in the artificial settings of clinical trials, and the effect size in pain is around 0.5 to 0.7, which is a good deal bigger than most of the conventional interventions that we use. Recently there have been some attempts to calculate the more difficult problem of effectiveness (effect in real world situations) and the estimate is that about 75% of the effect of both analgesics and antidepressants is the placebo effect. In other words about 75% of the specific intervention! So my question is: why don't we worry about the 75% instead of the 25%?

# How does placebo work?

Theories on how it works are predominantly about the 'power of the mind' and almost all about the power of the patient's mind. We talked this morning about the importance of meaning, and in the placebo literature this has been particularly championed by Dan Moerman who is an American anthropologist and has written a lovely book about the meaning response. He feels that it is all about finding new meaning for suffering, often through symbolism or metaphor, and that it is the reformation and the reconceptualising of the story that allows you to improve. But his are not the conventional ideas on how placebo works. These are psychological or neurophysiological, and all about the patient's brain. The psychological theories are about expectation and conditioning and the neurophysiological theories are about activation of descending inhibitory pathways of pain control and release of natural endorphins or neurotransmitters. Everybody (except me) who is into placebo research uses brain scans nowadays, which seem to me like 21<sup>st</sup> century phrenology and don't explain anything, but the whole concentration is on the brain of the patient. But I don't think it's about that, and much of this research (to which I have contributed) misses a critical point. The patient's brain is clearly an important effector of the change, but something else needs to happen to activate that change, and that is about the interactions between individuals, and the contexts in which they take place, and within that 'the space between them' as much as their individual words, emotions and behaviours.

Another thing which has come to light fairly recently in placebo research is that the response depends on the 'giver' as much as the 'receiver'. There has been a lot of concentration on the patient which goes back to the old idea that some people are

susceptible to suggestion (and probably a bit mad) and includes genetics to see who is the most suggestible. But we now know that some people are better at producing a placebo response than others. There are two rather amusing trials, one done by Suarez-Almazor et al. and the other by Ted Kapchuk's group in which there was a sub-analysis of the responses produced by different care-givers in the situation of giving a sham and a real intervention or a no-treatment/observation control group; and what both of these show is that you can train people to be really empathic and optimistic, and sure enough that results in better responses on average. But some people can get a great response even if they are being surly and negative, and some people can't get a good response even if they are trying to do it properly. So it is very much the individual giver. The other stuff that has come up through a number of channels is that the *good intention* of the person who is giving the treatment seems absolutely critical. So our intentionality as interventionists matters. And I think that probably screws the whole evidence base of medicine! There are a number of good examples in the literature of experiments that have been done by a sceptic or a believer in exactly the same conditions, and the believer gets a good result and the sceptic gets no result. If you think that through in terms of our trial technology we can't believe evidence if it depends on the intentionality of the person doing it, and never think about that or try to measure it.

I'm going to detour for a moment into Greville-Harris's work on the nature of the interaction. She was one of my PhD students a few years ago. David [Reilly] was talking about safety this morning, and it seems that both giver and receiver must feel safe. How often in the medical consultation do the doctor or nurse and the patient actually feel safe? Almost never, I should think, when they first meet. Being safe is about activating the nurturing response, which is the exact opposite of the fight or flight response; we have this hard-wired response which allows us to look after young babies and to work in groups. So it's no wonder that when you tell people that they have cancer they don't hear anything else, because they are immediately in fight or flight, and then they don't hear things properly and you can't communicate with them. Both sides must be safe, and Maddie (Greville-Harris) had good empirical evidence for this. The other thing she worked on was the importance of validation as the key to a good placebo response and invalidation as a way of invoking a nocebo effect. Validation is more than empathy because it's about the receiver as well as the giver; you can be very empathic but if the person next to you doesn't know you are being empathic there is not a lot of point. So validation is about the patient knowing that the other person really understands and cares for you. Invalidation can occur if the patient thinks that you do not really understand or care, and can occur inadvertently when you think you are being very empathic and reassuring, for example when you try to reassure someone, like when the doctor says 'Oh don't worry, I don't think there is anything much going on here to worry about'. That gets interpreted as 'he does not believe me, he thinks there is nothing wrong with me - the bastard'. And that is very damaging; we think it is happening all the time in routine consultations and produces a tremendous nocebo response. That curmudgeonly old doctor Wickam Barnham who I portrayed earlier taught me that any doctor who did good more than 50% of the time was a bloody good doctor. I thought he was a silly old fool when he said that, but I think he understood that mostly we get it wrong, and our research suggests that he was right about this. But the other side of this is that Maddie's experimental scenarios suggest that bad is five times more powerful than good, or in other worlds nocebo is five times more powerful than placebo. And that fits with a lot of other sociological and educational literature. Teachers know that you have to give five times more encouragement than criticism.

# Placebo effects – curiouser and curiouser!

So that is the conventional placebo stuff, but it's actually much more interesting than that. Placebos do amazing things. They work on animals, and 'good intention' works on plants as well as cells in culture. Placebo treatment can cure cows of mastitis and prevent rabbits from getting atherosclerosis. In a randomised trial in which some rabbits were fed a high fat diet and some were not, in general those in the high fat diet group got atheroma and most of those in the normal diet group did not, but one group on a high fat diet got no atheroma. That really confused the researchers. In trying to discover what was going on, they got to the point of studying how the handlers of these rabbits worked. They found that there was one handler who used to cuddle the rabbits when feeding them and be loving to them. So they repeated the experiment comparing the results in rabbits looked after by this individual with those of other rabbit handlers. And sure enough his got no atheroma. Isn't that cool! It does seem like caring for the animals because the conclusion of the vets involved in the mastitis studies was the same, that they got those results because when they were giving the cows the placebo they patted them and gave them attention they didn't normally get. Now lots of these experiments have not been able to be repeated, but I'm comfortable with that as some people can do these things and some can't, so to expect them to be generalisable kind of misses the point.

The plants, seeds and cells stuff is very well documented, (and is the subject of a meta-analysis by Chris Roe of many good studies published in Explore 2015). Healing intention can allow seeds to germinate better, seedlings to grow more, and cellular enzymes to behave differently. The effect of healing intention is actually bigger in plants and cells than in humans. I suspect that may be something to do with the complexity of experimental design, but you get quite a reasonable effect with all the studies of this sort of thing with people who feel they are able to designate themselves as healers through intention. That's pretty amazing.

## Distant healing

So it seems that this is all about the induction of what we might call a 'healing response' in one living organism, through the good intentions of another. And if that's true, maybe it can work at a distance. The idea of healing at a distance has always been particularly difficult for conventional science, with its materialistic view of the world, and no obvious means by which any transmission of any message or energy or anything else could be possible. But there is now strong experimental evidence to show that it can occur, and there are new ways of thinking that can help explain it. There are loads of strands of experimental evidence, from the extra-sensory perception (ESP) literature, from human interactions with animals, near death experiences and the like, and brain scanning experiments. Hundreds of ESP experiments have shown that it works with odds against chance findings ranging from 8.5 x  $10^{46}$ : 1 to 2.6 x  $10^{76}$ : 1. If you saw anything like that with anything conventional and acceptably 'scientific' you wouldn't question it, would you. You'd say: my God, it works! But these are phenomena that are not accepted by scientists. (The phenomena studied are knowing you are being stared at, even from some distance; dice psychokinesis, making the dice fall to the number you want; and Ganzfeld remote viewing where you put someone in an insulated chamber and someone miles away transmits a picture.) These things are hard to argue with but people do.

There was a great discussion on BBC Radio 4 a few years ago about this stuff between Rupert Sheldrake and Richard Dawkins. Dawkins was saying I don't believe it, so Sheldrake said "well, this is scientific evidence" and Dawkins replied "I don't care how much evidence you give me I'm never going to believe it"! So nobody believes this stuff, but there it is.

And then there is the animal data which is very intriguing, There is loads of stuff about animals 'knowing' when their owners are about to come home, or 'mystic mogs' who know when people are about to die. A palliative care doctor who is a friend of mine told me that if they didn't know who was going to die soon they just looked to see whose bed the cat was sitting on, and it was always right.

# I totally uphold that; I worked for years in a hospice and the cat was always right even when the doctor was wrong – whether it was the smell or ...

Of course it might be the smell, but it also might be something to do with the weird phenomenology that I am suggesting.

And now there is brain scanning. The first experiment I know about was actually done ages ago in 2005 by Achtenberg who was interested in native healing in Hawaii. She went there and asked healers to pick one or two subjects that they thought they could connect with particularly well. These went into a brain scanner while the healers who were the other side of the island sent healing intention in 2 minute bursts at random times. The scans of the subjects reproducibly changed during the periods in which the healing intention was sent. That sort of protocol has been repeated quite a lot and people are now using what are called hyper scanning techniques, where you can put two people in scanners at the same time in different places with exactly the same scanning protocol, and look at synchronisation of their brains, and it works.

But it's all a bit underground, this stuff, and not talked about a great deal because it doesn't fit conventional science.

## Explanatory frameworks

One of the proposed explanatory frameworks involves quantum mechanics and 'entanglement'. I don't understand guantum mechanics; when they are explained to me I feel for a moment that I am getting the plot and then I lose it again. Apparently electrons can be in two different places at once and react in exactly the same way at exactly the same time. Another involves consciousness research and the concept of the 'non-local mind'. So we seem to have three strands coming together: quantum mechanics telling us that it is all as it probably should be, distant healing which has always seemed a bit weird, and consciousness research. Regarding the 'non-local mind', within the biomedical model we believe that consciousness is generated by the brain, but there is little or no evidence to support that hypothesis, and quite a lot of evidence against it. Many former scholars like Jung didn't believe in it. Nor indeed do the quantum mechanics people, and several of them share Max Plank's belief that 'matter is derived from consciousness' and that there is no matter without consciousness. I have no idea what that means, but I think that the idea of the nonlocal mind makes a lot of the phenomena we see in medicine and that we have been talking about today, like placebos, easier to cope with than our current materialistic, positivist hypotheses. So the idea is that consciousness is out there and our individual brains are receivers and filters of consciousness, and of course because

our brains are different and have developed differently our experiences are all different; and our contributions back and forth are different with different people but we are all trying to connect it in to the bigger picture.

In the healing community people are often presented with this kind of schematic [below] whereby as humans on this earth we are body and mind and that dominates because it's about survival, sex and tribalism, but we also have our soul, our spiritual side which is the bit that is connected with the greater consciousness out there and that bit is about connectedness.



## Discussion

Thinking about empathy, there seems to be evidence of neurones in the front of the brain that can communicate with another person's brain ...

...yes, neuronal 'mirroring' is a well-established phenomenon and that is the phenomenon that David [Reilly] was talking about and illustrating – if you are with someone and they start crying you start crying as well; and you get mirror neurone effects so the emotional part of their brain lights up and that lights up in you as well. The neurophysiologists try to explain why we empathise in that sort of way without the need for anything metaphysical, through things like micro-expression and body language which are clearly important in communication. They may well be right, but I suspect that it might be a product of a deeper connection.

It's a bit like coming out! So many of us have been reading about this stuff and had experience of it and yet ... so it was great to have it laid out like that. What sort of

# audiences have you tried it out on? Have you pushed the boundaries of more conventional groups?

It does feel a bit dangerous. This does upset a lot of people. Forgive me for another story I may have told before: about a year ago I had some really bad trouble with my knee and I couldn't walk much. I was considering having a knee joint replacement; the X-ray showed that the joint was completely screwed and I got as far as seeing an orthopaedic surgeon friend who said he would do it in time. But instead I went to a healer and it got better. One of my daughters is a doctor and when I saw her for the first time for a while she noticed that I was walking properly again. She said "You went and had your knee joint replaced without telling me, didn't you?". So I said "no, no – I've had healing on it" – and she looked at me … I could see that look meaning he's really lost it! … and then she stopped herself and asked "have you had it re-X-rayed?" (which I hadn't). She said: "well, if you get it X-rayed and it seems to have got structurally recovered we're all buggered, aren't we?" - meaning the whole medical profession, the whole evidence thing – the whole premise goes away. And that is the fear. She was right – if it is true we're all buggered.

#### What does the X-ray show?

I have not had it re-X-rayed. [Laughter]

There was a great story told to me by a patient whose mother, an MP, had had healing on her painful hip and had no more pain. About ten years later she started to get pain in the other hip. She went to see an orthopaedic surgeon who X-rayed her and told her that the hip that was hurting was not too bad, but that he was more worried about the other hip which didn't hurt at all!

To answer your question about where else I have tried this out on: I have done this with my ex peer group i.e., with rheumatologists and orthopods. The last time was in Seattle at a big meeting of the Osteoarthritis Society, and I risked something along these lines. I was quite scared but the reception was fabulously positive. People came up to me and said "I knew there was more to it but nobody has been prepared to admit that." I feel very safe in this audience but there are some with whom I would still feel anxious.

At one time I was involved in a trial of homeopathy and the 'problem' was that it was coming up with positive results. It was a fantastic lesson for me about the cultural nature of science, and the non-acceptability of anomalous results. The beast that can be unleashed ... the fundamentalism within scientism. There had been about 200 trials in the world of which the majority had been positive. But I decided to stop as I realised that if there had been 300 trials it would make no difference. It's intriguing that you have felt that you have crossed that line.

Regarding the possible practical applicability of this: when the steering committee got together to discuss what we were going to talk about this year I was rather keen on talking about the future of pain medicine, but you came up with this much better suggestion of the power of the mind. It seems to me that apart from some relatively minor technical improvements in intervention, pain medicine has stopped progressing. I think it had almost stopped before I retired 16 years ago. It seems to have met an impasse. So can I invite you to speculate about what this sort of thing may hold for the future of pain medicine – indeed medicine in general? Is it a way out of the impasse?

I am encouraged, because if I talk to medical folks as groups there is scepticism, but if you talk to them as individuals there is not – particularly GP's but also people in pain medicine and palliative care. They are incredibly receptive to a 'spiritual' model of health care; a model that is more about understanding the spiritual aspects of the essence of a person that might connect them with something else. So somehow the barrier is not the individual but the culture. But I think if enough individuals don't accept the culture there will surely be a break point at some time.

... which takes us back to a previous meeting we had on changing the culture of pain medicine.

... [incompletely audible contribution] some aspects of medicine ... a lot of us are practicing in any case on the premise of the reality of the placebo response ... maybe things have begun to shift ...[away from] the age of pharmacology. I think we are beginning to realise that a lot of the drugs that we actually use... the huge use of antidepressants ... [are unhelpful, provoking] such a backlash against the pharmaceutical industry that [the zeitgeist] might be shifting. There are certain areas ... pain, neurological things ... where this response is all important and others where it is not. ... you are saying individuals get this and some always have done. I would love to see ... a lot more scepticism about pharmacology.

I agree with you and feel encouraged that ... of course the timing is critical and whether this is the right time to be using this language I don't know. Larry Dossey has for a long time and a few other people. Is it time for a shift?

It doesn't have to be one or the other, because there is the treatment effect ... having that plus concentrating on how we increase the non-specific treatment effect as well ... I agree entirely that we don't spend enough time on that - we don't understand what we are doing but huge benefit could be got from those clinicians who are not giving that part of the treatment and not making the most of it.

I gave a similar talk to this one just last week in Hull at a meeting of palliative care doctors and someone asked: "you are saying intention matters – what is that and how do we practice it?". I risked a further word that I haven't used this afternoon: "I think it's just pure love". I think that is probably it. That's a word you daren't use in medicine.

David used it this morning. In a traditional sense it feels very scary. In the scenario you painted with your play that word wouldn't have been appropriate at all.

Surely that's part of being professional – part of the vocation of care.

One thing that has come to light recently is the practice of facet joint injections. I'm convinced that is a placebo effect. For the last 23 years I have watched my trainees putting needles everywhere but in the facet joint, but that doesn't matter; what matters is me muttering "oh that's marvellous – I'll be out of a job soon if you carry on like this ..." and the patient gets better.

We're talking about magic and that's the magic pill that's got 75% effect whatever the other 10-15% on top is doing. Mysticism in medicine played a huge part not very long ago, and we all may have met someone who has actually been like a mystic. When I think back I have certainly encountered people who still have this power of love but

also wisdom and understanding. When you are young you don't understand; it can't be taught but only experienced. There are wonderful drugs like aspirin or penicillin but they have been taken over ... I think this is probably an unintentional side-effect of very good medicine in one way, but it's taken over the old tradition of shamanic medicine which connected people and we need to have that theatre ...everybody knows from childhood how it works.

It goes back to the old monasteries; the monks were indeed mystics.

It might be to do with non-local effects or transmission but it doesn't matter. People respond to care – that's what we are, it's a central aspect of our being. People talk about theatre and performance but that doesn't resonate with me so much. When there is a genuine caring it changes ... it touches people.

For the last 30 years I have been going to Lourdes with the Jumbulance Trust. I'm not a Catholic and some of the nurses I go with are Hindu ... people from all walks of life come as volunteers ... we always have a healing service with laying on of hands, and I have seen incredible things, and for me it's love in action. I'm very happy with that word. There are people here involved in Jumbulance and we have seen similar things on holidays, where there isn't anything religious and it is about living together in that context and voluntarily giving people your total attention for a week. We're not using drugs or anything else – just ordinary people giving something to other people; it works miracles.

Sarah (Goldingay) bullied me into going to Lourdes with her to look at the effect on people's pain and I was very impressed. I went prepared to be very sceptical, but you can't be sceptical there. There is something magical about it.

There is something that has become very clear from our work in Lourdes in collaboration with the neuropsychologist Miguel who is a Catholic. There are two stories I want to tell. There is a wonderful woman called Ann Solari-Twadell who is professor of nursing at Loyola University in Chicago, and every year Ann takes the final year nursing students to Lourdes for two weeks. When I went out to Lourdes to do some fieldwork I chatted to these amazing people who had had a very intense two weeks – a lot of rubbish wheelchairs, very high curbs, very stressed Italians - asked them why? – What do you get out of it? And the answer was: "you lose the checklist, the script. You don't know what the diagnosis is, you probably don't speak the same language as the person you are with ..." – "So what do you do?" – "You touch!" Wow!! – How dangerous is that? They call it the deliberate touch; it can mean stop, it can mean I am here for you, it can mean turn this way, slow down, or speed up – instead of using words you just touch. So there is this other language, but in all of this love is the absolute underpinning force.

Adam is a gastroenterologist at Bart's who has led a pilgrimage to Lourdes for a number of years and collecting data from patients off and on the Jumbulance service. Adam said that for a lot of the volunteers who go (who are non-medicals – they might be stockbrokers or whatever) it's not just the sick people who go to Lourdes who find benefit, but the volunteers who are emotionally well find benefit through this altruistic process of giving and receiving love, even if they don't self-identify as someone ...

How do you cuddle a plant? I can see how there can be an interaction with rabbits but ...?

You just have to love them. If you have two pots and decide to love the contents of one they will do better. That's all – there is no physical contact, no different treatment. There are wonderful stories in the literature about plants sensing negative and positive interactions between people. There is one about a patient who came to see a psychiatrist in a dreadful state, everything was negative, and as the consultation went on the plant in the corner started to wilt! Is that a nocebo effect?

## What about cursing?

Indeed - the nocebo effect is incredibly powerful - as witness voodoo deaths.

[?] tells the story about a man who was dying and the priest gave him the last rites and he died appropriately. A few minutes later it was realised that the priest had gone to the wrong bed!

#### Has anyone compared outcomes from individual carers?

Yes. It is a study I have tried to do but it is incredibly difficult for ethical reasons to say I want to compare good and bad doctors, so it's only been done by sub-analysis of other trials. There is some work coming out with questionnaires.

# Brief Psychological and Hypnotic Interventions in the Management of Pain

# Giving control back to the patient

## Ann Williamson

I was in General Practice for 32 years (although I have now been retired for several years). In the late 80's I got very fed up with only being able to help my patients with diazepam (before we had Prozac). The only people I could get help with were the suicidally depressed or actively psychotic. I tried various approaches including hypnosis training with what was then the British Society of Medical and Dental Hypnosis (BSMDH). As a GP I am a generalist; I don't have any adherence to a particular model or way of looking at things. As we were saying yesterday we make up our own stories. The danger comes when we start to believe them. Because I was working in a GP setting, time was of the essence. There was no way I could have an hour's session with a patient; I was confined to ten minutes. I could do a group at the end of surgery and I did use this to teach self-hypnosis and various tools and had short sessions with people individually. (Now that I only see private clients now and again I have the luxury of a whole hour.) So I was looking for things that worked guickly and approaches that seemed to get in to the nub of the difficulty. I joined the British Society of Medical and Dental Hypnosis (BSMDH) which joined together with the British Society of Experimental & Clinical Hypnosis to form the British Society of Clinical and Academic Hypnosis (BSCAH). The thing that marks us out from all the other myriad of organisations that offer hypnosis training is that we will only train health professionals. We don't train them to be hypnotherapists: we train them to use hypnotherapy within their own field of expertise. I have a lot of information for patients on my website www.annwilliamson.co.uk. Time being of the essence I wanted my patients to look at stuff first so I didn't need to spend too much time on it in the session. Now, thanks to modern technology, I have two self-hypnosis and guided imagery tracks that are downloadable from my Dropbox so patients can go away and play with those. BSCAH has a new website www.bscah.com with a lot of information.

Talking about chronic pain, I have an article about to be published in September in the American Journal of Contemporary Psychotherapy<sup>10</sup> with the same title as this talk.

The other thing I wanted to mention is the Science and Medical Network. I was exhilarated yesterday to hear about the non-local mind and other things beyond the boundary of our reductionist scientific paradigm. The Science and Medical Network is a body of people, many of whom are very erudite medics, physicists and other scientists, who come together to discuss things on the edge, which I found about 15 years ago. Someone commented yesterday that it is good to have a safe space to talk about these things, and this provides such a space. I do recommend their website www.scimednet.org.

<sup>10</sup> http://link.springer.com/article/10.1007/s10879-016-9327-6

[At this point, audience members were invited to settle themselves down comfortably and allow their eyes to close, or focus them on something in front of them, and just begin to notice their breathing - not changing it in any way, but just being aware of the rise and fall of their chests and the flow of air in and out.]

They might notice that the air flowing into their noses is a little cooler than the air flowing out. We all live such busy lives that it's good to have a moment or two to just be. You may be relaxed but you don't have to be. If there is an area that is uncomfortable you can just breathe out into it and let it go. You may find that thoughts flow into your mind because that's what minds do, but that's OK, just gently redirect your attention to your breathing. You can imagine breathing in the colour of palms... Each breath is in a new beginning and each breath out a letting go. You can take yourself in your imagination to somewhere calm and peaceful where you feel secure. You will find that as with any skill, as you practice this will become easier and quicker to recapture that feeling just by focussing your attention ...

[And then we were invited to gently reorient ourselves into the room, noticing the chair, sounds; opening our eyes ...]

When we use the word hypnosis people usually react: "ah ... someone's taking over" and we have to fight against that. When I started I used to avoid using the word and just say I can help you to relax etc. but now I want to educate people so I do talk about it. But you've got to have time.

#### It crosses over into meditation.

Of course it does. I have done mindfulness and meditation training and it seems to me that they all go to the same space as self-hypnosis, but what is different is the intent and what you do there. In self-hypnosis you tend to be using more active imagery; like a "therapeutic daydream" as a colleague called it. With mindfulness and meditation you also have a goal, but it's slightly different. I think that all 'complementary' approaches - massage, aromatherapy, acupuncture - have that capability to take someone from their busy day-to-day existence and put them in a space where they have a sense of being rather than doing, with a healing intent. They all have different stories because we don't really understand it.

I do see, and have in the past seen a lot of patients with pain and also as a GP a whole plethora of different conditions, so sometimes I shall be talking about pain and sometimes about other conditions. When it comes to a patient with a problem so often their attention is so focussed on the problem it becomes their identity: they are their pain, their difficulty, their anxiety, their depression. The prime thing we have to do is to change that focus of attention, and this is where self-hypnosis and the other techniques are so important. The other thing is that people fight against their problem; they deny it. I well remember a guy with post-herpetic neuralgia saying it felt like his side was raw and open and someone was rubbing salt into it. He hated it and wanted it to go away. His imagery was of a black octopus clamped to his side. After a few sessions he made a real step forward. I don't know what went on in his mind - I don't think he knew - but his imagery changed to blue fluffy cotton wool. The way he experienced his problem had changed when he started to gain a measure of acceptance rather than fighting it. One of the many metaphors I use with patients is to say "You've got a pain. Pain is obviously a message, but with chronic pain we don't read the message in the same way. Say you are a busy mother in the kitchen

and you toddler comes clamouring for attention you're going to say "oh go and play – Mummy will be with you presently". Does the child go away? Of course not! Their demands get louder and louder, and that's what pain does if we don't just accept it for ten minutes". One of the suggestions I make under hypnosis if I'm working with pain is that as long as things are going on all right the pain can whisper – it doesn't need to shout. If there is something you need to attend to you will be aware of that.

The other big thing is uncertainty. People hate it: they like labels, because they give them a certain amount of validation. ("It's not all in my mind" – well of course everything is in your mind and in your body, but people don't get that.) Getting people to tolerate uncertainty is what a lot of us have to do.



Left and right brain

I like this diagram, which was created by my colleague Les Brown, and draw it out for patients. Note the different types of communication. Patients will know that it is silly to have a panic attack at the sight of a tiny spider. Telling themselves that doesn't make any difference, does it? So how can we talk to both these parts – left and right brain – of our processing? That's where imagery comes in, and why that and visualisation features in so many approaches including CBT. The other thing is that the left brain is kind of analogous to our conscious mind and the right to our unconscious mind. All the world's greatest teachers used story and parable and painted word pictures to get their points across. If any of you have been in the presence of a great story-teller like Helen Forrest; I came across her at a folk festival once and she was telling a story. I looked around the room and everybody was entranced. This is the power of the words we use to paint stories.

What is hypnosis?

In the old days it was very authoritarian: "you are feeling sleepy – you are going to sleep" etc. But this was then in the context of authoritarian medicine. The doctor was

god and you came to him and he told you what to do and you obeyed. If you got well he was a great doctor, and if you didn't ... that's life. Nowadays our feeling of what a trance state is is on a continuum from just closing your eyes and imagining – a form of hypnotic processing - to being able to undergo major surgery under hypnosis; and from an outer to an inner sense of awareness. I tell my patients it's not like flicking a light switch. Sometimes in a session you are more aware of what's going on around you and other times you will be more focussed inside. In the same way, you sometimes get lost in a good book and don't hear when someone is talking to you, but you'd soon respond if someone shouted "FIRE"! You can either have a kind of 'conversational' hypnosis or a formal hypnosis session. I rather like this definition:

Hypnosis is an altered state of consciousness characterised by changes in mood, sensation and perception, and allowing for greater access to unconscious processes. (J. Barber)

Our minds are the most powerful tools we have if we can learn to use them better.

People often want magic bullets or wands: "you're going to put me under and when I come out everything will be wonderful". If only it was that simple. Hypnosis itself is not a therapy; it is a tool that can facilitate the delivery of therapy in the same way as a syringe delivers drugs. It doesn't make the impossible possible but can give people an experiential way of discovering what might be possible.

Few patients will abandon their symptoms until they feel strong enough to do without them. (Hartland)

It depends so much on the person as to how quickly or slowly you can work. I have done a lot of work with PTSD; there was one chap with a normal childhood and no previous problems. He was working with large sheets of plate glass and one fell and killed a workmate. He was having nightmares; he was drinking and smoking too much, not working: a typical picture with hypervigilance etc. His insurance company paid for three sessions with me. But because he had a good background I was able to do it in two. But there was another lady I saw for two or three years because there was a little bit of progress. The difficulty as a GP is that you don't want to keep seeing people if there is no progress. If there has been no shift after three sessions I either say this isn't the right time to be doing this or I am not the right therapist for them. Some people will do a bit and then plateau.

People are experts in their own problems. We talked a little yesterday about people needing to be validated. So often as a GP I see people who go on and on and on about their problem. OK, it was good for them to vent, but they had vented and vented to the counsellor and me, and it wasn't helping because of course you re-traumatise every time you go through whatever the traumas were. I needed a way of breaking that flow of talk and switching it to something more positive. So I developed a way of interrupting that doesn't break rapport, like dropping a pen or moving my position; and then saying something like: "You were saying that last Wednesday you felt you were doing rather better – how did you do that?". Or, I have a bracelet that has a bit of a dodgy catch and I fiddle with this ... then within the next second or two focus attention towards solutions. Again, it depends on the person and the context. I had one elderly lady who came in and said "I don't want any therapising, but I want to tell you my story." She had a history of terrible abuse at a convent in Ireland. She had never told anyone and had chosen me to tell, as she just wanted someone to witness

her story as she was getting old and might be dying soon. I wouldn't normally have done that with her but the context was different. So it depends on the context whether or not to use all these tools. You have to balance validation and change. You can't get anywhere without rapport.

## The power of words

There is story, which may be apocryphal, about the patient told by an Australian surgeon that "You're going home to-dye", and finished up in ICU where nobody could figure out what was wrong with her, which shows how the meaning of our words may not be what we intend. People latch on to certain words. As a GP when I had to explain to people that they had to go for cone biopsy because their cytology screening showed some abnormal cells, I would say that there were some precancerous cells we needed to keep an eye on, and we're going to remove these and you should be fine. But what do you think they heard? Cancer! They'd ignore all the rest. So instead I would tell them a story: "Think of a beautiful English village with a village store and a pub, and a village green with a duck-pond. There is a village bobby striding about but all is calm. Suddenly down the lane a group of bikers comes roaring up and parks in front of the pub for lunch. So the policeman thinks he had better keep an eye on them. So your cells are a little bit like the bikers: we have to keep an eye on them. We are pretty sure that they will go away without causing trouble but if not we will have to put them in jail". So you get the real message across rather than just the word cancer. Stories are really useful.

The 'unconscious' does not process negatives. It's no good saying: whatever you do, don't think of an orange giraffe with green spots. But you can say think instead of a green elephant and supplant one image with another. If you say: don't worry about it or this won't hurt, it just doesn't get processed. The negative is our default position. We need that for protection lest we dismiss a lion rustling the grass as just the wind and finish up as his dinner. We need to be aware of that. Emotion makes one more suggestible as we're going into that right-brain processing with better access to the unconscious. If someone comes into your consulting-room in an adrenalin-charged state, the things that you say are going to have a much greater effect. Adrenalin 'fixes' memories. You may say something as a throwaway line and it will be there as an imprint on that person for the rest of their lives unless they deal with it. For instance, when dealing with people with fertility problems I quite often used to find that the psychological block to pregnancy was something that someone in authority had said to them when they were in a vulnerable position and that they had taken on as an imprint at an unconscious level and they weren't even aware of it.

So in any therapeutic intervention you want to facilitate a different perspective on whatever their difficulty is - and *to engage the imagination*. That is a wonderful tool that people have. When patients say: "I'm really anxious", I say "that's wonderful! – because to be anxious you've got to have a good imagination to imagine all these terrible catastrophic scenarios. So let's use that in a way that's more helpful for you."

That goes with focussing the attention. Until you focus your attention on something you are not aware of it; you were not aware of your left foot but as soon as I mention it you are. There are different ways of getting patients to focus their attention and it doesn't matter how you do that. It could be teaching meditation or self-hypnosis. I had a patient - a young girl - who was a dancer. She went and danced her problem and then danced what she wanted to feel. One of the most difficult patients and most

damaged person I have ever worked with, which I did for two or three years, was a young woman who had had a huge amount of abuse and rejection in a terrible childhood. She was very inarticulate: she couldn't put what she felt into words. So I gave her a drum and she drummed what she felt, so she was externalising it and getting it out there. Once you have got it out there you can do something about it. Another thing I did with her was to write down all the negative things she wanted to get rid of. She then put them in a carrier bag and left them on a shelf in my office, so she could go away feeling 'I don't have to carry that baggage any more'. And when the time was right we went and had a little bonfire. For someone who wasn't articulate she wrote the loveliest poem.

That accessing being state is really important ...

There is a dance teacher who works with street children in Brazil. She gets them to imagine what it feels like if you're happy and then move like you do when you're happy. I have been using that ...

... you can experience what you want whatever way you can, whether it's drawing, writing, playing, moving – they're all good ways. You can access these being states when you are involved in an activity; that's why people go running.

### Imagery

There are recent fMRI studies that show that what happens in the brain when you imagine something under hypnosis seems to be very similar to what happens with the real thing. This is why imagery and visualisation is so useful.

Kosslyn *et al.*, (2000) used two groups of subjects, one under hypnosis and the other just using mental imagery. They were both asked to imagine the colour of squares. Only in the hypnosis group were colour areas of the visual cortex activated when asked to perceive colour; just thinking about it didn't work. In another study, comparing physically induced pain, hypnotically induced pain and imagined pain, brain activation was almost the same as physical with hypnosis but minimal with imagined pain.

Imagery isn't just visual; some people are great at visual imagery and it's really good to work with them but some can only get an 'awareness'. It can be auditory – I had one patient who was only able to enter a hypnotic state by imagining playing her violin. It can also be kinaesthetic, olfactory or gustatory or spatial. Another thing you need to be aware of is if you're seeing yourself 'over there' it doesn't have the same emotional impact as if you are actually doing it. Imagining you are on a roller-coaster is much more frightening than being on it. That means that we want to associate with things that are good. So when we are setting a goal when we are doing a mental Rehearsal, of something like going to the dentist feeling calm, we want to associate the person in the image so they are looking through their eyes, hearing through their ears, being themselves. If it is something traumatic we want to see it over there at a distance. We don't want to get caught in with the trauma.

There are several uses of imagery. I like, when I am working with someone, to get them to develop a special calm place for themselves, I always prefer client generated imagery because something that comes from a person's unconscious will be far more powerful for them than anything I can suggest. I ask them what sort of things come to mind when I say the words peaceful and calm. They may find they already have a resource for getting calm feelings.

We can help with getting rid of things. We all have negative feelings and if we sit in them it doesn't help us at all, and throwing them away can be useful. We can help our patients to get in touch with their resources; they have so much within them that they don't realise and even with the most difficult fat-file patients, if we listen to their stories, we may wonder how they managed to get through all that – it's sometimes surprising they aren't ten times worse! So helping them to get in touch with that resilience that has brought them through is part of 'therapeutic history-taking'; it can be really important what kind of questions you ask. If we change what we see, by which I mean internally construct, then we change what we feel. If I am seeing myself as useless, unlovable, I'm not going to get anywhere. That's what I feel I am. So if I can change that and get that person to begin to realise that actually... yes, OK ... yes.

I work a lot with depressed patients as this is so common in General Practice. I had one lady with chronic depression who brought me a gift of a cross-stitch picture she had done. We spent the whole session – 10 or 15 minutes – exploring; 'what does that tell us? You've got an eye for detail, you're patient etc.' A whole lot of resources in that one place. She'd never thought of that. With another person who was really depressed the very fact that they'd got dressed and come to see you – that's a plus!

So you can change how you see yourself. (Is anyone here perfect?) You know how depressed patients often say "as soon as I open my eyes I know what sort of a day I am going to have. They are giving themselves negative suggestions. So I give them this little exercise to do before they get out of bed:

[The audience were invited to close their eyes and imagine a full-length mirror behind them.]

There is a picture of you in it the way you are now and the way you don't want to be. It doesn't have to be a clear visual image, just an awareness. Now I want you to imagine a mirror in front of you with a picture of you the way you do want to be – acting the way you want to act and feeling the way you want to feel. So after a few moments make a conscious decision as to which mirror you want to step into. Then step into the one in front and feel how that feels. Say something internally that is appropriate like 'now I can do this' and then open your eyes. Now close your eyes again and repeat the exercise. You know what to do now. It's important to open your eyes between each exercise.

That is something quick you can teach a patient and they can take it away as a tool to use. If they have difficulty at first we explore that and try again so they know they can do it for themselves. I also use it for stopping smoking: the mirror behind showing you as you are, smelling like a stale ashtray, coughing, breathless - and the you you want to be – smelling fresh, breathing easily - in front of you.

I went through a phase when I seemed to see an awful lot of people who were being harassed and bullied at work. The conversation would go like this: "How do you feel?" "I feel threatened". "What do you think your body language is like?" "I retreat into myself." "So the person who is bullying you sees that and responds. If you can change who you are you can change them. How do you see them? As a puppet? Can you shrink them down, etc.?

To give you an example of my own: my husband used to work for the Royal Mail; he was quite high up in the management and I used to have to accompany him to dinners. There was this chap who thought he was God's gift to women and would invade your personal space. It was spoiling our dinners. The image of him was *here*, large and colourful so I pushed it away and shrunk him down and put it over there. And changing my response changed how he was as well. In couple's work if you can change one person's response you can change the whole thing.

There are all sorts of ways you can use imagery. I once saw someone who was being bullied art work and feeling really squashed and it just came to me to suggest that she might try smiling at the first three people she met when she went into work; she did and it changed the whole context. A little change can cause a ripple effect. A lady with very severe endometriosis which was causing her a lot of pain who had undergone laparoscopy to deal with some of the adhesions used the imagery every day of washing her inside with healing fluid. When she went back for further surgery the adhesions had actually gone. Whether this was the effect of the imagery or natural progression we shall never know.

## Auditory imagery

I often find it useful to focus on self-critical dialogue and try to change it. The trouble with it is that it always sounds so believable. Part of us knows it's not but it still feels believable. But how believable is the voice of someone who has inhaled helium? So how about changing the internal dialogue if it's something that keeps being repeated by making it a Donald Duck voice? Once again simple things can make a huge difference. And when you start changing something you are taking control.

### Discussion

Rather than people with difficulties needing to be taught, is it that those of us who do cope have an innate ability? I self-hypnotise myself regularly and an awful lot of what you have been talking about is intuitive common sense. I'm not aware if there is any evidence of a deficit of that in people who don't cope or whether it gets destroyed.

I haven't seen any research on that. People who have difficulties in their background usually have fairly low coping mechanisms. As a GP I'm not averse to teaching these but a person-centred counsellor might be. I've had many people come to me after many sessions of counselling saying I know where these feelings come from but I don't know what to do with them. I think you need both.

It represents something we are missing. We talked yesterday about the amazing potential of placebo and David talked about how you garner areas of the mind .... There is something there that we don't really understand, but when we use these techniques we are linking with it and turning things round for patients. I wonder whether we will ever understand this common link.

I'm happy to say I don't know.

In the context of what you were saying about the power of words (and incidentally the context of our topic for next year) could you comment on the use of the word 'fighting':

as in 'fighting' cancer, or in obituaries, that someone has died after 'a long battle' with cancer?

I'm a bit ambivalent about it. I think one needs to fight insofar as you want to help yourself to be as healthy as you can be. I know people use imagery about white cells eating cancer cells but in that context fighting generally doesn't feel right. You're getting into that adrenaline state as soon as you start to fight ...

... violence ...

... failure if it doesn't work ...

I would never use the term fighting; I would say "we'll use imagery to help your body to be as healthy as it can be" and that might include white cells mopping up cancer cells – or 'healing light' flowing down – or however you like to imagine it.

We all have cancer cells in our bodies so the healing goes on every day. So it's a process, not a war. I never talk about 'wear and tear' but always 'wear and repair'.

# You quoted a study comparing imagery with hypnotic trancing: why were the results different? What was the element in hypnosis that made the difference?

I don't know why it's different. Hypnosis is a ritual and one of the many rituals we have. When I am teaching someone when I first see them it's a bit like making a new dish: you follow a recipe to begin with and then after a while you don't bother to look at the recipe; you just do it and you might add a bit of this and that, or take short cuts. So I will teach them a few recipes to get into that state but they don't have to stick with that. If they can find their own way that's great. I remember a guy who was having his travel vaccinations and the nurse came in to tell me that he was in a terrible state of needle phobia and she couldn't do it. So I saw him after surgery and my first question was "what do you do that helps when you start to feel panicky?". He replied "If I wake in the early morning and start feeling worried I play my favourite tune in my head." He already had a resource and I didn't need to do anything.

I was interested in this some years ago because I thought that hypnosis held the clue to a lot of the complementary therapies. I learnt that a lot of what I had been doing in clinical practice could be labelled hypnosis although I didn't know that; and the sort of things you have been talking about are incredibly valuable.

But we were talking yesterday about the fact that the things I was going on about the metaphysical - is rejected entirely by the scientific community. I get the feeling that the majority of the medical community does not accept hypnosis for the same reasons. Why do you think we can't accept the common sense of what you have been talking about?

I think the view of hypnosis has been changing since the late eighties; there has definitely been a shift which has started with the general public with the profession coming along behind. My view of hypnosis may be different from others: I have a much broader idea – to me hypnosis and trance states are just descriptive words. You can go into the 'zone', you can have ecstatic experiences with prayer - they are all allied. But because we don't understand it and we don't like uncertainty, and if when we try to find explanations they don't satisfy we dismiss it as mumbo jumbo. The Royal College of Psychiatrists have now got a spirituality section.

You're actually getting behind the so-called monkey brain and the loud noise of outer lives ...

You've got to be aware of what you are doing before you can change it. The first step is to step back and observe, and then you can make a change.

I've not had any experience of hypnosis but it struck me: are you talking about a continuum? One of the earlier suggestions was that maybe we do these things intuitively. I can think of things that we can suggest to people that might make their experience worse when we want to move people in the other direction. If we think about a continuum of hyperawareness and low awareness of sensation in consciousness; is that what you are manipulating?

Yes – we all go in and out of these different levels of awareness, like driving along a familiar road without any conscious recollection of the last few miles ...

... we have to demystify the idea that hypnosis is something special ...

... just different ways of functioning ...

... what we are in any moment is a sort of hypnotic state ...

There is a book called Trances People Live by Steven Wolinsky.

# Ann Williamson Session 2: more about metaphor and case histories

The other thing I would like to say about metaphor is trust yourself. Empathic metaphor is really useful. If you're working with someone and it suddenly comes to your head: "Oh - I think I might tell them that story or give them that example ...". It's almost always relevant. You can preface it with something like: "I don't know why this came to mind but I thought I would share it with you."

[An audience member volunteered to help demonstrate the use of imagery in controlling pain. He had a moderately severe headache and pain in the back of the neck.]

Just close your eyes and imagine something in front of you that is that headache. What would it look like? What colour would it be?"

Black on a red background

Is it a particular shape?

A blob with spiky things coming out of it. It's moving.

Does it have a temperature?

lťs hot.

As you look at that blob, if you could make a little change in it to make you more comfortable, what would that be?

That it would keep still.

Anything else?

Take it away ... or shrink it.

Just allow yourself to make those changes ... open your eyes ... is the headache any different?

Less - from 6-7/10 to 3 or 4.

There's another nice one for headache. Did you ever play with copper sulphate crystals when you were a child and we all had chemistry sets? So what if that headache is being contracted into a few crystals? Then you remember what happens to the crystals when you pour water on them? So you can just let your headache crystals dissolve. [Our subject found the effect 'amazing'.]

Ideomotor movement<sup>11</sup> is routed in a different way through the brain and is perceived as involuntary. I use it to monitor unconscious thought processes in all sorts of ways. With migraine, one of the things that I find most effective when someone gets a migraine aura, is to teach them this little process using ideomotor movement. I adapted it from something Harry Stanton told us way back when. I describe it as the sort of movement we make when we gesticulate when we are talking, or nod or shake our heads; we don't think about it and it just happens. I teach this to a lot of patients without ever mentioning or doing hypnosis. It helped my brother who is epileptic and used it when he got the feeling that he was going to have a fit. I use it at the beginning of a cold with the idea of 'boosting' my immune function. You can use it for almost anything and I don't even have to know what the problem is. This is the technique I use: put your hands about three or four inches apart. Now select something you want unconscious help with (because that is what it is) If it's OK to work on the problem your hands move together, and if it's not OK they more apart.

I tried this with my daughter who wanted to stop smoking: "is it OK to work on your problem with smoking?" ... and her hands moved apart! So it wasn't appropriate at that time and you have to respect that. If you notice that your hands are beginning to

(https://en.wikipedia.org/wiki/Ideomotor\_phenomenon#cite\_note-1)

<sup>&</sup>lt;sup>11</sup> Ideomotor phenomenon is a psychological phenomenon wherein a subject makes motions unconsciously. The ideomotor response (or 'ideomotor reflex'), often abbreviated to IMR, is a concept in hypnosis and psychological research.

It is derived from the terms 'ideo' (idea, or mental representation) and 'motor' (muscular action). The phrase is most commonly used in reference to the process whereby a thought or mental image brings about a seemingly 'reflexive' or automatic muscular reaction, often of minuscule degree, and potentially outside of the awareness of the subject. As in reflexive responses to pain, the body sometimes reacts reflexively with an ideomotor effect to ideas alone without the person consciously deciding to take action. The effects of <u>automatic writing</u>, <u>dowsing</u>, <u>facilitated communication</u>, and <u>Ouija boards</u> have been attributed to the phenomenon.

come together - and I use the kind of language that suggests that you are neither going to make them move nor stop them, they're just going to please themselves – as they come together your mind can gather up all the information it needs about the problem. Then when your fingers touch one hand can begin to come down to your lap as a signal that the unconscious is gathering up the resources you need to help yourself. You might not know which hand this is going to be and you don't make it move, you just let it do it itself. By the time it reaches your lap you will have all the resources you need, whether it's hormones or blood flow or muscle tension or whatever. Then when that is complete you allow the other hand to come down by itself as you begin to use those resources within you.

I work with a lot of chronically anxious people. For them, to be relaxed doesn't feel right. If you teach them a relaxation technique they don't like it because it's so foreign to the way they have been living their lives. What I do with them is to get them to visualise a physical activity that they have enjoyed – walking, swimming, horse-riding, cycling – at first very fast so they put a lot of energy into it. That matches the adrenaline state that they already have so it is easier to do. Then I suggest that they might want to slow it down, for instance gradually slowing their swimming stroke until they are lazily floating. I might be that there isn't time to do that in the time they have with me, but I will get them to go and practice it, and just slow it down to whatever feels right for them at the moment. And the next time they find it that much easier because the thing with hypnosis is that you always want to use suggestion.

If you just take someone into an altered state it's like giving someone an anaesthetic without doing any surgery. So having practiced and got used to the feeling of being more relaxed then the next time I will teach them a few more recipes.

Empathic metaphors can be pearls. I once was working with a lady on a training course looking at phobias and how to deal with them. This lady was a spider phobic and couldn't even look at pictures of spiders. One of the great things about hypnosis is that you don't have to have the actual spider (or the actual snake) there because you are using the person's imagination. We were going through a desensitization process and the vision came into my head of the spider doing a Morris dance! So I shared it with her, I said "You're going to laugh at this but I've just seen a spider doing a Morris dance!". She burst out laughing and of course if someone does that you've disrupted the source of their anxiety completely. The amazing thing was that she was a Morris dancer and I hadn't known that!

We talked a lot about symptom management. My feeling is that this will work up to a point but you've got to look at the underlying psychological drivers like selfpunishment and that is where I find ideomotor stuff is very useful. A lady with hysterical aphonia told me under hypnosis (and she hadn't really been aware of this) that it had started when her mother died when she was on holiday and she hadn't been able to say goodbye to her, so was punishing herself by taking away her voice. Sometimes when you find an underlying driver you can get a key that is really quick. Someone else whose problems had started as a travel phobia which spread out, just after the disaster of the Herald of Free Enterprise, had experienced a panic attack on a ferry. She wanted to visit her family in Ireland but couldn't, and was very distressed about it. So I took her to look at the time she was on the ferry and she remembered that the alarm sounding when the bow doors closed was just like the apnoea alarm when her daughter was born. I couldn't normally have made that connection but she had gone inside and it had come up. Our memories are so faulty we work with what we have; what the patient gives us: but we don't necessarily think it's true. So it's important that the patient knows that the narrative you are working with may be symbolic but you are using it as if it had happened.

I got a desperate lady with very bad migraine to look back under hypnosis at the first time she got migraine. She recounted (I have no idea if her story were true or not but it doesn't matter) that it was when she was walking home from the paediatric clinic having just learnt that her daughter was profoundly deaf. Once she had allowed herself to help that younger person to realise that that was terrible but she had come through it and her daughter is now a bubbly teenager (with implants) she was able to let go of that protective reaction. All the symptoms we have are there to protect us in some way and we have to acknowledge that they are useful, even if they can outlive their usefulness. I taught her various techniques for symptom management but the one thing that really made a difference to her symptom score was resolving that time when she first had it.

Has anyone used hypnotherapy for complex regional pain syndrome?

I don't know if there has been a trial but I have heard some anecdotal stuff on that. It has been used a lot with phantom limb pain – like with the mirror box.

I have a question about the state of hypnosis. In years gone by we used to talk about people who were either hypnotisable or not – distorted, but what you are describing is that anybody can have imagery. Is there a difference?

I think there is. Like any other ability there is a spread: some are virtuosos who can play in the Albert Hall and some can only pick out Happy Birthday with one finger, and everything in between, and that's the same with hypnosis. One of the difficulties with experimental stuff is that they are very hung up on a rigid framework especially as regards depth. People go to the depth they need for whatever it is they are processing.

People thought I was mad to do a hypnosis session after a long day in the surgery but it helped me!

# Hypnotherapy for migraine

# A pilot project

# Patrick Browning

I didn't start as a hypnotherapist: I started as a barrister and a chartered accountant. and then I became an investment banker and a finance director. Twelve years ago when I started to train as a clinical hypnotherapist my friends were a little surprised! But I have to say that I have found it such a rewarding thing to do in terms of job satisfaction to be working with people in a way that helps them to change, that I consider myself very fortunate. So how did I get to be doing a pilot project on migraine? Imagine that a few years ago you are sitting in a classroom at Kings College where the Institute of Clinical Hypnosis (I am now on the faculty) has rented a classroom and I am teaching a module on pain management. When you're teaching a lot of people with disparate backgrounds and you have to demonstrate how to use a technique it's always a little bit dodgy: is it going to work? Have I got the right person to demonstrate on? And being a pain management session, is there anyone in the room with pain that I can use? As it happened there was someone there with migraine – in fact they had migraine at that moment. So I used glove anaesthesia which involves inducing numbness or at least reduced sensation in somebody's hand, and then inviting them to spread that numbness to wherever they have pain. So I went into the routine of inducing hypnosis – by this stage of the course they were well practiced at going into a trance without difficulty - and induced glove anaesthesia, and then he put his hand on his head and spread the numbness to his head. I don't know if the migraine completely disappeared but certainly the pain was considerably diminished, and remained diminished for the rest of the day. Everybody went ooh ... we must try this ourselves. So they practiced it but of course they had to role play. A little after that I was at a meeting of the Royal Society of Medicine where Dr Giles Elrington, the medical director of the National Migraine Centre in Charterhouse Square was giving a talk. I asked him if he had thought of using hypnosis for treating headache and migraine. He hadn't, so I asked if we could meet so I could tell him about it. We met in his office and his first words were "you haven't got any evidence, have you?" Luckily I had done my homework and printed out lots of articles (including the Review of the Efficacy of Clinical Hypnosis with Headaches and Migraines by D. Corydon Hammond (2007). So he had to accept that a lot of people had worked on this sort of thing, and agreed that we could do a pilot project. There was no funding (they are a charity) but I was prepared to do it unfunded. So that's how it started.

(I'm going to say mee-graine rather than my-graine as not only does the OED use this and it comes from the Greek hemicranias, but also because if you are a migraine sufferer 'my' implies ownership. I don't want them to feel that as I would rather that they regarded it as something that happens to them that they can do something about.)

There are a lot of people here who know more about migraine than I do but there are one or two things I want to say about it. Firstly it is more common than epilepsy, diabetes and asthma combined, so it is a pretty big problem. It has been estimated that there is a cost to the UK of £3 or 4 billion due to lost days at work or school, so

it's a pretty big drag on the economy as well as the individual. Once I started working with people with migraine I discovered just how painful and awful it could be and how devastated they could be for quite long periods.

While the causes of migraine are still argued about by specialists there are certain triggers which seem to be significant in setting off the neurovascular event that causes so much distress. We have usually found that more than one trigger is more likely to bring on a migraine than a single one. So it is helpful to learn about people's triggers. These may include hormonal factors, especially in women, missed meals, lack of sleep and work stress. Those are things for which there is a potential for doing something about using hypnosis.

## The National Migraine Centre Study

I told Giles Elrington that I wanted to work with groups and to compare this with working with individuals in terms of outcome. So we agreed that I would see three people one-to-one and have three groups of eight people whom I would treat essentially the same way, but in groups. They all had chronic migraine and were taking medication. One person dropped out so there were 26 patients in all.

I was expecting to find that I would get more or less the same outcome in groups as with what I was doing already, which was more or less applicable to all types of migraine. Treating people in groups was obviously much more cost-effective and there was a hope that someone in the NHS would take some notice and that treating migraine in groups would reduce the load on the economy.

I ran five one-hour sessions at weekly intervals. The attendance rate was 88%. They were all given CDs to practice with and notes, and the intention was to teach them self-help techniques. I know that when I am working with a group (and I have done a lot of group work with people with cancer in Paul's Cancer Support Centre in Battersea) whatever I do people are always going to feel better at the end of the session. But of course that is not enough. What we need is for the person with migraine to be able to take something away that they can use for themselves. So that was the plan.

There is plenty of evidence that hypnosis can be helpful in pain management, so I knew I could help people diminish or manage their pain. I knew I couldn't cure or eliminate peoples' migraine, but I was hoping to reduce the frequency or the severity of their attacks, or perhaps a bit of both. I knew that hypnosis would help them with relaxation, so that was one of the first skills we were going to teach. It would help not only with stress reduction but also with motivation to better manage their lives so the triggers were less likely to coincide and trigger a migraine.

I knew from previous experience that we were going to have some group dynamics, and that the interaction between the members of the group was going to be helpful. Some people would come thinking "I'm not very comfortable in a group and I think I'll just sit very quietly and not say anything". That's fine, but probably by the second session they would be more open to the idea of joining in. So in the first session all I asked them to do was to say a little bit about their ego. We had to be careful not to get 60 minutes of life story from one person so I had to be a bit tactful in controlling that conversation. What I wanted to get from them was firstly a sense that they were all sharing a common problem, and that what I was offering was a series of solutions

that was bound to fit each one of them, perhaps in different ways. They said a bit about their migraine and how bad it was and I was discovering how serious it could be. There was one woman who had such severe nausea and vomiting that she was beginning to get dangerously underweight. There were others for whom it had become a daily occurrence. There were some who didn't seem to be helped by their medication. The tryptans that are prescribed for migraine have only about a 50% success rate.

So I was confident we could help them to improve in some way. In that first session they would say a little bit about themselves, I would then talk a bit about hypnosis and then give them some experience of it using just a group relaxation approach. Most of them had never experienced hypnosis and required a bit of explanation, reassurance and encouragement. I asked them to keep a migraine diary and wanted them to be able to measure how bad things were on a 0-10 scale and they all found that fine. In the second and subsequent sessions I would go round the room and asked them what had happened since the previous session so we were getting some kind of progress report. Then I would teach them one or more self-help techniques. I was hoping that at least one person would say "I've tried what you suggested and haven't had a migraine since!" so someone who hadn't had any benefit might think "well, it helped him so maybe if I give it another go it will help me." So the group effect was to encourage people to put a bit of effort into the self-help techniques. And that went well. The one-to-one sessions also went well and there was no significant difference in outcome between the two groups.

## Self-help techniques

So what was I teaching? First self-hypnosis, which I teach to practically every client I see. I know they are going to find it useful; if they don't use it indefinitely they are bound to find it helpful in the short term even if it only gives them ten minutes of relaxation they wouldn't otherwise have. I gave them a CD which would make it easier for them; otherwise the first time someone tried self-hypnosis all by themselves they might not be sure they were doing it right or whether it was working. With the CD they could recognise the sort of state they went into during the session and be encouraged. They might not be able go very deeply into hypnosis but that would come with practice. (The CD's I use are mostly also available as APPs.) In subsequent sessions I would teach them disassociation for pain management. The principle of this is to enable the person to think of their body being 'here' and their mind being 'there'. The message just isn't so relevant. They don't feel 'here I am suffering' as they are 'somewhere else', separate, different; close enough as necessary but far enough away that they don't have to pay so much attention to the pain. I suggest that they should have cue word which they can use to get into that dissociated state without too elaborate a preamble. There was one person on the course who was in fact a scientist involved in research on pain management. She wrote an article for a website called Migraine Monologues about disassociation, about which she was initially very doubtful, but found that in the sessions she could float away and not be connected to her body at all. But that needs quite a lot of practice and she noted that she had found this harder to do later.

Master control imagery is something we use a lot in hypnosis where we imagine a master control room where we control everything that is going on in our body. You go and visit it and see screens and dials and a technician or two in white coats, and you discuss with them what little changes could be made so that whatever it is could be

less significant. Symptom imagery can be very helpful: you imagine what your symptom could look like or feel like, and then have a dialogue with it, perhaps becoming your symptom and looking back at yourself. This can provide a new perspective on what is going on ... changes in someone's lifestyle to help them to not suffer with the symptom quite so much. Is the symptom telling them something? Perhaps that they are working too long hours or whatever. We can often help people to avoid triggers. For example people often get migraines at weekends; the reason sometimes is that their sleeping patterns are different: they lie in and change the pattern of their day. So avoidance of triggers using self-hypnosis can motivate you to do whatever you have to do differently.

## Stress reduction

I taught three techniques:

With worry time you make a note of your worries and set a time - perhaps five o'clock - when you are going to deal with the worry. If you forget about it when the time comes that's fine because it's no longer a worry, but if you do need to deal with it you can save the rest of the day from it.

Internal voice tempo change is a very interesting technique. You know how an anxious thought can go round and round in your brain? If you ask someone if that is at the speed of a normal conversation or faster the answer is always faster. So you get them to say their anxious thought slower and slower and notice how it feels different. So then they can get in control of that thought, because they have established that it's not so powerful and they can simply feel differently about it.

Bilateral stimulation is based on EMDR (Eye Movement Desensitization and Reprocessing) and is a very simple technique to teach people to deal with emotional overload. I use it in at least half my clients and it's helpful 19 times out of 20.

#### Outcome

The medical director of the National Migraine Centre wanted me to use HIT-6 (Headache Impact Test). This is a series of six questions to which you answer never, rarely, sometimes, very often or always. These are:

- When you have headaches, how often is the pain severe?
- How often do headaches limit your ability to do usual daily activities including household work, work, school, or social activities?
- When you have a headache, how often do you wish you could lie down?
- In the past 4 weeks, how often have you felt too tired to do work or daily activities because of your headaches?
- In the past 4 weeks, how often have you felt fed up or irritated because of your headaches?
- In the past 4 weeks, how often did headaches limit your ability to concentrate on work or daily activities?

The problem with that as I saw it, and as was proved by the answers we were getting, was that if you answer something before you start, after you finish the course, and

three and six months later, 'in the past four weeks' seems to suggest that the question could mean 'in my entire life experience.'

These are the scores:

HIT- 6	Before	After	3 months	6 months
	66.4	62.6	61.1	62.7
Δ		3.7	5.2	3.7

The range of scores for HIT-6 are 36 to 78 so as you can see from the 'before' score this was a pretty bad group. At the end of the five week course it went down by 3.7 with a further fall at three months and a small rise at six months. So we had a noticeable improvement. Although these may not look like very big changes they are statistically significant. Other measures we used were MYMOP (Make Yourself Medical Outcome Profile) and EQ-5D (EuroQol five dimensions questionnaire). What I wanted to use was the migraine days and peak severity score. We did measure that, and got improvement at the end of the course and at six months but it was not sustained at six months. If I was doing this project again I would suggest monthly follow-up sessions to keep people on the straight and narrow, as I suspect some people were no longer using the techniques.

I also asked them for qualitative comments and these were very revealing. One of the questions we asked was "Would you recommend hypnotherapy to other people with migraine?". Out of 26 people 25 said yes (regardless of how well they had done).

Sadly we haven't been able to raise funding to do a proper RCT, but I am using the same techniques with other migraine sufferers. One thing you might find interesting is that I didn't include glove anaesthesia in the group treatment because I thought it would be difficult in that setting, but I did use it in two out of the three one-to-one people and they rated that intervention very highly.

# I see a lot of migraine patients and there is a huge variation in what people call a migraine or a headache and the distinction seems blurred. Does that affect your therapy?

I don't think it does. As far as I am concerned this is a person in pain and I am offering self-help techniques which can be just as helpful with tension headaches as migraine. The thing about migraine of course is that you have people with medication overuse headache. Giles Elrington and I thought that if we could take it further this approach would be ideal for them as they could come off all their medication for a while which would be very uncomfortable for them but self-help techniques could fill the gap. But we haven't been able to put this into effect.

## More information

- <u>www.nationalmigrainecentre.org.uk</u>
- <u>www.browning-hypnosis.co.uk</u>
- To learn self-hypnosis go to the Apple App Store and search 'Patrick Browning'

# Creativity and the Use of Metaphor in Primary Care

# Maureen Tilford

I started doing hypnosis with my patients in about 1992. I was very nervous when I first started. I suspect my colleagues thought I had gone bats but the patients thought it was great.

## Score Dance

This is an NLP (Neuro Linguistic Programming) thing originated by Robert Gilps. It's for people who are in a situation they don't want to be in any more.

[The audience were invited to stand at this point, to move to their right and think of something they want to change.]

Where you are at is called the symptom. So you step forward a couple of inches into your symptom and make a little sound about how you feel about this problem. Now I want you to open your eyes and flick it away ... and then consider if you have achieved the desired outcome: if you have arrived at the place where you want to be. It doesn't matter how that happened. When you are in that place, step forward into the outcome and take on the body language and make a little sound to do with "I've got there". Now take another step to your right and forward into the effects. These are all the amazing spin-offs that will come into your life when you have achieved the outcome. In the demonstration that I went on, a person in the group had fallen off a horse, and couldn't get on again. So getting back to riding was the outcome she wanted, but when she had achieved this the spin-offs in her life were amazing. People need to find their own resources, and this is where their creativity and metaphorical ability come into play. So I ask patients "what would your source of power be?" This could be earth energy, hurricane force, nuclear power, the sun anything you want. Then I ask them to close their eyes, think about their power source, and really get it on board; let it flood through their being, their feelings, their physical bodies. It's their source, it's totally inexhaustible and it's always on them; it's amazing, it's huge. Then they can step back into the problem spot where the symptom was and see what is left. Has it changed? Then they can move into outcome again and get the body language and the voice ... and having achieved their outcome, they can step into effects again, then more resources, then visit the symptom, then the outcome (perhaps a little quicker), the effects, the spin-offs, and back to resources and so on.

The horse person did get back on the following week.

### Metaphors

Metaphors may be as necessary to illness as they are to literature, as comforting as a bathrobe and slippers. (Broyard 1992)

We speak and think in metaphors; the right brain is full of metaphor and everything is represented as metaphor and symbol and the seat of imagination. The left brain is

more concerned with critical and rational, logical thinking. So in hypnosis we have to put the critical left brain on one side and communicate with the right brain. I once heard an amazing talk by Jill Bolte, a neuroanatomist who had had a left-sided cerebral haemorrhage. She recounted how all her words and numbers just went and she couldn't read or speak or think clearly. When she had the stroke she tried to make a phone call but couldn't read the numbers on the phone; she managed to dial her colleague by comparing the apparently meaningless squiggles on a card with the symbols on the keypad, but then found she couldn't speak. But what was unleashed was her amazing right brain, and a profound hallucinatory nature of experience.

Patients use metaphor all the time: pain like a knife in my back; a tight band round my head; lighting shocks down my leg; pain crushing, gnawing or cramping; my heart is broken; I'm cracking up; my whole life just flushed down the toilet. They try to impress you with this powerful imagery so you really get it. There is emerging evidence from research that the use of metaphor is more effective than standard educational interventions in helping patients to understand the complexity of chronic pain. Melzack and Wall's 'gate' is a metaphor and you can talk to patients about 'slowly closing the gate'.

## Case Histories

I once saw a guy with psoriasis who had experienced a very stressful time in his life when there was fighting in his family over who should have ownership of his grandmother's ashes. He had severe psoriasis all over his torso for about two years with no relief from creams, and was really fed up. So I suggested hypnosis. I usually ask people to close their eyes and think of their own wonderfully peaceful place. His was lying on wooden decking looking out over a lake surrounded by mountains and blue sky. I asked him "what would your immune system look like if it was going to heal your skin for you?" His was a blue fleecy dressing-gown coming down from the sky, which would magically go on him and would be soothing, smoothing and warming. I did five or six sessions with him and it went. Of course in general practice you have people for 30 years and more and you can't discharge them, and he came back with a cough about two or three years later and he pulled up his shirt and did a little dance around the room.

Health anxiety is a common problem. One lady - a paediatric nurse - was very embarrassed about always coming back; she had seen all three partners with abdominal pain and other symptoms that 'might be cancer'. Her imagery was a beach, so while she was lying on the couch in a hypnotic trance I gave her a posthypnotic suggestion by saying "put your hands on your tummy and feel a nice warm sensation - soothing and relaxing, and your tummy is comfortable ..." – a very simple approach. She got better after a few sessions and stopped coming back, so that seemed like a success, but about two years later, she came in for a sick note. The discharge letter from the hospital revealed that she had had an appendicectomy, having sat on her appendicitis for two or three days! She thought it was her neurotic abdominal pain and had been using the techniques I had taught her until her appendix was gangrenous – so sometimes you have to tune it down a bit.

I had another patient with an inoperable tumour of his gallbladder who had been given about six months to live. His imagery was standing on a beach on the Indian Ocean looking at the surf breaking over the reef, and using the power of the ocean for healing. His image of his immune system was of millions of green pack-men whizzing around his blood-stream, and that of his tumour was a big, brown, hard rock under his diaphragm. Every week we would set the little men off and they would nibble away at his tumour like little fish. In the middle of his six or seven sessions he went back to his home island in the Indian Ocean where he dreamed about his grandmother. In the dream she asked what was wrong with him, and when he told her that he had a tumour she put her hand in his abdomen, shook it and put it back in. Later he went into the mountains and picked some of a herb that the grannies had always used when children were ill. He came back for a few more sessions, and on the last day he got off the couch and said "I've got the last bit today". His next scan showed that the tumour had gone away. About six months later he was still alive and he thought maybe I should get it checked out by somebody, so I sent him to an eminent professor of gastroenterology in Cambridge. In my letter I mentioned a few of the things I had done with a few references to other people who had done this sort of thing. He completely ignored this, looked at the scan and opined that it had been the wrong diagnosis, and discharged him. A couple of years later he was still alive; it was suggested that the first people had looked at the wrong slide, but they proved it was his by DNA. He lived for another eight years. I think his immune system was just holding this thing; I don't believe it had completely gone away. His daughter was in a very dodgy relationship with a very violent young man. My patient was a very benign easy-going person; I think his daughter had been very traumatised by her father's diagnosis. Anyway, all this furore came into his life and he was dead within a month.

I heard another story at a hypnotherapy conference about someone with a parotid tumour as he didn't want surgery. It went away, but when his partner died it came back.

So there is something in the emotional universe that seems to hold things together as long as it can.

In the midst of winter I finally learned There was in me An invincible summer. (Albert Camus)

# The Power of Mind: a Surgeon's Perspective

## Eamonn Coveney

I have been a general surgeon in Bury St. Edmonds for about seventeen years. I started taking an interest in hypnosis about eight years ago. I was frustrated by a lot of patients with functional abdominal pain and IBS for whom as a surgeon there is very little you can do. I didn't have any psychological training or skills to deal with this but I had had some encounter with hypnosis with colleagues and friends which led me to undertake some training at UCL. Like a stone in a pool of water I started with a couple of cases with interested colleagues and then over a couple of years some of them, including breast nurses, surgical care practitioners and breast radiographers also went for training. Eventually we ran our own training programme and trained about 25 people in the hospital. There are now about five or six people who routinely practice hypnosis in their clinics.

I like to get my excuses in early; I am a surgeon and a bit like the dog saying his prayers at night and asking "dear God, bless Auntie May and Uncle Bob, and please let me see colour!". Surgeons are slightly blinkered individuals; I haven't any psychological training but I know I encounter patients for whom, for one reason or another, I am fairly certain that their problem is functional and that there is some degree of psychological underlay, or there are at least some psychological contributory factors. When you encounter these people the first thing that strikes you about many of them is that they are sad. I don't have the time or the skills to explore this but maybe I can help them a little bit, if not with their pain, but with their suffering. This is what has led to my interest in hypnosis.

I always say that hypnosis is the fine art of learning to be comfortable when feeling uncomfortable. The truth of the matter is that I encounter patients who have been referred to me for hypnosis and I have absolutely no idea if it is going to work or not. It's just the same as when I see a patient to treat for pain or some other problem and I prescribe something; I don't go home and lick my wounds if it doesn't work; I just think – well, that's medicine. It's the same with hypnosis: I'll have a go and if it doesn't work it isn't the end of the world. I've given my time - and I usually make sure that they know it's my lunch break to motivate them to respond! A lot of people will say "I don't know if I have enough time", "I'm not sure it's the right patient", "if only it was yesterday or tomorrow". But now is the right time.

# Hypnosis for pain management

So why would we consider using hypnosis for pain management? We know from neuroimaging studies that chronic pain is accompanied by neurological processes in the brain; these can be modified and we can demonstrate this with an fMRI scanner. There is a very good body of evidence out there for the use of hypnosis in acute and chronic pain. To some degree unfortunately, in terms of analgesia suggestibility is important but about 80% of the population have moderate to high suggestibility so most patients will respond to some degree. We don't clearly know the mechanism but we know it involves some order of high brain processing, it is more effective than placebo, it's not endorphin mediated and doesn't involve spinal gating as a primary mechanism. The meta-analysis by Montgomery *et al.* (2000) of 18 studies involving

900 patients showed that hypnosis was comparable to CBT and certainly more effective than placebo for those who are medium to highly suggestible.

## What is hypnosis?

I tell my patients that it is very much an everyday experience; it's what I call outpatient hypnosis when I go out with a piece of paper and I scan it and say "Maureen Tilford? Maureen Tilford?" and there's no response! They are just sitting there off in their mind having a daydream and that's really what hypnosis is. You are focussed, you are utterly unaware of what's going on around you, you are engaged in something that is usually very interesting in thought and feeling, and time seems to fly by. So I say that it's like a daydream but what I'm going to do today is to give you a structured daydream. You're going to learn to drive a car and I am your instructor, but you are driving. You might drive like it's a Ferrari, watching every bump and curve in the road but I'm just there to smooth out the ride, and if you want to stop at any stage you can. They have control. The other idea I like is that of the autopilot. You're driving back from a BPS meeting and thinking "I wish I'd said that... I wish I'd asked him about that ..." and you're driving ... and when you get home you think "did I drive past Tesco's or did I go the other way? I can't quite remember". Yet all this time you can't remember about how you were driving a car at speed without crashing - doing something highly complex while you were off in your mind somewhere else having this altered experience. That's a very useful picture as it's a way a lot of people experience hypnosis: they sit there, close their eyes and you describe a scene. They are off on the beach but they are also here in the chair ... most people have an expectation that it is going to be some way different, but the truth of the matter is that we daydream so much that it's not going to be different, it's going to be quite normal. I introduce that idea and then I sometimes use it as a way of inducing hypnosis: "I'm going to take you to a special place in your mind and then when you are there I'm just going to talk to the autopilot that looks after you in the background as you lie on the beach on a sunny morning", and then I try a string of suggestions that are hopefully therapeutic. We're going to bring a whole variety of issues; the ones from the point of view of hypnotherapy that probably matter most are motivation and expectation. They are the two best predictors of success with a hypnotic intervention. even more than suggestibility. You bring your training and your experience but probably what you need most, as in any other aspect of healthcare, is your flexibility: can I establish a rapport? Can I help this patient find somewhere that they can become absorbed in? And then can I make some sort of structure, some kind of wording ... the words that we use are just trying to create an experience in somebody's mind, that's all it is.

So how can you do that? It's something we get good at with a little bit of practice and experience. One such experience was when I saw the wife of a member of staff with chronic severe back pain since she had fallen off a merry-go-round as a child. She had experienced lifelong crippling pain; she had been to the pain service without any benefit. At the end of my course she announced that her pain was no better and I felt crushed – all that time and all those lunch breaks and she was no better. But then she said "you know, hypnosis is the best thing that ever happened - because now I sleep; I used to wake up every time I turned over and get up exhausted but now I sleep soundly for eight hours and wake refreshed". This was what I call the law of unintended consequences: you set out to help somebody with their pain and you may do other things for them instead. So sometimes I suggest at the end of my intervention that they may be pleasantly surprised at some feelings: a sense of

control which may extend into other areas. Even if what I do today doesn't help your pain something else may be better: you may sleep better, feel more relaxed or have a better mood. But there may be improvements in your sense of control and function that may be of value.

Again, learning hypnosis is a bit like going to a cookery school. We learn all these various dishes but we all just pick out one or two that we like and serve them up to the kids every day of the week! So this is your dish. You can do all these various techniques until you're tired but I just tell them to choose something simple. And then I use some sort of imagery and progressive relaxation, suggesting that their eyelids are so heavy they can't open them even if they try (note try – trying assumes failure) so they think – he told me to open my eyes but I couldn't because I am so relaxed, so maybe this will work. Then with them lying on a bed I might say "just picture yourself floating on a cloud - this is really easy. Notice that your shoulders move up and down every time you breathe in and out" so they get a sense of movement. This is just a way of trying to tap into their internal experience. Then I take them to some place where they feel safe, special and relaxed, and while they are there I talk to that autopilot that looks after them in the background and make my therapeutic posthypnotic suggestion that this experience, this wonderful comfortable feeling, will become easier and easier as time goes on, and the more you listen to it the easier it will get.

There is a whole range of therapeutic approaches such as disassociating – leaving your painful body while the comfortable you goes for a walk, or a dial which is your pain that you can turn up and down, or going back to a time when you didn't have pain; or maybe you can use glove anaesthesia (which dentists use a lot). Maybe you can identify an element of secondary gain – you're not really anxious to get rid of your pain. Are the periods of relief getting longer – and you experience the pain less and less? Perhaps (as anaesthetists) when you are about to stick a needle in someone you can take them to a special place.

You know sometimes when you wake up in the middle of a dream: it's really strange but it *feels real*. That can be useful: I can suggest something to you which normally you would regard as tosh but under hypnosis it can feel real. I can take you down a corridor into a room where there are all the switches that control the nerves from the body and you can turn them down, and it can *feel real*. A patient will buy into that.

# The West Suffolk Hospital Project

Montgomery also did a meta-analysis of a whole pile of RCT's looking at the size effects of hypnosis in surgery for a whole variety of different aspects of recovery. He found a major effect on mood, pain, medication, recovery and treatment time. So there is good evidence that it can be very useful. Probably the one study that has been most widely quoted is that by Montgomery *et al.* at the Sloane Kettering, taking about 200 patients having breast surgery, most of whom with benign disease. They were women in their fifties with breast lumps which they were having out under Propofol and LA. He gave them a 15 minute intervention with hypnosis or just attention control, and found a significant reduction in analgesia use. He also saw a significant reduction in nausea, fatigue and distress (pain and unpleasantness are processed by different areas of the brain). So a simple brief intervention could have a huge impact on a patient's recovery.
But he had huge resources and psychology students to do the interventions and interviews. So I thought: what about sleepy Suffolk? Could a few trained nurses and radiographers do the same? We decided to do an audit using a brief intervention. We operate mainly on patients with cancer so we took these and looked at their experiences. They were mostly in their sixties and seventies. We got them in on the day of surgery for a short period of time and gave them the option of taking apart. We measured the outcomes using a Visual Analogue Scale.

The sort of environment I was doing it in involved sitting in a bay with people next to us chatting or having their blood pressure checked and one was acutely aware of noise. Not in a nice quiet room with incense burning: this was a clinical session. I would tell them to close their eyes and use some imagery to take them to a special place. I would say, "You're here today for surgery and you would probably rather not be here. You would rather be somewhere else, and if you could be anywhere else in the world, real or imagined, somewhere safe and nice, where would that be?" (Often on a beach in the sun.). I would get a little description of that and then feed it back to them. I would then tell them that I was going to leave them there while I talked to the autopilot that takes care of them. Then I would say, "You'll shortly be going down to theatre and you'll be pleasantly surprised that you can stay in your special place, and the time will seem to fly by. In no time you'll be waking up in recovery, and you may be aware of certain sensations in your chest, but they won't bother you because you notice how hungry and thirsty you are and you're looking forward to returning to the ward, having something to eat and drink, getting dressed, going home and putting all this behind you now your cancer has been removed". That's all - it takes about twenty seconds - and I would finish with some post-hypnotic suggestion about how these feelings will be with you for the rest of the day.

About half of our patients accepted hypnosis, and it is interesting that although they were a little more anxious to start with, when they got to the anaesthetic room their anxiety levels had dropped quite dramatically; but the others' increased. I have done the same for gall bladders. But had I done them any favours? If you look at the post-operative scores the median for pain dropped from 30 down to 16. You only feel pain if you pay attention to it. There was also a reduction in post-op nausea; not much change in fatigue but they were an old set of patients and probably pretty tired anyway! Basically it compared very well with Montgomery and the Sloane Kettering study, but even in the conditions in a busy DGH we work in (I was using a Surgical Care Practitioner – a nurse – who had just done the BSCH course) you can deliver this and improve peoples' post-op experiences.

That's good on a global scale but what about the individual? Let me tell you about a young lady – a 31-year old – who was referred by one of my colleagues for surgery on a suspicious nodule in her thyroid, and she needed the thyroid isthmus removed. She had anxiety and depression, panic attacks and obsessive/compulsive disorder which makes for low suggestibility; and she had a morbid fear of general anaesthesia. She wanted her surgery under local anaesthetic and had heard I did hypnosis. Oh God! What do I do?! I said I would only agree to do this if she came to see me four times. (Half hoping that she might fail to comply which would give me an excuse for cancelling! But she came four times!) So I gave her some training in hypnosis. Her special place was crabbing on a pier in Dorset. I asked her to put her hand in the bucket of water she had to put her crabs in, and let the cold feeling migrate up her arm to her neck until it felt cold and numb. The night before surgery I made a recording for her to listen to me rabbiting on, and gave it to her the next morning. We brought her into theatre and put the headphones on and waited until she was on the

pier in Dorset. I did a little bit of infiltration with lignocaine. I noticed that her pulse was slow but mine was racing! What had I taken on?! (Luckily I had a very kind anaesthetist with me who was an advocate of hypnosis.) I dissected her thyroid off her trachea *with no additional local anaesthesia,* finished the job and stitched her up. I noticed that her left hand was shaking and very cold. Unfortunately the histology of the lump came back as a papillary carcinoma of the thyroid, and as the first procedure had gone so well she had the rest of the thyroid removed under hypnosis, dissecting it off her trachea and her carotid arteries etc. - all without anaesthesia. That tells me that patients can do extraordinary things.

Another not dissimilar case was that of a poor 63-year-old lady who could have been 93 who came in with a strangulated femoral hernia. This lady was not fit for a haircut; she had emphysema, end stage alcoholic liver disease and was in renal failure. The anaesthetist said if I put her to sleep she will die on the ventilator. But I felt it was unfair to let someone die in agony because a strangulated hernia is ischaemic and a cruel way to die. So I brought her down to theatre and did a special place routine with her. She said she would like to be at home in bed with the duvet tucked round her, nice and cosy and warm. So I got her nicely tucked up, proceeded to make the incision with a little local anaesthesia, and there was the black, dead bowel. My anaesthetist said "I suppose I had better put her to sleep" but I said "don't – just ask her where she is". She replied "at home in bed". Then I opened the femoral canal, released the bowel, fired the stapler across it and did a side-to-side anastomosis, and she didn't budge once. I made some post-op suggestion and she didn't need any analgesia for 48 hours until she unfortunately but predictably died. But she had a good death.

Another lady who needed a wide excision of a pre-malignant breast cancer wanted it done under hypnosis. Her special place was playing tennis. I told her that I was going to put my hand on her shoulder and when I do that she would drift back to playing tennis. I made the suggestion that she would be aware of some sensations going on in her chest but she'd be enjoying the tennis so much she would hardly notice and the time would fly by - which it did. (I did use 30ml of LA.) I made the mistake of reorienting her to the room before I took the dressings off which she said was the worst part of the operation!

Yet another example of the use of distraction techniques was a 55-year-old lady on the waiting list for a laparoscopic cholecystectomy with a history of post-op pain, nausea and vomiting. People like her play movies in their minds about how bad the pain and nausea is going to be, so before the operation I took her through the experience of having it and just how well everything would go. I suggested how hungry and thirsty she would be (you can't be nauseated and hungry at the same time - and nobody is nauseated once they eat). She had her surgery, needed no analgesia, and she had to be fed while she was in recovery – one of the nurses gave her one of her lunch-time sandwiches!

#### Do you suggest people won't be in pain for several days or ...?

I'm always a bit careful. I say "you may be pleasantly surprised by how little pain you have". If you say "you will not" and they have excruciating pain there will be loss of future trust – and that these feelings will last through the dreaded hours after the operation. I also say that I will put plenty of local in – is it that or the suggestion? – We don't really know – at least it's an adjunct. And it has been said that you only feel pain if you pay attention to it.

What about procedures? There is a lot of evidence to support hypnosis for placeborelated anxiety and pain. The most quoted study is that by Elvira Lang (2000) looking at hypnosis for vascular procedures comparing hypnosis and attention control. Patients without any intervention have rising pain and anxiety throughout the operation; this is attenuated with attention control but with hypnosis the scores actually tend to drop.

There is a 47-year old member of the staff, who needed an MRI, with such severe claustrophobia that she would walk all round to the back of the hospital to avoid going one floor in the lift. She was terrified. I agreed to see her and asked when she was having the MRI. In ten minutes! Her special place routine was on a sun lounger on the beach with her husband beside her holding her hand, which made her feel safe. So I took her there – after all she would be lying in the scanner - and suggested that holding the edge of the couch would be like holding his hand; so really I was just using what she had given me, with a few other suggestions like time distortion ("time will fly by") and "you may be aware of noise but you can ignore that".

Another man needed excision of a large lipoma on his back. I took him off to a beach in Portugal. I'm operating away and it's very quiet, so after about 20 minutes I ask him "what are you doing now?". "I'm going for a drive". Another 20 minutes ... "where are you now?". "In a restaurant". Later still ... "it's dark now ... I can see the harbour and there are boats ... and I'm drinking Rioja". And so on. At the end I said now I need to reorient you to the room. "NO! I don't want to, I like it here!"

#### Chronic Pain

There is very good evidence such as the review by Jensen 2006 showing by a series of RCT's that in all three of the groups studied of people with neuropathic pain, musculoskeletal pain and headache, hypnosis afforded sustained improvement in chronic pain (from 2% to 57%).

A 14-year old girl came to me with knee pain which she had developed while running; within weeks she was on crutches. She had had everything including amitriptyline, Oromorph, Gabapentin, lidocaine infusion, lumbar sympathetic block and physiotherapy. She came in on crutches with a typical dystrophic foot, cold, blue and hypersensitive, so she could not put it to the floor. I asked her under hypnosis what her pain was like and she described it as being on fire. In a sense that cognitive representation of what is going on is critically important, so I say "why is it not like a knife? Why is it like fire?". That image is critically important to the experience so if you can change it maybe you can change their experience. Her special place was a beach so I got her to lie on the sand with the sea coming in, just as far as her foot, and then perhaps become aware that it was cool, nice and soothing. Then I suggested that she might have a magic sock. She was sitting there with her foot in the air but as the procedure went on she allowed it to drop, very slowly, to the floor. I brought her back into the room and we chatted about her experience. After about ten minutes I drew her attention to her foot which was still on the ground like the other. She was off crutches within a week and when I saw her again she was fully recovered and had gone back to Karate.

## Cancer Pain

There is an interesting study by David Spiegel of group therapy and self-hypnosis for patients with metastatic breast cancer. This was based on the precept that pain is necessary but suffering is an option, and he was trying to help people to "filter the hurt out of the pain" - to restructure their experience by focussing on an alternative sensation, something more tolerable like tingling, warm or cold.

A 70-year-old man with prostate cancer and bone metastases was referred to me by my oncologist colleague. He had severe pain in his left hip radiating to his thigh. He was on methadone. Oxycontin and Gabapentin, and showing some signs of methadone toxicity. He had undergone radiotherapy and chemotherapy, and been tried with several other drugs as well as epidural and other interventions. Under hypnosis his special place was standing in the sea on a beach in Bali. This was before he had developed his cancer. There is an interesting use of paradox: most people with pain can tell you when their pain is worse and can describe that graphically for you. So you get people to turn the dial up and describe that experience of pain getting worse and worse until it is unbearable and then turn it back to where it was. You keep doing this a few times until you create an association between the dial and turning the pain up, because if you can make the pain worse by turning it up you can make it better by turning it down. You can help them to turn the dial down to a comfortable level (but not to turn it off as there may be secondary gain) and give them the post-hypnotic suggestion that they may be pleasantly surprised at how these feelings of comfort can last in the ensuing days and weeks. This patient was able to reduce his experienced pain from 7/10 to 2/10, to reduce his methadone and finally get off it altogether. He achieved this by going up to his bedroom twice a day, sitting comfortably, going to the beach in Bali and turning down his pain to a comfortable level.

## Functional Abdominal Pain

I see lots of people with 'functional' abdominal pain, who have aroused some frustration. They often seem to be sad people. You see them on a ward round with battle-scarred abdomens because everybody has had a go. There is no medical explanation. It often occurs in children. Visceral hypersensitivity seems to be involved as it may also be in IBS. There is some evidence that visual imagery may be helpful. There is some good support for this including a paper by Youssef (2004) on using guided imagery in functional abdominal pain in childhood.

I saw an 11-year-old girl with functional abdominal pain and nausea; she was waking early and missing school. She had had four previous admissions, and investigations including ultrasound. She had been referred to the Bath paediatric pain service. She was taking paracetamol. She was a lovely little girl who described her pain as being like tight bands around her tummy. She would like to be having a sleep-over with her friend. "OK, let's take you there – and that's somewhere you don't usually have any pain. Now let's have a look inside your tummy – what can you see?". "I can see the bands". "So now take a moment to find a pair of scissors and reach inside and cut each of those bands and feel that the pain is better." I then made some posthypnotic suggestions so she could generalise the experience day-to-day. In two weeks her pain scores had fallen, she was sleeping well and had stopped taking paracetamol. It's a bizarre idea that you can cut bands in your tummy, but in hypnosis that can be very real for people.

A 15-year-old girl with a two-year history of cramping abdominal pain had really been through the works: she had undergone laparoscopy, endoscopy, a variety of blood tests and screens, with repeated admissions. It was interesting that her daddy had left home two years ago but strangely nobody, not even the paediatricians, had thought that was relevant. I asked her to describe her experience and what her tummy felt like, and she said it was like clothes all jumbled up in a washing machine; and they should be ordered and nicely piled. I took her off to her sun-lounger in Spain, and suggested she could take a moment to look round and become aware of her washing machine. When she opened the door she would notice that the clothes were all mixed up, and she could then take a few moments to re-order them. I made a few suggestions as to how she could generalise that experience. When a few months later I asked my paediatric colleague if her pain had improved he replied "yes, it's gone, but it's very curious – she keeps seeing washing machines everywhere!".

#### Bombardment Techniques

There are a number of occasions when a particular single approach doesn't seem to be working with a particular patient and I may try multiple strategies in what is known as bombardment, as described by Crasilneck (1995). In a session lasting an hour he would use serial inductions each lasting about ten minutes employing relaxation, displacement, age regression, glove anaesthesia, hypnoanaesthesia and selfhypnosis. He found that ten out of 12 patients responded at the initial session and achieved up to 80-90% relief of pain at one year.

So I might do serial inductions, perhaps taking them onto a cloud, then back into the room and then say let's try something different, and so on. I tried bombardment with a 54 year-old lady with long-standing left-sided neck pain, which sometimes used to trigger a migraine. She had been attending the pain clinic for two years where they had tried R/F ablation, trigger point injections with LA and Botox, and physiotherapy. She was on Amitriptyline and CoCodamol. I used a 'fractionation' technique, getting her to float on a cloud to her special place which was a forest with bluebells. She was sitting under a tree with the light filtering through the leaves. Then I got her to be aware of the dial that she could use to turn her pain up and down to see if that was helpful. I brought her back to the room, and then back to her bluebell wood. I suggested that she might be aware of the rubber sap from the tree dripping on to her neck and seeping into it, and notice how flexible it made it feel. That seemed something worth trying, but I re-oriented her to the room and once again to the bluebell wood, and this time got her to leave her painful body under the tree while she went for a lovely walk, finding a stream of cool water to numb her neck. Next I tried age regression: she left the bluebells behind and found herself bodyboarding off a beach in Dorset (I had asked her beforehand about the last time she felt really good), and how free her neck felt. Checking back on the value of these experiences she felt that the age regression had done the least for her. So this is a way of exploring which of a variety of techniques might work for a patient. I asked her to make a fist with her left hand every time she felt comfort, the idea being to make a kinaesthetic and verbal cue for the comfort afforded by each experience. What I call 'loo' hypnosis is particularly valuable in children when the only relief they get is when they go to the loo. The door is locked and you have thirty seconds to yourself; closing your eyes and breathing in and out, then making a fist to bring you back to the experience and the feeling of comfort that goes with it. That all took about 35 minutes, which is a lot of time to spend with somebody. Normally the interventions I do take about 20 minutes.

I record all the sessions and give them CD's or download them onto their smartphones etc. There is very good evidence that taped interventions are as good as live ones, so you could argue the case for saying I can't really offer this service but maybe I could sell it – for instance when you are doing a pain procedure you could offer a tape made by a colleague or someone.

So hypnosis is a very useful tool, but it is just one tool among many. You know the old saying that if you only have a hammer in your toolbox everything needs hammering, and we need lots of tools - skill, experience, knowledge - and one of these is hypnosis. Hypnosis is a useful adjunct to the management of patients experiencing pain or undergoing medical procedures, and there is now a sound scientific evidence base to support its use. Reduction of pain may be a secondary goal.

I don't have any psychological skills or training, but you can potentially use hypnosis to help people to find resources that they already have to manage their own pain. Self-hypnosis is a good example of the old adage: "Give a man a fish and he eats for a day. Show a man how to fish and he eats for life". Maybe it is time to reclaim ownership of hypnosis as a clinical tool

#### Discussion

[Audio recording started late] .... during surgery?

There is some evidence that if you use nitrous oxide it increases suggestibility. There is also some evidence for the benefit of playing recordings during surgery, but how much it influences unconscious processing is a little uncertain.

Is there an advantage of being an operator anaesthetist? Or rather operator hypnotist – in other words doing the operation and being in charge of the hypnosis at the same time, rather than having a separate person ...

Have you had hypnosis having an effect other than on the patient – for instance on the people you are working with?

I've had relatives sitting in a corner nodding off, but not my assistants. There was a time when they used to worry about disturbing the patient under hypnosis and think you needed complete silence but now it's all quite normal.

We have talked a lot in this conference about how to overcome prejudice within the profession against this sort of approach... how long have you been doing it now?

Eight years.

...and in that time how many of your registrars and other trainees have been influenced into trying it?

I did learn a useful lesson when I started. I went off and did a diploma course at UCL, and then I approached the drugs and therapeutics committee about using hypnosis as a procedure. The response was "Oh dear ... I don't know ... would you have someone in the room ... would you record it ... make them sign a form ...?". So the lesson was: if you want to do something – just do it!

But as people have seen me using this and what it can achieve, some of them have gone and started using it themselves, and they may have influenced somebody else. So now at the West Suffolk hospital, if you come to the oncology unit, or bring your child to see our paediatricians, or suffer with hot flushes, you may be offered hypnosis. It's the stone in the pond and ripple effect. People may not buy the theory of it but they see the practice; they may not understand how it works but if they see it to be effective they buy into it. If you encounter resistance it's usually from clinicians rather than patients.

In my surgical practice I see patients I have never met before and within ten minutes they grant me permission to render them unconscious and scar them permanently. So what's a little bit of hypnosis? People are generally inclined to trust clinicians; this is extremely useful and you can leverage that. But you will encounter problems with colleagues. But what we do is to give licence and permission. You get a lot of nurses who train and go back to their pain clinic and find their bosses don't really buy into it, but the fact that I have done that has made it possible. It has made it possible for juniors who have worked with me to do it. We have trained eight consultants, so that makes it possible for other people who work in the same department to train.

Have you spoken on the subject at major surgical meetings?

Yes, I have.

... and what sort of reception do you get?

They're surgeons!

# The Role of the Mind in Pain Management Programmes

# Alistair Turvill

I am going to examine the role that mind and emotion plays in the experience of suffering and the perception of pain. Then I am going to consider how creativity can be used within the pain experience, how some patients are currently using art or singing, and the possible mechanisms of action, and the possible role for creativity within the clinical encounter.

What do we mean by mind? There are a number of different ways we can conceptualise it involving our physical brains, our conscious experience and our unconscious processes or combinations of these. There are a number of systems we can use to conceptualise these in terms of conscious vs. unconscious, involuntary vs. voluntary and rational vs. emotional. Philosophy has faced a similar challenge in clearly defining the self and the mind. We refer to this now as the mind-body problem: the problem of explaining how mental states, events and processes like beliefs, and thoughts are related to physical states, events and processes, given that the human body is a physical entity and the mind is considered non-physical. For the purposes of this presentation I am going to focus mainly on unconscious processes and emotions.

When we talk about emotions, we usually mean involuntary reactions to internal or external events or stimuli which are consciously perceived. The limbic system is often associated with these processes, and includes what is known as the 'reptilian' part of the brain, which is quite a primitive structure and one of the first to evolve. Coincidentally we often find emotions portrayed as quite primitive reactions and contrasted with our rational thought processes. But it's important to highlight the roles that these different systems serve. Emotions generally tend to be more involved in instinctive, fight or flight, survival actions whereas rational thought processes are more to do with problem solving and social interaction. This echoes Herbert Simon's theory in 1967 that the primary function of emotions is to interrupt and reorder processing priorities. Canadian Psychologist Donald Hebb wrote that "man is the most emotional of all animals", referring to the fact that the degree of emotionality increases across species with the development of more sophisticated nervous systems. He theorizes that emotions allow for more flexible and adaptable responses to circumstances by replacing simple on/off reflexive responses with an emotional response that allows us both to prepare to respond and to continually evaluate and moderate our reaction to the situation. This paints emotional reactions in a different light, as a complex form of cognitive reflex which allows a degree of appraisal rather than just a simple automatic reflex. So we are seeing emotions, in a different light, as helpful.

Every day our brains are constantly appraising the bombardment of stimuli from all our senses which are a lot more than we consciously perceive and which our brain needs to filter through and decide where our attention needs to be focused. So we have what has been called a 'spotlight' system whereby we focus our conscious attention on a particular point while in the background our unconscious processes are continuing to monitor low level processes looking for significant information. I am sure you will have heard of the 'cocktail party effect' whereby when you are engaged in conversation with somebody and you hear your name spoken the other side of the room; you weren't previously aware of that other conversation although your senses were keeping tabs on it and grabbed your spotlight and swung it away to this new area. It is not voluntary or anything we can control.

Emotions play an important role in focussing and mediating our attention. There have been a number of studies that demonstrate this, including Phelp's *et al.*'s 2006 investigation into the way fear changes visual perception. They primed participants with fearful or neutral faces, and those primed with fear showed very significantly improved visual search and perception in a simple orientation discrimination task. The authors conclude that the emotional content of the visual stimuli is picked up by the amygdala and identified as important, and attention is stimulated accordingly. Ohman, Lundqvist & Esteves (2001) asked participants to search a crowd of faces for either threatening or friendly faces. They showed that people looking for friendly faces take their time but threatening faces are detected more quickly and accurately. These studies clearly show that our unconscious emotional processing helps to orientate our attention based on the emotional content of the stimuli.

## Hypervigilance

How does this relate to pain? Hypervigilance is a common phenomenon, not just to do with pain but something we frequently come across in pain research. It has been defined as 'an enhanced state of sensory sensitivity accompanied by an exaggerated scan or search for threatening information'. In chronic pain we often see hypervigilance towards pain signals. It is a measurable construct; we can survey people's feelings towards painful stimuli and how anxious they are about them. We find that people who are more anxious, more vigilant and more concerned about these things are more likely to develop long-term chronic pain and show poorer outcomes after treatment, and we can identify a population at higher risk of a poor outcome.

So what is motivating this hypervigilance? What is the emotional drive behind it? The 2013 EEG study by Waymar of Event Related Potentials (which looked at people scared of spiders rather than pain) showed that hypervigilance is facilitated by a fear response which can observed in increased cortical activity. The fear and anxiety provoked by a specific event or object caused increased afferent processing and search for the stimuli. When people are looking for something they are afraid of their brain reacts differently right from the outset, and they put more effort and attention into searching for it. We see exactly the same in chronic pain patients. Khatibiti studied 170 people with chronic pain. First he asked them to complete a survey about their reactions to painful sensations, and found a range of fear and anxiety. They were then put through the 'dot – probe paradigm'<sup>12</sup>, a simple technique which

<sup>&</sup>lt;sup>12</sup> Participants are situated in front of a computer screen with their chin securely placed on a chin rest and asked to stare at a fixation cross on the center of the screen. Two stimuli, one of which is neutral and one of which is threatening, appear randomly on either side of the screen. The stimuli are presented for a predetermined length of time (most commonly 500ms), before a dot is presented in the location of one former stimulus. Participants are instructed to indicate the location of this dot as quickly as possible, either via keyboard or response box. Latency is measured automatically by the computer. The fixation cross appears again for several seconds and then the cycle is repeated. Quicker reaction time to the dot when it occurs in the

allows us to accurately measure the attention that is being paid to particular things. When he flashed painful faces to people with a high fear of pain they reacted significantly faster and treated this as a more important stimulus. Chronic pain patients with high and low levels of fear both shifted attention away from happy faces; those with low fear shifted attention away from painful faces, whereas those with high fear shifted attention towards painful faces. So for some patients, despite being in chronic pain, the latter effect doesn't exist, and it is fear that drives hypervigilance.

We have now a clear indication of how emotions are affecting the perception and experience of pain. This is not consistent between people and there is much individual variation. But what is driving the fear in the first place? There are differences in the way people are disposed to react but this isn't the whole story. People who have been through traumatic events already have a high degree of emotional dysregulation, i.e. a tendency to react in a poorly modulated and sometimes extreme way to a range of different things. People with PTSD for a range of different reasons and children who have been through traumatic events at a very young age are significantly more likely to develop chronic pain than the general population. The underlying factor in these is the emotional content and dysregulation associated with these events. At the moment there is no research being carried out to link these two areas directly but if we triangulate it we see a consistent link to personality disorders.

Is dysregulation distinct from hypervigilance? Are you saying that the nature of the response disorder is different and not just increased?

Yes. Emotional dysregulation can be to a range of different things, not just to fear.

Are such people more labile – more up and down?

It's interesting that there is more chronic pain in people with PTSD. I wonder whether one of the factors might be that you very often find that people with PTSD are highly hypnotizable and so are people with bad chronic pain. In the cold pressor test (seeing how long you can keep your hand in iced water) those who were highly hypnotizable couldn't keep it in for long because they were having to not put into place any of their skills, but were really good at focussing attention. I wonder if there is something there.

There was a recent study of a cold pressor task in chronic pain patients, comparing them with healthy controls, registering their pain scores after one minute. There were two groups, one who were asked to focus on their pain and the other asked to ignore it. At first the former scored significantly higher pain scores, but when the test was repeated several times over a few hours they found the scores getting closer and closer with the distraction group getting worse and the focussing group improving near to a point of crossing over.

previous location of a threatening stimulus is often interpreted as vigilance to threat. (Wikipedia)

What about children who have learnt to put up with a lot of pain? And have an emotional hypervigilance but not a physical hypervigilance?

The honest answer is that I don't know. Hypervigilance is specific to different things and might be related to the trauma they had been through.

Is there a vicious circle with hypervigilance to pain stimuli and that ramping up, and so on?

... yes – from a physiological perspective ... we know that with plasticity in the brain the more something is repeated the stronger it gets in a vicious circle and this feeds into that ...

... structural changes in the amygdala in childhood ...

... all sorts of factors in cortical development – no reason to believe that pain wouldn't be among them.

### Creativity

There is a large body of research into the relationship between creativity and emotions which suggests that there is a bidirectional relationship with each enhancing the other; people who are high in one tend to be high in the other. There is a link which we can explore further. There is research into the role of music in pain management which suggests that listening to music can have a positive impact on pain outcomes and experiences and even lead to lower usage of opioids. But I am going to focus more on the act of creativity rather than passive appreciation of arts in general.

There are a number of chronic pain patients who use art to help them cope with their pain experiences and there are online groups who exhibit their pain related art. One example of this is <u>www.painexhibit.org</u> whose mission statement is "to educate healthcare providers and the public about chronic pain through art and to give a voice to the many who suffer in silence".

The collective was founded by a chronic pain sufferer, Mark Collen, who found himself unable to clearly communicate his pain to medical professionals, and turned to art as a coping method and a release for the tension he was under. He shared the art work that he produced with his doctors, who found it to be a useful visual reference to help with understanding his and other patients' pain experiences. Mark reported that he felt that his pain outcomes improved directly as a result. He now exhibits a large range of chronic pain patients' art on his website which is very much worth checking out. This is one example:



the experience of pain to create art). They are quite conflicting, and show that this isn't a one-directional relationship.

Some of my colleagues in Derby are engaged in an ongoing project – provisionally named Singing in the Pain – which involves asking chronic pain patients to take part in a singing intervention. They were split into 3 groups: listening to music, singing in a group, and a control group which did neither. Preliminary results are very positive. The singing group shows some large and significant improvements in pain tolerance, pain associated fear, energy levels and general happiness compared to both other groups. Listening to music also shows significant improvements compared to controls. A group in Nottingham looking at pain patients singing in choirs (with the additional benefit of socialising) are seeing similar outcomes. The possible mechanisms of action include distraction, expression, control over the artistic process and the pain environment, physical and psychological relaxation, and communication. These definitely need more investigation. I don't think there is one single explanation and it will prove to be different for different people.

... [does this involve] hope and a fundamental shift in perception of one's life and future?

If we look at the Pain Exhibit website you will notice that the art produced is overwhelmingly negative. While this may serve a short term purpose you wonder if in the long term [word inaudible].

When I use art with my patients I get them to spend a limited time doing art on the problem and then I tell them to stop doing that and focus on what they would rather have: comfort, relaxation, calmness or whatever; and start drawing something that will relate to that.

Is there unexplored creativity within the clinical encounter to bring about healing? We know that it can improve communication and directly influence pain expectations and treatment outcomes. If people can feel they are more understood and more involved in their care and getting more out of the encounter than they previously had they are more likely to adhere to prescribed treatment.

So can creativity can play a role in pain management? Some physicians report that art provides them with a visual reference and a richer understanding of their patients'

pain experience. But it is something which is in its very early stages of development and something we may well see more of, and be more regularly used by clinicians.

### Conclusions

The mind, and especially the emotional mind plays a large role in the pain perception and experience.

There are strong associations between emotion and creativity.

Creative pursuits are reported to help Chronic Pain patients in a number of different ways.

There is potential for creativity and art to have a place in the clinical encounter.

Further research must be carried out to better understand the mechanisms of action and who may benefit from these kinds of activities.

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#### Discussion

I understand there has been some work using [mind games?] to distract patients from pain ...

We have seen patients using snow games for distraction during burns dressings. I think it's an excellent idea but considering what I said before about the role of distraction, you might expect the effect to diminish over time. So the game might to be modified or we might need different kinds of distraction. It's one thing using this for acute pain but for someone who has suffered neuropathic pain for twenty-odd years, finding new distractions is going to be a real challenge.

I would agree. There are two things: there are changes of state, and the stages of change. Of course you can play with games and distractions, and changing the mind's exposure, desensitise and so on, and this is of value but that's not a change process. Art, for me, needs to be in the context of changes in terms of stages of change. Unless the old story is honoured there will be no new story. You do begin with some detection, expression, words, images and writing honouring the old story – this is quite important and there is a certain containment in that. There is a movement into a new story and that is surrounded by a field of safety and a trusting relationship.

...it's like an emotional journey rather than a snapshot.

... a restitution process with stages to it.

[Inaudible] through creativity can add structure to that creativity. I have found the power of being successful at something is very important. That then leads people to try other things ...

... a vehicle for the story...my goodness, if there is something in me that can create that maybe there is hope ...

I am reminded of the story of the boy who was brought to the UK as a refugee and had been tortured. They wanted to find some sort of therapy for him but he spoke some very obscure dialect and nobody could find an interpreter. They installed him with another couple of guys in a flat opposite St Pancras station and gave him drawing and painting materials. To begin with he painted disembodied limbs and blood and tanks and stuff, but very slowly it changed and by the end he was producing amazing pictures of the station! There was no possible verbal therapy but he was able to use art by himself.

Are you using art individually or in groups? I have a friend who goes to the Christie Cancer Centre in Manchester and one of the key things that really helped her was the art class there. I have often wondered how much of that is the group process and being in a social context, and how much in creative expression. There has been a lot of work in palliative care to show that groups are helpful.

The social aspect is very important in a lot of things; I was considering bringing some research into religiosity and spirituality and the differences between them. The authors found that spirituality and prayer doesn't necessarily lead to better outcomes, but attending group worship with that social support is better.

Are you considering explicit art or music therapy, or are you thinking about creative activities that happen anyway but don't have a therapeutic intent? The way they are taught and their structure and shape are very different.

I would say that this would have to be guided by the individual.

#### The patient or the therapist?

The patient. Some like to be very involved in their healthcare, and some, particularly older people, prefer a more authoritarian approach. But in this case as distraction is often cited by patients as a positive factor and other people say they are using pain as a creative fuel, I would have thought that painting about pain was not a good way to distract yourself from it.

So you are suggesting that art therapy with the intention to bring about a narrative change in the patient away from their pain towards something else – that structured therapeutic model – would be better than simply going to a painting class. In view of the revolution in social prescribing<sup>13</sup> and what health care commissions are beginning to try do I am really interested in how we tell this story and make the distinction between a therapeutic practice and art for art's sake which is already available for many people.

The idea of trying to create a narrative leading someone through their experience rather than a snapshot of an emotional moment ('does how you feel at this moment - represent your pain right now'); creating a programme to lead someone through their emotional journey - has the potential to be a very positive thing. But as a research psychologist I am always going to say that we need to gather some people to do some actual...

... there is already a rich body of literature around art therapy and art classes, which probably comes mainly from creative narratives but there might be some work that will help you answer some of the questions you are raising.

<sup>&</sup>lt;sup>13</sup> 'Social prescribing' is a way of linking patients in primary care with sources of support within the community. It provides GPs with a non-medical referral option that can operate alongside existing treatments to improve health and wellbeing.

It would be interesting to compare people who take up art after they have developed chronic pain with artists who have developed it.

We have been running knitting groups for some years and have developed the idea of therapeutic knitting which I would define as the combination of knitting and knowledge; knowledge about your wellbeing and your health condition, but also how to use it as a tool ...

What is the difference between your 'standard' knitting groups and the therapeutic groups? How do you instruct them differently?

We get a pain education in under the radar and teach them how to use it as a tool, for example people with panic attacks can take something (knitting) around with them that they can use at any time of day or night when they feel their anxiety levels rising. They don't often need to use it as the knowledge that it is there may be enough.

Calling on another set of language, that of pre-hypnotic suggestion: the way the whole thing is framed, whether it's said verbally or not, by the implied process that is about to unfold - just as you have seen with placebo studies and consent forms for controlled studies where people have been told they may get aspirin-like effects and side-effects, or if they have been told it's opium they will get opium-like effects and side-effects from the placebos. So 'why am I going to the drawing class' is really a key active ingredient before you even arrive.

This may have already been mentioned but there was some placebo research published a year or two ago which showed that even if you tell people they are getting a placebo with no effect on their condition you can still see some improvement.

I think they had been told that there was some evidence that placebos work.

Whether you are an animal or a child or an adult there is a ritualistic picking up – something is going on here involved in taking and swallowing things – there must be something behind these people asking me to do things – so this is magic.

We haven't talked very much about hope in this meeting so far, and it has always seemed to me that hopelessness, fuelled by the repeated dashing of hope entailed in failed biomedical interventions, must be one of the worst aspects of living with chronic pain, and one of the major components of the vicious circle of pain and depression which perpetuates people's problems. So I was just wondering how the approaches that you people have been talking about can address that.

When I wrote this presentation it came out far too long so I had to cut out a big chunk, and one of the things that I had intended to talk about was belief, self-actuality and spiritual stuff. The belief that you have the ability to cope with the condition improves your outcomes. If you think that you have the ability to cope with the pain and the emotional strain you tend to be correct in the longer term.

Hope - the feeling that the future can be better than this – that's a new story already. But before you have experiential knowledge of that you need hope - you need faith. The encounter with the practitioner of the context, the taking of the placebo tablets is already the seeding of the new story. George Faithful Smith who was a very famous hypnotherapist in Glasgow recounted the story of a dentist who was treating a patient with such severe psoriasis that she couldn't open her mouth properly. He referred her to George Smith and she came back six weeks later and was completely clear. They said: "So you've been to see George?" and she replied "no, but I think about him every time I pass his office"! The moment the seed of hope was planted... the possibility ...

... in your first contact in a pain clinic when they say there is no cure - "you're going to have to learn to live with it" - that's why I was trying to challenge that by showing a couple of transformative reactions ... the potential that I was exploring ...

Yes, we have to learn to navigate without false hope or bullshitting about new drugs but rooted in the reality that people are capable of doing more than just coping – of resurrecting and coming to quality of life and experience. That's a lived reality, it's true of people but it's just that we are pretty hopeless at understanding and keying into that and helping people to achieve it. Even just having the title Pain Management Programme ... it's not going to get better you'll just have to manage it ...

That's a pre-hypnotic suggestion already.

Talking of the way names can affect peoples' perceptions and behaviour, one chest clinic with a lot of patients still smoking changed names so that one part of the clinic was the Chronic Obstructive Pulmonary Disease Clinic and the other the Smoker's Lung Clinic. They gave them exactly the same scripts and treatments and double the number of people in Smoker's Lung gave up. They didn't like to be identified as that on their cards.

I am a researcher with no direct patient contact but my colleagues in chronic pain psychology tell me that people come to them whom have been in chronic pain for twenty years, have had many treatments, and at that point the curative approach hasn't worked. So that kind of hope has almost gone for them, so the change in tactic to give some kind of strength and understanding does yield some improvement.

I had a patient recently who had been told by the pain clinic "Ok we've got ten drugs and we'll just work through them". He is now on seven of them, addicted and drugged out ... yes, we're hurting people ...

The system is conspiring against changing that: we have CCGs ruling that you can only have one more appointment after the first one. How are we ever going to change or develop?

The other thing about hope is that sometimes we have to carry hope to the patient and make them feel that they are more than their pain, more than the past events that have happened to them.

If we ourselves work in the context that we can only see lives that are pushed and pressed this is a toxic environment. We have to carry an experiential conviction of peoples' capacity for transformative change.

# Everyday Ethical Conundrums in the Pain Clinic

# Tim Johnson

These represent some of the concerns I have, none of which are about philosophy; some have ethical dimensions, some are more moral and some are legal. But they are all things that have troubled me behind my everyday work in the pain clinic. They probably apply to other areas of medical practice as well.

## *Culture and Language*

My first perplexity is to do with differences in culture and language between us and our patients and how we may respond differently to them. We see a lot of refugees and asylum seekers in Salford, though probably not as many as in other areas. These come from very diverse backgrounds – again more so than other areas with more fixed populations. I often feel a complete sense of helplessness dealing with these people, and that can lead to the feeling that you are not helping this group as much as you should, compared with patients you may feel more comfortable with. The discomfort here is uncomfortable inconsistency. There isn't a problem if you have an asylum seeker or refugee and you are working through an interpreter (often difficult to find; we have a telephone translation system in the hospital which works extremely well but even that can have trouble with some dialects) and can broadly establish the problem, make some reasonable recommendations, provide some advice about guidelines and safeguards - and there isn't a problem with discharging them back to primary care as there isn't any more we can do. I know from experience that referring them to my psychologist colleagues and the PMP isn't going to help. But nevertheless there is discomfort that we are not doing enough. I like to arrange annual follow-up visits for my patients to ensure that things are under control but I don't sense that I do that as much with this group.

#### Have any of them been tortured?

Yes, and that's another area. I have at times referred people to the mental health services in Manchester who have helped in the past with torture victims. It's not just torture in the worst sense; other, similar, bad experiences are almost ubiquitous in this group of patients.

# Benefit applicants

Benefit applications are another difficult area. How I respond to people wanting help with benefit application does depend a little, not so much on language but, on culture. If one senses that there is an element of factitiousness in the patient's symptoms and that benefit seeking is part of that – not a common occurrence but it does happen – one may react differently. My usual reaction to requests for support for benefits is to say that I don't do it, because I find I don't have all the information about the patient's medical conditions. And I find I am in the position of saying I am trying to help you and give you the best treatment for your condition; but if at the same time I am saying you're never going to get better; or thinking that you will not get better, but write a report saying you will get better, you probably won't come back and see me again. It's very complicated and a lot easier to say that I won't do it. However, sometimes I

do if I feel sorry enough for the patient, and I am aware of the inconsistency of that. The same applies to III Health Retirement Validation. We are trying to get patients back to work and at the same time being asked to help them to retire. I have done this occasionally but usually because I feel there is a particular relevance for the patient or I feel sorry for them.

### Ethics of Placebo

We have talked a lot about placebo at this meeting. I can get placebo to work very well; I have supervised trainees doing injections over the last 25 years and I know that many of these go into any part of the spine other than the facet joints or wherever they were aiming for, but as long as I am there muttering "you're doing really well, that's marvellous, I'll be out of a job soon ..." it seems to work extremely well! But if I read carefully what the GMC say about transparency am I walking on thin ice with this approach? I have some patients that I deliver treatments to that can only be placebo. I've tried to discourage them but they insist on coming back and I inject their back; I daren't just use saline but I do use very dilute, 0.25% lidocaine. I tell them I really don't think this is going to work but they say "it's always marvellous, doctor, it lasted about five months the last time and it's only in the last month I have felt I needed it again". So I end up doing these treatments and however much I trash them patients keep coming back for them. Sometimes we feel as clinicians that we are lying.

### Risk misinformation

It's not just me doing this. I see spinal surgery patients who probably don't have a lot wrong with their spine; they have a lot of pain and some degenerative changes. The usual story they bring to us is that a spinal surgeon has said to them "You've got a really bad back and I would love to operate on you but if I did that I would paralyse you". Operating has never even entered the surgeon's mind, guite rightly too. I do the same thing: I see patients who have been referred from other hospitals wanting me to continue or repeat a course of injections. I really don't like doing these things which I see as placebo procedures, although one thing I shall take away from this meeting is that they may be more valuable in the long term than I thought. There are some procedures I don't like doing, like facet joint injections in the cervical spine which have little evidence to support them and have some serious side-effects like injecting into the vertebral artery. So I tell patients that there are significant risks associated with them and I find the most powerful word, which I call the P-word, is paralysis. You may see it's a very low risk, less than 1:100,000, which most people would ignore, but if you say paralysis it changes peoples' views. I think that's quite naughty because I am introducing bad words and bad concepts, but I do do it if I want to put them off. I hope now I can avoid this by offering them something more valuable which is a very effective way of taking people away from treatments they don't need.

We've now got cost coming in as well and NICE guidelines which will say we shouldn't be doing facet joint injections. It's difficult to say to a patient 'the government say you can't have this'. It's easier to say 'well, they haven't really been working for you, have they ... and steroids can make your bones weak and give you diabetes' – true, but you're misinforming the patients with an economy of truth.

## A challenging story – what would you do?

A patient came to us from the neurosurgeons with the request: can you do an epidural? The notes read: History of radiating leg pain. An MR scan shows a compatible prolapsing disc; young man in his late twenties seen with a friend. He exhibited *extreme pain behaviour.* We are always alerted to problems when we see that. There was also an issue with a benefit application; I routinely ask about this, sometimes to my regret. There was an appeal in this instance. The patient was expecting an epidural, to which I agreed having given some advice and precaution (I didn't mention paralysis). As he left the clinic he was again exhibiting gross pain behaviour using a crutch and with his arm round the friend. It was the end of the clinic, so partly out of interest and partly because I needed to go and get a sandwich I followed him down the corridor and his behaviour remained unchanged at first but by the time he got to the car park, about quarter of a mile away, he appeared to have no disability whatsoever, and was laughing and joking with his friend.

So what should I do in that situation?

I would have asked him what the miracle cure was!

I was some way away. I am very familiar with covert observation in the medicolegal context and spend some of my weekends watching videos of patients taken from a supermarket trolley.

Your letter to the GP: ... PS I happened to notice and to my surprise etc....

A letter to the patient suggesting another consultation before going ahead with the epidural.

Sometimes hospitals make people behave differently.

What do you think was his motive?

I don't know at this stage. That is a very important point. In my medicolegal practice I see many people with pain and when people come to me as the defence expert they lay it on thick. They will tell me about it as it is at its worst. This is exaggerating to convince rather than to deceive. This is potentially the explanation here but ...

This sort of behaviour can be iatrogenic: it becomes more and more bizarre because people think it is the only way they can be listened to or believed as they have been persistently disbelieved in the past and things get out of hand.

Behaviour that may suggest malingering may involve subconscious triggering. I am reminded of an incident when I was taking our dog for a walk and he had an unfortunate accident when he was having a pee up against a rose bush! And for the rest of his life, when he passed that bush he would limp!

Was his leg pain compatible with his MRI and his clinical signs?

Well, any leg pain he had was grossly exaggerated. If he had come in walking perfectly normally one might have said, well, I could do an epidural but really your symptoms aren't all that bad.

I would have brought him back and said "I'm wondering how variable your symptoms are... because last time I happened to leave after you and noticed ... etcetera" without using a threatening tone, being very open, and leave that space to see what comes into it. That at least presents the option of a dignified withdrawal.

The other thing was that I had a registrar with me, and I did tell him about it. That put me in a difficult situation because I then had to do something about it. The thing I was concerned about was that with the knowledge I had (and wished I hadn't!) if I did an epidural and it all went horribly wrong I had done him a disservice because I hadn't put a brake on it, or it was a slot that had been denied another patient who could have benefitted more.

The point you made that putting it on for the doctor may not necessarily be factitious.

Doesn't everyone put it on for the doctor in some way? When I go to a doctor I work out my narrative before I go, and even though I am a doctor I am a little bit anxious, I want to get my story across and make sure they understand where they are coming from, because often they don't ... everyone who goes to the doctor surely has a narrative there which they have prepared ... there is always something of an act about seeing the doctor.

What does it do to us? We are seeing them with our best intentions, but haven't established the rapport that we hoped for. That nags away at us.

That was very much part of my reaction. I felt I had been conned. I needed more information. What I actually did was to write a letter to the patient simply stating what I had seen. Having had a number of experiences in my life when there hadn't been total transparency I know that this is absolutely vital, and you can't go wrong by telling the truth. So I wrote and said "on my way out I did notice ....", and copied that letter to the GP – I debated that but as it was on his record anyway it would have been difficult to keep him out of that loop. I just stated the facts and didn't draw any conclusions, but said that before I did the injection I wanted to be sure I had got all the information right, so could he come back for another appointment. To his credit he did come back and admit that he was putting it on strong, but he did have leg pain. I agreed to do the epidural, which seemed to be working at follow-up, so maybe it was the right thing to do. I'm sure it was right to call him back.

The bottom line there is do no harm. In the context of your other comments about fairness and being truthful ...

... I inherited a practice where one of my colleagues did a lot of stellate ganglion and lumbar sympathetic blocks for reasons which weren't ... that good. I wanted a reason to stop doing these procedures, and I would explain to them ... But over the years I saw a lot of patients who had had these procedures and swore that they had done them good. I told them that I thought that it was just a placebo and that there are risks involved, but they insisted that I should carry on. Even if it you tell somebody quite strongly something is a placebo they still get a response. If someone gave me a treatment and told me it was a placebo treatment, I believe in the placebo response and I might respond quite well. But beyond that there is an emotional element. You can intellectually acknowledge that it's just a placebo and not going to work, but if at an emotional level you believe it's going to work, it will. A placebo is so strong you can't counteract it cognitively. I had a similar experience of a lady with CRPS of the left hand whom I had inherited from another hospital who had refused to do the stellate ganglion blocks she had been having for about 20 years, at one time every six weeks. This was at a time when I was feeling very cooperative so I agreed to do them every six months. The area of her stellate ganglion is like leather with so much fibrosis and quite often the blocks don't work. But she insists on having them and I think that part of that is that they validate her condition. If I don't do them nobody else is going to give her the opportunity to come into the hospital day-case unit and all the ritual this involves. I sense that it is important to her relationship with her husband that she keeps having the treatment.

There are a lot of placebo procedures that are less safe like lidocaine infusions; then there are all the patients having i/v guanethidine which suddenly isn't unavailable any more. Some of them go away happily and we don't see them again, but some are very unhappy and we have to switch them to something else.

There is the issue: can you refuse to do something to somebody that they perceive as useful?

Only if it's actually dangerous. But it is difficult and not always the right thing to balance against do no harm.

These are physiological conditioned responses. That has been shown in rats and humans. The person will be getting physiological readjustment from the ritual. So you do have to ask yourself if it is ethical to withdraw the effect of care in evoking this. If the interval between acupuncture sessions is six weeks the effect will last five because that is a physiological response – that's the interplay of the narrative and the physiology.

There was a fantastic experiment where you give cyclosporine in a green liquid and you get fantastic immunosuppression and then you just give the green liquid and you get the same immunosuppression. You're actually conditioned to a major physiological response with massive changes in the immune system. Just once. There is a whole tranche of work going on now to see if that technique can be used to actually reduce the amount of drug you have to use, for example for transplantation. That is classical Pavlovian conditioning. The reason you get into problems with placebo is that you've got the patient to a position where you're getting that response and then it's very hard and probably unethical to stop, although you can switch to different things. You are generating that problem because you care. Doctors who don't give a shit don't get into this problem; they don't have people coming back for the same treatment because the patient knows they don't give a shit and they don't get a decent placebo response. It's because you're a good guy you're getting into this trouble.

I'll take that as a reinforcement!

I've been hearing about placebo responses and conditioned responses which are related but not quite the same ... I'm a bit confused ...

Placebo response is a large term. There have been many forms of action and means of triggering it. It's not one thing. Within the Venn diagram one of the circles would be classic conditioning. I've seen this in A&E: someone comes in with chest pain and

are given an opiate and it settles. They come back for two or three other admissions and some clever person injected them with saline and the pain settles, so they conclude that they were malingering. That's not true scientifically. I did an RCT in asthma and was able to show opposite effects from two placebos a month apart, with major aggravations needing steroids from placebo on one occasion which didn't happen on the other. This was to do with context effects and physician signals. These are powerful physiological responses.

That's why I studied homeopathy some years ago, looking for less toxic conditioning signals.

If you've got someone with a leather neck – and goodness knows there's a lot of anatomy - a lot of clockwork in there, it's probably not fantastic in the long term for their health to keep on with these procedures. So what should we be doing in the long term that will be safer? How can we get these patients on to something better?

That's down to relationship, trust, honesty and the creative movement of a narrative over time. You might say to them "When people have had a trigger like this of frequent injections over time, one of the things that happens is that the system is becoming more keyed up to create its own painkiller, and there have been good discoveries recently to help people to better create those painkillers, so they don't have to get the injections in the long run. We'll keep the injections going for the present but we might begin to wean in these other procedures." This is a clean-up job and the message to us all is for God's sake don't get people on to this in the first place, but let's not traumatise those we have hooked.

Using epidurals for the purpose of allowing them to move more and then gradually withdrawing that may be of long-term benefit - giving the epidural to allow something else to happen.

We were talking about this yesterday and saying that it is something we had all tried but none of us had ever seen it working. We like to think we are being helpful, but I have stopped doing facet injections and epidurals to get people to physiotherapy because it gives them a false sense that they are in a break and it's all going to be wonderful and they'll have their physio and it will all be better, they're going to be cured. But actually it won't; they will still have chronic pain and will still need to find ways of dealing with that.

It comes back in a way to my contention that the most important relationship is between the therapist and the therapee, and that the rest is just add-ons: if we tweak the system we may get a temporary improvement which we can build on, but we can't continue to rely on that. But then how many patients get sent as that one does for an epidural? - You've been told to do a treatment ...

This is symbolism and casting of bones... offering a prescription ... it's a Trojan horse. It gives very powerful messages. If you're going to inject me you are giving me a very big story. You wouldn't be injecting me unless you thought it was important and effective, even if you are verbalising reservations about it. Some need injections and that is the nature of my situation.

The whole nature of chronic pain ... When every new big textbook on chronic pain comes out I look through the index for any clue that chronic pain is actually chronic. It doesn't appear. There is chapter after chapter which tells you what to do – what

injection etc. for that, or this is a psychotherapy technique that might be useful – which may cure the problem and make it go away. We have to be very careful with the patient about how we suggest that the pain may not go away, but the central point is that chronic pain is chronic. The word comes from chronos, time, we're stuck with it, tough luck. If we behave in a different way we will be failing and the end result will be the sort of patient we have been talking about.

... It's been years since I prescribed things including apparently innocuous things like acupuncture, because of their symbolic nature ...

...everything we do – we talk about the benefit of treatment, but the evidence that anything does any good for chronic pain is poor.

Should we change the term from chronic pain to prolonged pain so it is possible to see the ending of it?

The Pain Society was originally known as the Intractable Pain Society but that was changed because it was thought to be too negative.

# Shared Reading and Chronic Pain

# Introduction

## Andrew Jones

Our previous studies of the benefits of reading include: *An Investigation into the therapeutic benefits of reading in relation to depression and wellbeing*, Billington *et al.* 2010; *Reading for Life: Prison reading groups in practice and theory*, Billington *et al.* 2012; and *A literature-based intervention for older people living with dementia*, Billington *et al.* 2013, and we wondered if we could apply this to chronic pain.

The rationale for this involves the neurology of the frontal lobes which are heavily involved both in chronic pain and reaction to the arts generally.

We undertook this investigation with the collaboration of the Reader Organisation. To get things started, we sought to recruit patients by putting out fliers in the waiting rooms of all our pain clinics saying "Come along to a taster" and only one person came! (She is still coming to our group.) But this encouraged us to persevere so we started sitting in the waiting rooms and nagging people and eventually we got a group of eight together. You will hear more about the model of shared reading later on.

They sit there for two hours. As we know, people with chronic pain have very poor concentration, but they progress more quickly to the more difficult literature than patients without pain. We've been doing it for three years now. The groups number twelve if they all turn up, although flare-ups of pain may reduce their numbers. They have all reported improvements in quality of life. They provide strong group support for each other and go to cultural events such as plays as a group.

### A comparative study of cognitive behavioural therapy and shared reading

# Jim Ledson

The most important thing for us to get across today is the practical demonstration of shared reading, but first I would like to share with you a little about our most recent research. I do not intend to give a formal scientific paper presentation, but you can find the paper by following the link given<sup>14</sup>. The authors are drawn from the Centre for Research into Reading, Literature and Society, of the University of Liverpool; The Reader Organisation; and the Royal Liverpool and Broadgreen University Hospital NHS Trust.

<sup>&</sup>lt;sup>14</sup> https://www.liverpoll.ac.uk/media/livacuk/instituteofpsychology/Comparing,Shared,Reading, andCBT,for,Chronic,Pain.pdf

We set about trying to compare CBT and shared reading for chronic pain, so our patients were recruited into a five-week CBT programme and went on to a 22-week shared reading programme.

We measured a whole host of things but the ones I want to draw your attention to are the 12 hourly pain and emotion diaries and the Positive and Negative Affect Schedule (PANAS) (with an addition I shall tell you about later). We also conducted video assisted individual qualitative interviews after both interventions which enabled us to corroborate some of our other findings on a first-hand basis, and transcribed the audio-visual recordings of all the sessions.

PANAS involves giving people this list of words describing their emotional state and [asking them to] score them from 1 to 5 as to how relevant they think they are.

- 1. Interested
- 2. Distressed
- 3. Excited
- 4. Upset
- 5. Strong
- 6. Guilty
- 7. Scared
- 8. Hostile
- 9. Enthusiastic
- 10. Proud

- Irritable
  Alert
  Ashamed
  Inspired
  Inspired
  Nervous
  Determined
  Attentive
  Jittery
  Active
  Afraid
- To obtain a positive score for affect one would look at I, 3, 5, 9,10, 12, 14,16, 17 and 19, and for negative at 2,4, 6, 7, 8,11,13,15,18 and 20. Each has a maximum score of 50.

We found from our pain and emotion diaries that when pain was worse emotions were worse. Or was it the other way round, that when emotions were worse pain was up? I don't know. I was reassured by this as it's something I've always accepted as received wisdom and not often seen it written down with a nice scientific p number next to it.

What was striking was that for the shared reading the pain scores in the diary were down for up two days after it, emotions were better after every session, and people reported better sleep. That's quite something: to be able to have an intervention that lasts beyond the immediate with these types of problems is something quite special. CBT resulted in lower pain and better emotions after each of the sessions, but we couldn't demonstrate any difference after 48 hours.

The PANAS scores showed a trend, over the 22 weeks of the course of shared reading for a higher positive than negative, which was not seen with CBT. This was a bit disheartening because I had quite a lot to do with delivering that CBT - and a bit puzzling. When we looked at the data in a bit more detail, if you took session 4 out of the 5 week CBT course, things looked very different. In session 4 we do set-backs and flare-up's. So people are being forced to confront the idea that flare-up is inevitable at some point and that they need to plan and prepare for it, and they don't feel so good after an afternoon discussing that. I'm not sure what to do about that.

The other thing that we noticed is that on the PANAS form there is a little box at the bottom where you are encouraged to put a couple of phrases or a few of your own

words, and the people that were doing the shared reading used a much greater diversity of words. The frequently used words that cropped up regarding reading were enjoyable, relaxing and happy. For CBT the words were more cognitive: interesting, informative and educational.

So where does that all leave us? In CBT participants are encouraged, indeed expected to explore thoughts that give rise to feelings and behaviours that ultimately denude them of their quality of life. The analysis and discoveries then allow this to be used as a doorway to change cognition and behaviour and somehow bring back some quality of life. With shared reading people can choose to vicariously explore the feelings and thoughts of the characters in the literature, as well as exploring the feelings and thoughts that the literature - and exploring the relationships between the characters - induces in themselves. This stealthy increase in self-awareness can be a powerful catalyst for change. Sometimes, it has to be said, we just enjoy a good story, and sometimes we just enjoy sharing a good story. But that is of incalculable value to people who are prone to social isolation.

On a personal note, I have noticed that when people who have taken part in shared reading come back for medical consultation, they are able to express their stress and emotions to a greater degree: and that is something that can only be of benefit when we are entering into a therapeutic relationship.

A final thought: we all have different selves - our perceived self, our hopeful self and our feared self. It seems intuitive that the further apart the domains of perceived self and hopeful self, and the perceived self and the feared self, the more trouble we are in. Does the exploration of literature allow us to positively realign these identities?

#### Patient experiences

#### Josie Billington

We videoed all of the sessions, analysed them, and selected particular clips to take back to participants and looked for themes that could be corrected or affirmed in some way. Here is an excerpt:

Doctor: "It sounds almost like you're not the same person".

Patient: "I was defining myself by my pain... I didn't see anyone, I didn't go anywhere ... I'm not the same person as I was before the pain".

Recounting her experiences helped her to get a lot off her chest; she lacks support and feels very alone. What she got off her chest explains her condition. The dialogue with her clinician was changed because her medication was changed. She was more expressive about what she was experiencing about her condition.

There are moments there where you can see that CBT is helping people with awareness; it wasn't like everyone said yes, and it gave people a language. But when we did a linguistic analysis of the recordings of the CBT sessions what we found was that there was no deviation from pain throughout the session; the only thing people talked about was their pain. This might be completely expected; this first session did involve inviting people to talk openly about their pain, but they never talked about anything else throughout the session. There were also a lot of negative constructions: I don't, I can't, I haven't - the language of subtraction, of diminishment and of not having. It's really important to be aware that CBT can often reconfirm people in a view of themselves - that sense of identity as a person in pain who can't do the things they used to do ...

... but they probably thought that was what they were supposed to be doing ... this is a pain intervention and we're all sitting around talking about pain...

... absolutely, and that was the invitation, but the hope would be that people should get a new awareness - a new acceptance - that change of perception moment. But the trend for this continuing throughout was worrying, although the person that was talking like this was also the one getting some benefit from CBT, so it's not a simple story.

Some people expressed a preference for difficult material as it took them further away from their pain.

[The remainder of the session was devoted to a number of video clips illustrating people's responses to reading. The recording was not of sufficient quality to transcribe these accurately and what follows is taken from the team's publication A Comparative Study of Cognitive Behavioural Therapy and Shared Reading for Chronic Pain

https://www.liverpool.ac.uk/media/livacuk/instituteofpsychology/PDFComparing,Shared,Reading,and,CBT,for,Chronic,Pain.pdf]

#### Change

In Shared Reading (SR), participants were more engaged with the idea or possibility of change, and more responsive to attitudinal shift than in CBT. Indeed, in CBT, discourse in this area was strongly characterised by the negative changes which the onset of pain had produced:

SH: I'm defined now by my pain; I am not who I was before my pain.

SY: People say to me, I'm not the same. I was very outgoing; now my friends and family think I'm not me anymore.

A: People remember me for what I used to be able to do.

In addition to the strong sense of a reduced or diminished life - 'of every tiny little thing being taken away' - there was expressed awareness of stasis, both literal/physical and psychological:

SH: It's the inactivity ... social and physical ... you just stay in one place.

This powerful sense of subtraction meant that openness to change tended to be very low in CBT:

Consultant AW: How do you feel about acceptance?

SH: You mean accepting that this is how it is and I've got to live my life with it?

SY/SH: (almost in unison): I'm not anywhere near that, no.

SH: On a scale of 1–10 I'm probably at minus 10.

Participant SY: Me too.

By contrast, animated appetite in relation to change was a feature of SH's response to Elizabeth Jennings' poem, 'Resemblances', five weeks into the SR group:

Always I look for some reminding feature, Compel a likeness where there is not one ... Some knowledge which I never could have guessed. (Elizabeth Jennings)

SH: 'Compelling a likeness.' Is it talking about just looking for normality? You just want something that's familiar. It's like saying, that's [pointing] like that, making it fit what's known already. But it's also saying, if you just go for the familiar, what about the new and exciting: you miss a lot.

Where, in CBT, SH's formulations were characteristically negative as well as expressive of matter that was certain and familiar - "I am not who I was before my pain", "I don't do anything ... anymore .... I can't even speak about it anymore" - SH's tone and syntax here is one of energetic questioning and grappling with what is 'exciting' in seeing afresh, changing one's vision. More, SH uses 'you' where 'I' was normal in CBT. Generic/impersonal 'you', linguistic analysis suggests, is a sign that 'something specific from the text world is transferred to the real world in the form of a generic claim', thus signalling 'a change of perspectivisation'. These deictic markers indicate a shift from SH's default attitude - staying with the habitual and familiar, 'what is known already' - towards an engagement with something beyond 'likeness' and safe normality, something 'new' or 'never known before'.

[Referring to a poem suggesting that in looking for the familiar we have often missed some recognition - something never known or acknowledged.] By looking for the familiar all the time you are missing something new and interesting. This is a woman who was always saying 'I haven't', 'I can't', 'I don't' – 'acceptance minus 10'. She is recognising here what she is missing - whether she is connecting to her own situation I don't know, but what is most impressive is that there is a kind of switch in understanding that CBT is aiming at most of all; the moment when you are surprised out of a default mode of attitude. So she seems a different person when she is reading the poem - she is animated, she looks forward - she comes alive. Part of it is that she recognises that when those moments happen they seem to be something to do with reading aloud.

[Referring to an interview recording a participant's reaction to another reading.] Without the interview we would have known something was going on there but we would have had no idea what it was. Does that matter? Well possibly it was good for this to come out, but my point is that this is different from conventional thought therapy because people were getting something out of this personally and therapeutically without anyone knowing what had happened in the person's life; why this moment was particularly pertinent for him. [The reading provided] a language that is articulating things that needed to stay in his mind which would otherwise be lost for ever. There is something here about the preformed language [of the poem] helping to articulate or express something that otherwise would remain inchoate and unexpressed; something to allow them to shift position between characters: the child who is suffering then becomes the adult who can give comfort to the child. People come to theses realisations in their own time – it isn't programmed.