

## THE BRITISH PAIN SOCIETY

Special Interest Group for Philosophy and Ethics

Exploring the future of pain medicine: caring for the  
patient and the clinician

RYDAL HALL 24<sup>th</sup>-26<sup>th</sup> June 2019



## Introduction

Peter Wemyss-Gorman

This year the group explored a variety of themes ranging from the link between childhood trauma and chronic pain to the future of pain medicine.

A welcome departure from our past tradition was that two of our speakers were general practitioners, reflecting the neglected reality that the great majority of chronic pain sufferers, and indeed all of them for most of the time, are cared for by their GP's, and that pain specialists only know them for a relatively brief episode within a lifelong of suffering.

Topics included integrating the art of healing and the science of medicine, the need to look beyond the biospsychosocial model and accept the complexity both of the needs of chronic pain patients and the world they inhabit, the challenge of providing a truly holistic pain service in a large complex department, and facing the reality that almost everything we think we know about pain enough to express in conventional language is probably wrong.

Although we were encouraged to believe that more and more people recognise what needs to be done or changed to provide a better service for suffering people, any optimism was overshadowed by the many accounts of the frustrations and administrative and financial restrictions people have experienced when trying to put these changes into operation, or even stop things changing for the worse. More depressing still, as I write in the spring of 2020, we have hanging over us the spectre of the Covid19 pandemic which threatens to devour all the available resources of the NHS.

As it says in our web page, one of the important functions of our group is to provide 'mental and physical recreation so much needed by people wearied by their daily work with human pain and distress.' (and, one could add, struggling with the problems referred to above). A lovely innovation to this end was our time of 'forest bathing' (from the Japanese *shinrin-yoku*) – simply wandering meditatively in the lovely woods above the Hall, just *noticing* our surroundings and savouring the sounds, smells and sights of nature.

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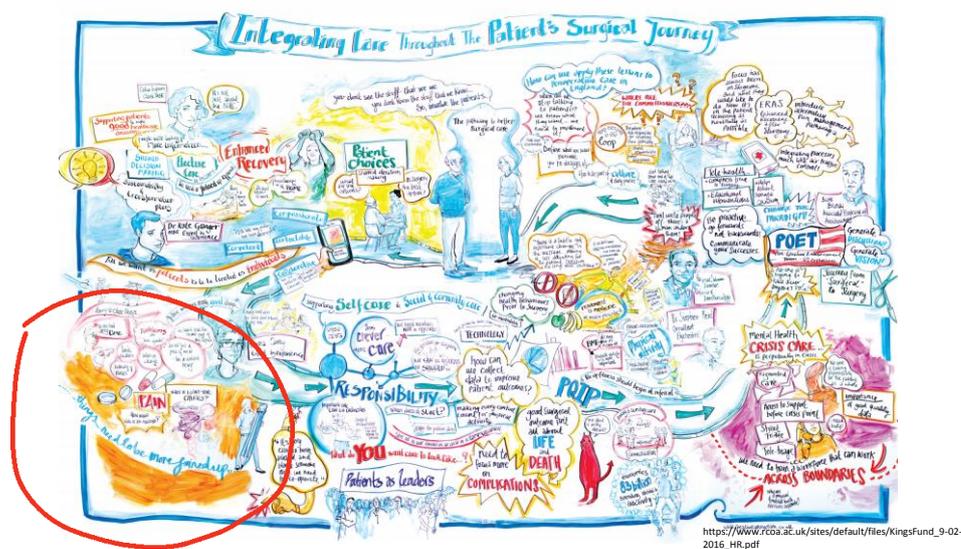
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## Chronic pain after surgery and the role of developmental trauma.

When will we talk about the elephant in the room?

Deepak Ravindran

I have been fascinated to find that this approach and its psychological underpinnings are being used across all healthcare now, but in secondary care we have been slow to take it on board. This is partly because we are not sure whether it fits



This is the mural at the Royal College of Anaesthesia and Perioperative Medicine (out college is rebranding itself as the latter). The focus is on high risk and frail patients. You can see that pain is there; the whole big picture is messy and and complicated but I hope to convince you that we are missing a bigger elephant in the room.

- 1 in 7 of UK population have chronic pain.
- 20-25% of Europeans – chronic pain
- 20% of americans – 116 million
- Almost 40-43% of UK – chronic pain
- 13-20% of Asians with chronic pain – underestimate

18 billion pounds of lost productivity.

3/12 most disabling conditions are pain conditions

**There are more fibromyalgics in the UK than stroke survivors and about the same as diabetics!**

**CHRONIC PAIN – THE SILENT PANDEMIC?**

"I suppose I'll be the one to mention the elephant in the room."

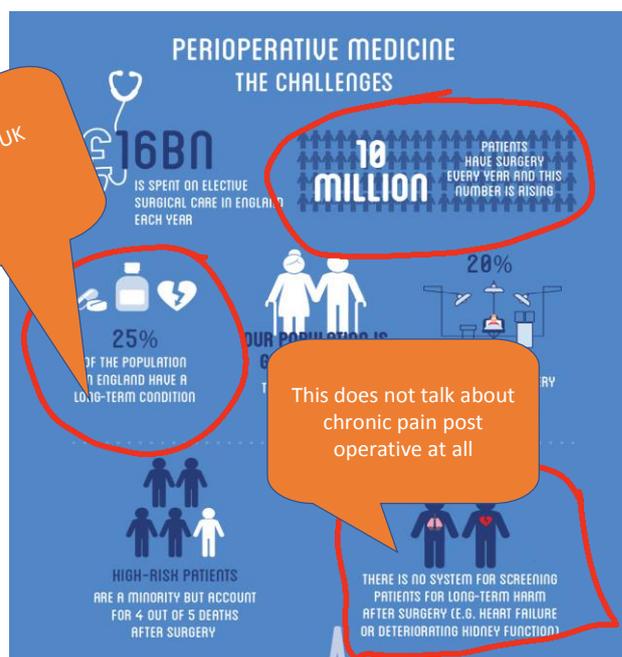
Although we talk a lot about chronic pain and the increasing numbers of sufferers we aren't doing much about it, and my mission is to bring it up to salience and get people aware and talking about it so we can come up with some suggestions as to what to do about it.

We as anaesthetists have potentially a great place to optimise the patients' journey from entering the hospital till they are safely home. We want to optimise fitness for surgery, to lower the risk and get fully informed consent to surgery. We want to see what lifestyle modifications we can be part of. We look at the systems: cardiovascular, respiratory etc..

The RCOA – the Perioperative Medicine College - want to provide personalised patient-centred care for complex patients and have introduced the Pathway to Better Surgical Care:

## PERIOPERATIVE MEDICINE –RCOA DOCUMENT PATHWAY TO BETTER SURGICAL CARE

Upto 1/3 to 1/2 of UK population 28 million



There is one thing missing: *there is no mention of chronic pain*. There is a tacit assumption that if perioperative care is satisfactory chronic pain won't exist. But the numbers are high and increasing. There are apparently more fibromyalgia patients in the UK than stroke and diabetes combined, but all the funding goes to the latter two. We need to have a better plan in place for recognising it and managing it.

So if we are going to deal with a pandemic of this sort what are the questions we should be asking? What is the root cause? Are we operating on more people than necessary? Are we medicalising normal life experiences? Are we taking people on the wrong surgical journey. In perioperative care, are we not doing the right things at the right time?

We have a very siloed\* approach in secondary care with the biomedical model: if you've got a knee pain you go to a knee consultant, for back pain you need a spinal surgeon, If after L5 surgery you have bladder problems you go to a urologist, and so on. But that really doesn't work.

\*kept in isolation in a way that hinders communication and cooperation : separated or isolated in a silo

## “Debbie”

I'm going to tell you a story about a patient you will all probably recognise. Debbie has been in the pain clinic in the Royal Bath Hospital for the better part of eight years now. It all started with a trivial episode of low back pain while at work which rumbled on. A scan at that time revealed an L4/5 disc bulge. Her GP referred her to the pain clinic; she was initially seen by my colleagues. She had a discectomy in 2012 which left her with more persistent and intense low back pain with left-sided L4/5 radiculopathy. She then developed knee pain so went to the knee surgeon and had an arthroscopy and where they found some medial compartment changes so she had a knee replacement in 2013 which left her with some persistent post-surgical pain. Then she got some shoulder pain for which she had a subacromial decompression; that seemed to have worked but three months later she developed pain in her right shoulder. Over the years she had several arthroscopies for various joints. In the pain clinic we did facet joint injections and an epidural. She was sent to London for spinal stimulation but ended up with an implant infection so it was taken out. She saw the neurologists who diagnosed atypical migraine and put her on a migraine drug. She saw the GI people with tummy problems for which they offered her a diagnosis of IBS, and was also treated for an 'irritable bladder'. She was on codeine, cocodamol, naproxen, tramadol, opiates and ... - *what were we doing?* What was the real problem?

I took her on about three years ago during which time she has seen me at least eight times for drug changes etc. About a year ago she was seen by a rheumatologist who diagnosed fibromyalgia and suggested she went to the pain clinic. She was already my patient – by the way she had also accumulated diabetes and hypertension. But she didn't want to keep taking so many drugs. I wondered: where do I go? - this is her third volume of notes.

And then I thought – you know what? – I am seeing so many Debbies in the perioperative situation for anaesthetic care; some of them only for a small procedures in day care; I am seeing them on ward rounds, in outpatients and community clinics. So where does the problem lie – is it the patient or the service? It got me thinking and reading and wondering what we can do about process. So we got together with the Community Health Trust in my area who look after mental health and set up an integrated pain and spinal service involving physiotherapy psychology, consultants from spinal surgery, rheumatology and pain. We got funding for one day of a pain consultant and a 300% increase in physiotherapy and psychology provision at a stroke with that kind of rearrangement. We were able to provide one to one physio and psychology and group support, all at an intermediate care level, quickly where there was none. Being part of that process made sure that some patients were coming to a triaging set up so we introduced complexity into secondary care. I became even more aware that regardless of whether I was working in secondary or community care *I was seeing the same kind of patients* with multiple, complex issues. The physio's had previously been told to focus on the knee or the hip if that's where the pain was, but that really is a flawed model. We got this through, we got some rewards for it and proved that it was viable and sustainable, and it has been running for about three years now. But it didn't change the trajectory of patients like Debbie. So what could we do perioperatively? The research is there: we know that if people have pre-operative pain or are in a certain age group or have psychological predictors like anxiety or depression if we use enhanced recovery pathways to modify the change. There has been a big focus on using regional analgesia, good surgical technique and shorter operative duration – all of this should matter but does it reduce post-surgical pain?

**• Inguinal herniorrhaphy 10-15%**

**• Breast surgery 10-30%**

**• Orthopaedic 20% post THR/TKR**

**• Thoracic procedures 20-50%**

**• Gynaecological and LSCS 5-10% with TAH being upto 30%**

**• Post amputation 30-50%**

**• Lap colorectal surgery 15-20%**

**• CRPS**

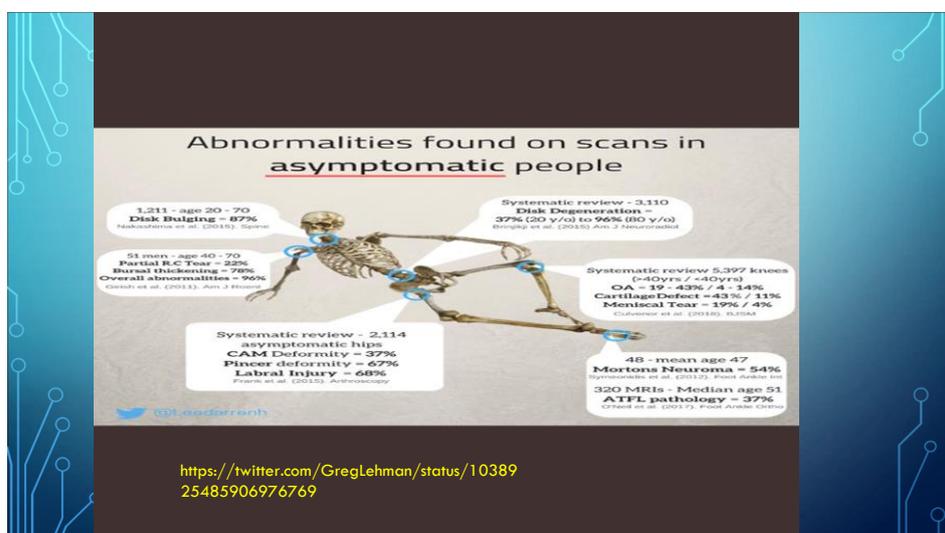
- Arthroscopic knee surgery 2-4%**
- Carpal tunnel surgery 2-5%**
- Fasciectomy for dupuytens 4-40%**
- Phantom Limb pain 50-80%**
- Chronic donor site pain – 40% at 3 months decreasing to 19% at 2 years**
- Post cancer – Diff to estimate**

**EVEN IF YOU DID AN AWESOME SURGERY...**

This is the incidence of post-surgical neuropathic pain after any surgery be it gynae, orthopaedic, cardiothoracic or whatever. There are 200,000 hip and knee replacements done every year; assuming 20% get CRPS then 40,000 new cases are added.

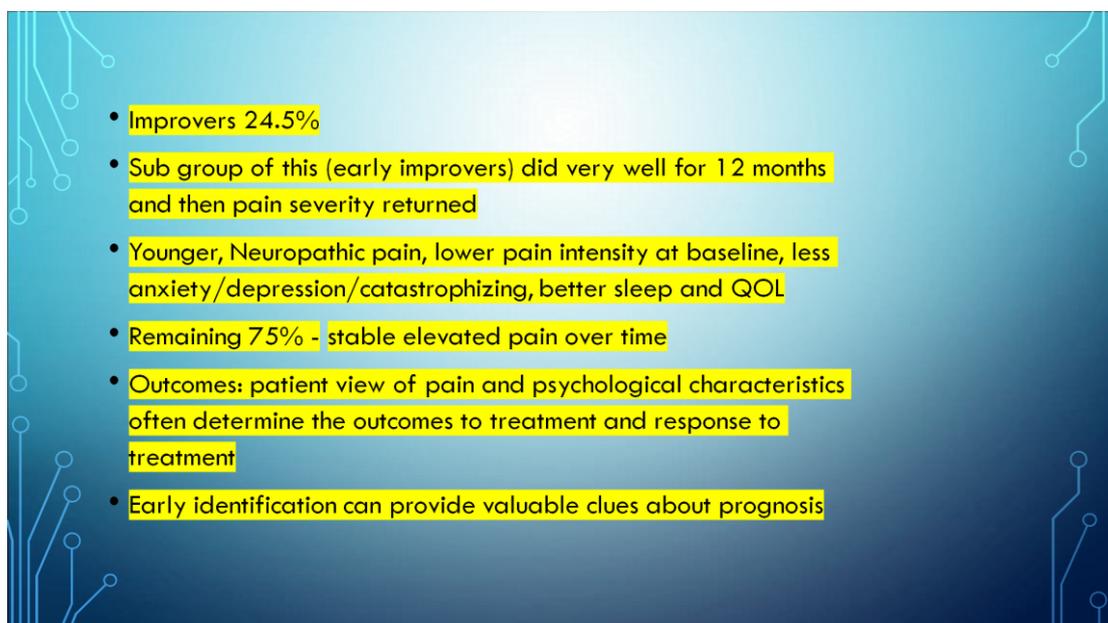
We are not changing that trajectory at all. Is it that the surgeons are doing a good job but our data collection not right, *or are we not asking the right questions?*

I audited 100 patients in Reading in 2010 going for knee replacement and again in 2013 after the first cycle of the enhanced care pathway. Then in 2016 I had the idea of enquiring if all the wonderful things this entailed had made any difference to the incidence of chronic pain. But there were still 22%, in line with other literature, with chronic, severe neuropathic pain. So is enhanced care just about getting people up but not changing their long term perspective? So should we be choosing more carefully and more mindful of what *kind* of patients we put through surgery? A lot of the patients who come to the pain clinic tell me that their pain was the same before and after surgery or even worse. So are we doing the right surgery?



We know that MRI's on backs show that disc degeneration and age-related changes are present in a high proportion of the population, and although most GP's are aware of that it's just not being talked about. NICE are clamping down on knee arthroscopy but shoulder surgery has seen a 750% increase across the world. That is asking for trouble; what are we going to do about the chronic pain afterwards? When we tell them to think about CBT and all of that stuff it is difficult because they have had a story in their heads for many years about what the problem is and asking them to tear down that fabric is probably not going to help them.

We know that if the patient already has pain at the site of surgery or other pains or psychological issues we should do something about it and take a biospsychosocial approach but these data came from Canada, looking at the long-term trajectories after pain management programmes,



Only a minority – 24% - showed any improvement in the overall symptomatology of pain and these tended to be younger with less pain before intervention and less prone to anxiety etc. Pain in the remaining 75% stayed stable or got worse.

But besides their psychological characteristics, what did make a big difference in the outcome was *the patients' view of their pain: their story of what their pain meant to them.*

This is vitally important as when I looked at my and my colleagues' outcomes of pain management both in primary and secondary care, most of the patients seemed to keep coming back after a new crisis. (We don't have an open door as we are only funded for eight or ten sessions of PMP; we may investigate them again or do another intervention.) So I got to be thinking: what can we do differently? What are we missing?

Descartes' model was fantastic for its time; his thought processes allowed the unbinding of religious shackles and laid the foundation for scientific medicine. But we know that the concept of mind/body separation is flawed and outdated; as long as it lives it is going to put up barriers. If you look at Fibromyalgia with the Cartesian model you will fail every time. However if we reframe pain as an evolutionary adaptation and chronic pain as a maladaptive process it begins to make a lot more sense. We are beginning to realise that chronic traumatic stress, which is being

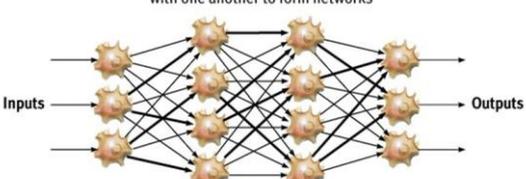
talked about in every field from nutrition to lifestyle and of cancer and autoimmune conditions, makes an impact in the context of the chronicity of pain. So if you are willing to accept the flaws in the Cartesian model then this new definition starts to make sense: *Pain is a mutually recognisable somatic experience that reflects a person's apprehension of threat to their bodily or existential integrity.* (Cohen 2018) So anything that threatens a person's sense of self and identity and danger to their survival is sometimes going to manifest as pain. If we perceive pain as a fundamental alarm system that can get over-protective we need to believe in that. The neuroscience backs that up. We know that there is a difference between pain and nociception: I try to educate my patients about this and tell them that what they feel is different from the chemical activity in the nervous system that is happening all the time. We also know that the Gate Theory has been superseded by that of Bayesian predictive processing and encoding: our brain makes a story, docks it in the background, understands the background and decides what the response will be the next time round. It predicts and rearranges its prediction each time having looked at the error rate in the prediction.

## The neural network

### A Simplified Neural Network

Neurons learn to work together as a team.  
Neurons that fire together, wire together  
=

Neurons in the brain connect  
with one another to form networks



The brain learns by modifying  
certain connections in response to feedback

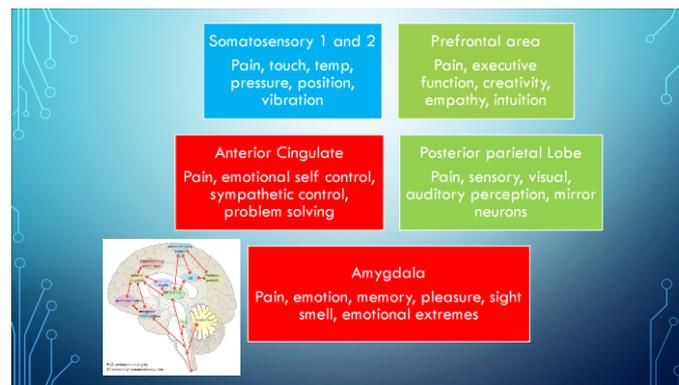
<https://slideplayer.com/slide/8668596/>

### Bayesian predictive modelling and visually reinforced



<https://www.slideshare.net/luv2hoop/brain-plasticity>

Everything we see in our technological world like Alexa is based on our understanding of the brain with its multiple neural circuits that can adapt, wire together and fire together. The wiring together can happen at any point in life. So if this occurs early can it lead to poor circuits that make people hopeless?



We know that there isn't a pain centre, that there are nociceptive pathways but not pain pathways, and that there are multiple processing areas in the brain. Pain and visual inputs are both processed in the posterior parietal lobe; we are visual learners and if we are told that our spine is crumbling we create links. So it is vitally important that we address all of that stuff. The concept of mirror neurons is now very well understood and does explain a lot of how you react when you see something painful. But this is being correlated by all these areas; every area that we think is doing something else is going to have an influence on pain. In the same way a lot of other central sensitivity syndromes such as IBS, central post-stroke pain start to make more sense because it is fundamentally a problem of the human connectome, the neurocircuitry that can result in a series of syndromes affecting multiple organ systems. The siloed perspective of Individual consultants in relevant specialities leads them to give them different labels, but they are all linked to the same dysfunction in the CNS.

It has been said that by the time we come out of medicine 50% of what we know is wrong, but the problem is that we don't know which half.

Most pharmaceutical companies have given up on research on antidepressant drugs because they have realised that they can't find a proper molecule to fit the serotonin hypothesis. We also know that all our dietary hypotheses, like the fat and cholesterol theories, are flawed. So everything we learnt in medical schools is being progressively debunked.

### Immune system over-activation.

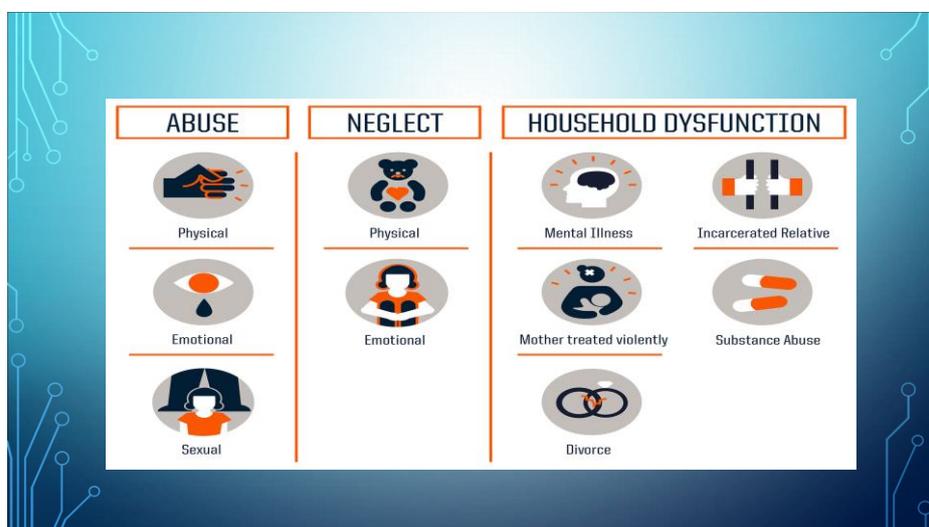
In my reading over the last two years I have become aware of a lot of studies on the concept of immune system over-activation. In his book *The Inflamed Mind* Edward Bullmore reveals that the immune system is implicated in most mental health disorders. Regarding the microbiome, I heard a talk by John Cryan in which he claimed that only 10% of our cells are of human origin and the remaining 80 to 90% are essentially microbial (and that we are a little bit more human when we come out of the toilet!) There seem to be implications of this in every condition I read about.

There is now a concept of behavioural economics. In long term conditions we want to encourage behavioural change in our patients but how? We think we consciously know everything that we do and do the right thing. But we are riding an elephant - the elephant of the unconscious mind, the amygdala, the chimp brain - call it what you will. That has its own motivation and purpose. Sometimes we think we can control it but what changes the unconscious mind? That is where the concept of Adverse Child

Hood Experiences (ACE) became so fascinating for me because it provided a means of unification. (How many of you are aware of it? [several hands up] This has been game changing for me in the last year or two but whenever I give this talk, whether to GP's, physios or nurses or anaesthetists, only one or two seem to have heard of it.)

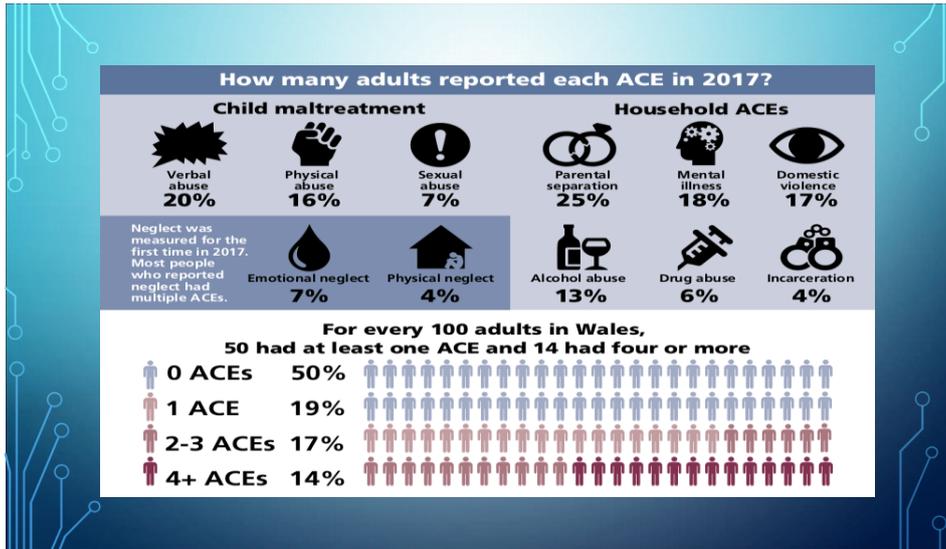
Feletti was an American GP who was trying to introduce a weight loss programme in a group of patients in the 90's but found he was unable to get them going, or to persist in keeping their weight down. So he took a narrative approach, and sat down with them and asked: "What is going on in your life?" – and so on. It turned out that 70% of them had experienced sexual abuse before the age of 18. So he wondered what relevance that had? So he collaborated with the CDC\* to study the whole of his practice encompassing 17000 mainly white middle class people in San Diego. He found that if they had had four or more ACE's they had a significant increase in health care utilisation, resource consumption and chronic diseases including obesity, hypertension, cardiovascular disease, osteoarthritis and autoimmune conditions. As we have spent the last twenty years spreading the message about diet, do ACE awareness is now being pushed in many other countries, including all the four nations of the UK. Scotland is now an ACE aware nation having signed up to the entire concept as of October last year. The data are remarkably robust; I know correlation doesn't prove causation but the associations in studies across all health domains have been remarkably consistent.

So when I last saw Debbie I asked her: have you been physically abused? And she said "yes, my father and mother both used to hit me, and my father used to beat my mother, and went to jail for it. She was an alcoholic and he was into drugs. I was sexually abused at the age of 13. I was sometimes sent to school in unwashed clothes. So she ticked the boxes (apart from divorce) in all of these categories of ACE:



So when I looked again at the three volumes of her notes and all the conditions she had, I was forced to take stock and think: what am I going to achieve by giving her a Fentanyl patch or another facet joint injection?

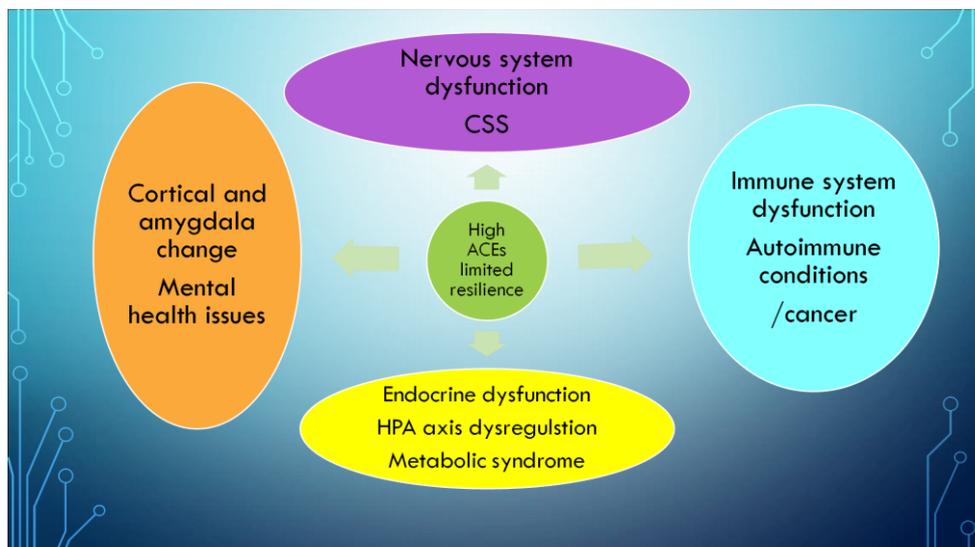
\* Centers for Disease Control and Prevention, the leading national public health institute of the United States)



This does not even touch all the other problems that so many of us have to face *now*: bullying, the stress of looking after children who may have issues themselves, poverty and other social problems.

People with more than four ACEs comprise three times the national average number of smokers, ten times the alcoholics, 16 times the drug abusers, 2.5 times those with heart disease and 20 times more have attempted suicide. Adult victims of childhood maltreatment report more pain and headaches, GI and respiratory symptoms, gynae and neuro problems, greater symptom severity and utilisation of medical and surgical services.

So it is vitally important to recognise that in the context of providing healthcare wisely The doctors these people consult offer localised diagnoses from the blinkered perspective of their specialisations. So we as pain professionals have a much bigger role to play in interacting with our primary care colleagues to go much more upstream, rather than sitting at the end and picking up the pieces after the huge amount of healthcare they have used all their lives.



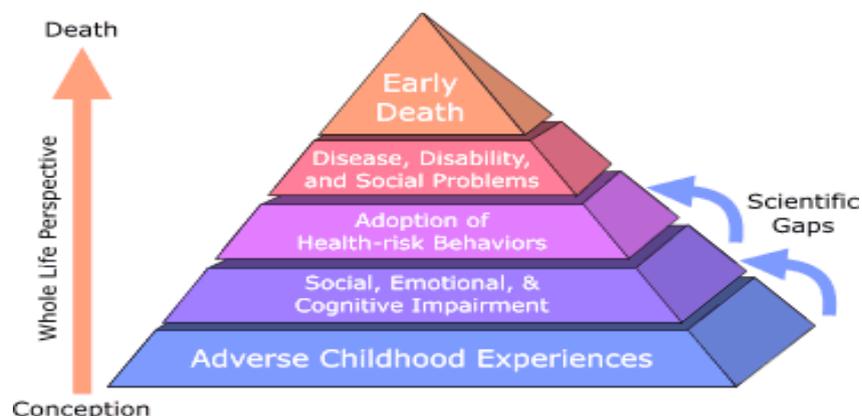
This for me is a unifying concept which underpins much of health care. If you have a large number of ACE's and your resilience to adverse factors in your environment is poor you are going to get a huge number of central sensitivity syndromes; the impact on your immune system will be reflected in all the autoimmune conditions; and all the monoclonal antibodies and things we throw at them will not be useful if you don't address the root cause. There is some recent research which suggests that the same may even apply to cancer. A large number of metabolic syndromes may result from endocrine dysfunction. And finally the changes in the amygdala and prefrontal cortex are probably responsible for a great proportion of mental health issues.

### The Reading ACE and resilience survey

So I got to thinking: is that really a problem in my own practice and my own hospital? I wanted to assess the prevalence ACE's and explore the feasibility and acceptability of administering the standardised ACE questionnaire at the Royal Berkshire. So I got permission to submit ACE and resilience questionnaires to everybody who came into my pain clinic over a ten week period in 2018. I also asked them about any co-morbidities they might have, and common ones were asthma, hypertension, IBS, anxiety and panic attacks. Of 150 questionnaires 134 were completed. We first asked the simple question: did you have a happy or an unhappy childhood? 63% said happy, and they didn't have to answer any more questions. Of the 37% who had an unhappy childhood (about double what might be expected in population with the population demographic of Reading) 73% - 40 – of them reported more than four ACE's.

So what do we do with them? All we are we equipped to do is to give them stronger drugs, recommend an intervention or offer them a one-size-fits-all PMP. We know that resilience is hugely important but it's not just something within patients themselves; although some people are amazingly resilient the research suggests that it is a product of their environment and support. Unless you have this support you just can't be resilient enough. So providing this support is vitally important not only in the context of pain but in recognition of the contribution of ACEs to an increased incidence of a range of diseases from cancer to diabetes and stroke. And you are not going to get medication compliance etc. in any of these conditions with that drama going on in the background.

### The ACE pyramid



On average ACE survivors are going to die 20 years earlier. We don't think much about this sort of thing when an 80-year old comes in for emergency treatment or surgery. But if we see a 60-year old with many ACE's and little support or resilience, would we still want him to have hip replacement or other major surgery? It's a ethically provocative question, but should we be asking it? Would it make a difference to the outcome for that person if we withhold major surgery because we haven't got the systems in place for aftercare?

Small periods of stress can be taken by any of us. If my car breaks down that is fine as long as I have the support of the AA. But if the stress is constant the whole nervous system gets subjected to intense pressure and it fails. It affects the HP axis, the ability to trust or have empathy. Both physiological and psychological mechanisms are involved. The changes in the CNS increase negativity and neuroticism with increased somatisation and vulnerability to chronic pain. From a psychological perspective, if you can't have a secure and organised attachment you can't adhere to any protocols or believe in anyone for any length of time. You overdevelop 'life-preserving' brain functions and neutral cues seem threatening. By the second or third decade this group of people are going to manifest mental and physical problems when the next crisis comes along. They are going to keep falling again and again and we in the health system need to recognise where to take stock. When we think of our chronic pain patients all of this starts to be seen as much more relevant and important.

Epigenetics, expression of genes in the context of environment, for instance diet and lifestyle, can have a great impact. So we can make a positive difference to the epigenetics if we can recognise the negativity and go about making necessary changes in the environment.

Preoperatively, we wouldn't think twice about delaying surgery in someone coming for hip replacement who presents with a haemoglobin of 4. We would want to give an iron infusion and optimize physical health. But we need to do something similar with patients with a large number of ACEs because they are psychologically frail. So we need to have some sort of preoperative screening for them. We could introduce a PCS (patient catastrophising scale) into our preoperative booklet, and if they score high introduce some psychological interventions before surgery, or reconsider whether surgery is the right thing for them. Already they have a routine physio assessment and a package of a few sessions of physio, and the anaesthetist's assessment of their cardiovascular fitness. But where on this pathway can we make an effective intervention and acknowledge that these psychological factors need to be address because they can affect the outcome and long-term trajectory.

## Post-operative addiction

We need to acknowledge the risk of post-operative addiction and drug dependence. Research has identified four structures: the amygdala, the striatum, the prefrontal cortex [and one other – inaudible] in a circuit which is involved in all kinds of addiction. If the trigger is right the circuit gets established to anything. So it's not so much that opioids are addictive, it is the context in which that particular stimulus gets applied. Once you don't have the resilience factor or a support system in place

The experiment from which we all derive our understanding of opioid addiction involved a single rat in a cage with access to two drinks, one with heroin in water and the other pure water. The rat kept going back to the heroin until it died, thus proving that the heroin was addictive. But this was challenged by Bruce Alexander who repeated the experiment but this time suggested that instead of a single rat in a cage they could have a rat park, with have several rats and slides and grass and other distractions. Some would taste the heroin and go back to it occasionally but as

long as they had a nice park and the right social interactions they would not become addicted.

The implications of this have been explored by Joaon Hari in *Chasing the Scream*. He teaches that it is the environment which determines which pathway becomes established. In the context of perioperative care, ACE survivors do not have the right resilience, support or empathy and they are sitting ducks for opioid dependence. So these days I am more circumspect; I ask my nurses to find out patients' social systems. If they are going to be on some sort of drug after surgery the pain team should be actively involved in medication changes, making sure that instructions to GPs are crystal clear and giving clear boundaries for stopping opioids to prevent long-term usage.

Frequent flyers in emergency departments are also very vulnerable to addiction and a big problem. My colleague in A&E in Reading tells me that 60% of their juvenile patients are also frequent flyers in gaol, and that about 89% of them have pain issues.

Management of other comorbidities such as diabetes, asthma and obesity makes a huge difference. I asked my anaesthetic colleague who is involved in bariatric surgery whether there were any studies on the incidence of a history of sexual abuse and other background factors in patients coming for bariatric surgery and if these were taken into account when selecting patients. Because we know that if we do massive surgery and reduce their weight, if the fundamental problem is at a deeper level of childhood adversity they may have a worsening of their mental health and pain after surgery.

I make use of the concepts of motivational training and neurolinguistic programming in my consultations. In PMPs we try to change peoples' behaviour and to give them some values and beliefs but the reality is that if they have significantly high ACEs their problems are at the level of identity. If you have suffered childhood adversity or are depressed, your rational processes and the neural circuits which mediate good prefrontal cortex development fail. So you are not capable of rationalising your thoughts. So what is the point of PMP's giving you ACT or CBT when your system is just not capable of the boldness necessary to challenge your thoughts and beliefs? That is why a lot of PMPs don't help these people because they don't address the legacy of ACE. You have to change their environment and behaviour so as to give them more abilities and only then can you hope that CBT can make some change in their identity. In something like smoking, you can change the social environment in which they smoke, but it is very difficult to make a change if they regard smoking as part of their (or their family's) identity. We don't try to make that distinction in PMPs or discover the context of their pain or how far back it goes. So one-size-fits-all PMP's may have poor outcomes which may have implications for commissioners.

## Challenges

Firstly, cognitive dissonance. A lot of GP's and my colleagues in secondary care and trainees will say: "This is too much!" It may even challenge the fundamentals of what they believe about medicine and how they practice it - this may be a particular challenge for surgeons.

Then there is the worry about what can be done with all the data we have been accumulating about ACE's. Can it be used to ration resources? My argument is that it is already out there. A lot of companies are using it. In the USA all of the social healthcare policy ... everything that is being done with ACE's is documented... charity or third sector taking the data on board. In another five years that predictor is

going to be there to decide what kind of people are going to be treated and what support they will get.

So we have to embrace the good but be mindful of the problems. Some of my nursing and other colleagues have said that we can't risk opening Pandora's box. If we precipitate a crisis we haven't got the resources to cope with. I don't have an answer to that but that is no reason not to talk about it because when it comes to value-based healthcare commissioning and sustainability, and outcome-based treatment, this is a conversation that needs to be had in some way or another. If we continue to pretend the problem doesn't exist the NHS is always going to be broke.

So what can we do?

I have been trying both to challenge my own beliefs and to challenge my colleagues in hospital, GP and public health and invite them to collaborate in implementing them.

When I see patients with fat folders and symptoms that I can't easily fit into a nice box, I have the narrative in my head that I am trying to focus on the question, not 'why are you like this?', but 'what happened to you?' How much can I influence in this thirty minute conversation? How careful must I be in offering intervention and drug therapy? The most important thing I can do is to validate them and their trauma and just listen to them for half an hour or so. I may then have a reason for saying that I don't want to give you an opioid or do an injection that isn't going to work long. Or I might use the intervention as a bargaining chip and say if I give you an injection which is going to work for a few weeks what changes are you going to make in that time? They need to have some skin in the game and I try to incentivise them by making the necessary effort on their part a condition of further treatment. Our pain management programme has a 15 month waiting list and I have to be careful that the people I send to it are really likely to benefit. As doctors and consultants we have a responsibility to make PMP's more attractive and valuable. Some patients still get the impression that they have been sent to the PMP because the doctor can't do anything more for them, and the teams feel they are a last resort. Pain management has to be reframed as a valid tool to be used alongside conventional medical treatment. As with other measures like Yoga or mindfulness meditation it needs to be sold to the patient and we are in a good position to do that.

These are potentially psychologically frail and complex patients and we need to find a better way to optimize their outcomes.

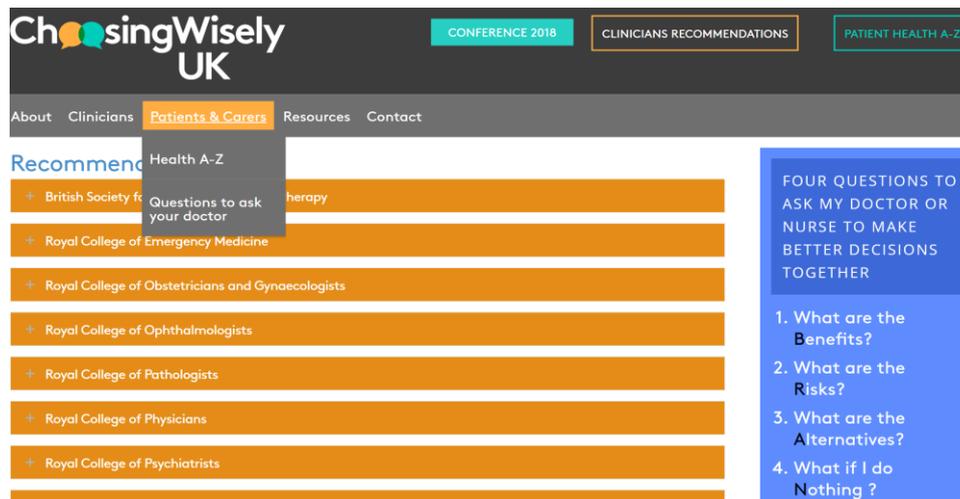
Perioperative care models for pain

We are never going to have a silver bullet. It has to be on a multidisciplinary basis – we don't do that now but that has to change. There are existing models such as the Toronto perioperative care model which includes a transitional pain service for people with psychological or chronic pain issues: the pain team see them before surgery and formulate a perioperative plan including controlled use of opioids if necessary with clear boundaries; they look after them throughout surgery and send them back into the community with a further plan to be reviewed in a few months.

As for preoperative psychological screening, I have been suggesting to my colleagues that we should be introducing some form of ACE screening. The Patient Catastrophising Scale is already in use in the perioperative setting in a few hospitals including Bournemouth where the pain team did a PCS score on patients for knee replacement. They took the patients who scored highly and gave them a two hour brief psychological intervention with a bit of physical therapy before surgery and made them aware of what to expect afterwards. Their anxiety and depression levels

were much reduced and they left hospital a day earlier. There is an internet-based perioperative pain psychology intervention from Stanford called My Surgical Success to give patients the skills and tools they need, and the Self Care Kit for Breast Surgery. But this needs to be brought in at the scale of the NHS.

So this has been my driving force, my mission, for the last two or three years. We talk a lot about the elderly and the young, but we should be talking about this vulnerable group as well. There are indeed initiatives in the UK such as the online site:

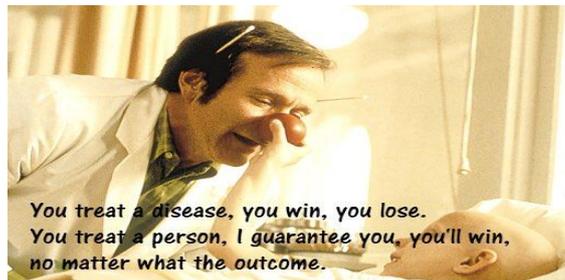


My colleagues are encouraging patients to ask these questions.

To end with a story. Four strong swimmers come to the edge of a huge cataract. There they see a great number of men, women and children flailing around as they fall over the waterfall. One of them jumps in and valiantly tries to pull out as many as he can. He saves a few but most keep on drowning. So the other three go to the top of the waterfall and see if they can prevent more people going over. Two of them tear branches off the trees to give people something to hang on to. But this doesn't work – there are still people dying. (In pain clinics we are at the bottom of the waterfall. My surgical and A&E colleagues are at the top.) So when the two get tired of throwing branches they look round for the fourth swimmer and see him swimming strongly upstream. They ask him to come back and help but he says: “no- I'm, going to see who the hell is throwing them all in the water in the first place!”

So we need to get upstream to see if we can make a difference. We need to be thinking about the psychosociobiological model much earlier in the patient trajectory. I heard recently that all the DVP give immigrants and homeless to live on is £60 per week basic universal credit. How can we ever achieve pain relief for people who are struggling like this when they turn up in hospital? The social environment has to change before we try to mess around with the biology.

## An integrated holistic PERIOPERATIVE approach – Pain MEDICINE



### Discussion

*Some of you may remember Diana Brighthouse who was one of the founder members of this group. She went through the usual trajectory of an anaesthetist who started taking an interest in pain and was doing a lot of intervention, but they were finding in Southampton that they were seeing more and more patients with long-term complex problems, so she retrained as a psychotherapist. She managed to persuade an unusually enlightened management to fund a session for her to see a very small number of patients for a weekly hour of psychotherapy for a year. Not only did this help the individuals concerned but it was cost effective because of the reduction in the number of other consultations and interventions. So I was wondering about the role of psychotherapy in these patients and how many pain clinics nowadays employ a psychotherapist? Can you really manage these patients properly in the absence of a psychotherapist?*

*There is a national shortage of psychotherapists as well as psychologists*

Only a few clinics in a few areas have psychotherapists who work in the NHS and very few in pain clinics

*There used to be in [GP] surgeries. We did a survey in one I worked in and found that patients were seeing their doctors much less frequently after only six weeks. There was another survey which showed that a huge proportion of people having unnecessary operations had a history of abuse.*

We make these small pockets of change. Trauma informed practice has to be introduced at a systems level. If you get just one or two practitioners involved it may help a few patients but this is very demanding work and they may soon get burnt out.

In my area there is a 'join the dots' campaign; ICU have signed up to it ... The question to be asked is how do we contain these people in a safe and compassionate manner. Some of the severe damage cannot be undone. Changes in the neural circuits may be irreversible; there may be a few anecdotes of a happy outcome but we need to have plans how to manage this group of people effectively instead of investigating every attack of pain.

*A radical approach would be that you cannot make an isolated decision on your own for these people whether it is surgery or another intervention. It has to be a group or a multidisciplinary decision. Surgeons may have a vested interest ...*

...the economy is ripe for change; in my area we have gone from fee-for-service to a block contract [which facilitates] integrated care. As anaesthetists we have embraced

the concept of comprehensive perioperative care; we can be more objective than the surgeons ... when we see patients preoperatively we can listen to their stories as well as assessing their airways etc. We can make a difference.

For example: a colleague was telling me about a 75-year old man who had come for hip refashioning surgery. He has mild Lewy body dementia, but is functional. He had hip pain for four or five weeks; his GP referred him for physio but this didn't work so he was sent to a surgeon who recommended hip replacement. He told my colleague that he was a bit confused because his neurologist had told him that surgery might make his dementia worse. It turned out that he still does an hour of gardening every day and is completely independent; he only takes the occasional paracetamol, so after discussing it with the anaesthetist he decided not to have the operation. Would the surgeon have had the time to have this sort of discussion?

*Perhaps an anaesthetist needs to be an epidemiologist. What you are describing is a public health, epidemiological problem which we are trying to approach one problem at a time. Maybe we need a totally radically different approach; as in the Victorian era it was realised that the survivors of infection had developed antibodies, inoculation with an antigen would produce resistance in a population, maybe we should be looking at something like that, at people who have despite all the bad things have done well and learn from them.*

Data are coming out which seem to point to the fact that creating social set-ups, working with public health, social and health wellbeing and getting your systems in place are vitally important. And there is an opportunity for some perioperative physicians to actually take that up. The Royal College is saying that we need to do perioperative care; the Pain Society is saying that what we do is not being commissioned effectively. Most of the money goes to secondary care rather than primary. But pain physicians can be part of the solution if we collaborate not only with perioperative physicians but with primary care and public health as well.

They say that surgery is a 'teachable moment'. When someone is coming for surgery we want to reduce their care so why don't we make advice about diet and lifestyle part of preoperative care and take the opportunity to invite public health to participate in this.

*I have been in primary care for many years and one of my functions has been to try to protect my patients from the sort of thing you describe. My frustration is with the complete lack of joining up of the psychological with the physical and lack of resources for that.*

*The other thing is that as clinicians we have to take some responsibility for this. We have so much invested in trying to fix the [? bleeding] here but we can't just let things be. We certainly need to talk about the patients and their environment but we don't talk about ourselves and our attitude towards treating things; we are missing something...*

... that goes back to medical school – we need change at the level of what we learned from our professors ...

*I was trained as an anaesthetist to make my patients as fit and happy as possible post-operatively. I notice that some of my junior colleagues don't seem to understand that. I'm really in to pre-emptive analgesia. The surgeons I work with will infiltrate the skin with LA before they cut it, as they realise that very few patients will need opiates postoperatively. These little things can make a huge difference.*

*To pick up on David's point [about anaesthetists as epidemiologists above] and to go back to one of your earlier elephants: the idea that one of our problems is that we are*

*all in our silos. It seems to me that you are not getting out of the silo as an answer to a problem that needs us to get out of the silo. You are talking about changes in the way we practice perioperative care, but we need to think much bigger about system change and consider the whole constraints that we have in our conventional biomedical model – it's as big as that.*

My talk was based on perioperative care and public health and the opportunity is already there to make changes, but if you are going to change the biomedical model it has to go back to medical schools

*Suppose we don't have medical schools – maybe we need to think even bigger than that!*

*Maurice Dematteis is an addiction psychiatrist in Grenoble. In his addiction programme which addresses addiction and pain and sleep etc. – huge – the biggest thing was encouraging their clients to get a dog or a cat. Nothing to do with medicine at all.*

*There are a lot of people who undergo major surgery who remain on opioids for up to four to six weeks. Probably 95% of them will stop. Maurice was talking about people getting dependent on opioids or cannabinoids being a matter of vulnerability. If they are vulnerable they are far more likely to get addicted and that is exactly what you highlighted. Past adverse clinical events that contribute to those vulnerabilities are often ignored; patients may not want to go back and exploring this probably needs a repeated and sustained process.*

... all these psychotherapeutic options do start to open up but we don't talk about them, we just carry on with the same biomedical model. Spiralling costs are an issue. There are pockets ... there are ways forward, but no easy answers. If secondary care and doctors understand that they have a role and start talking about it they can make a difference.

*One fear that patients with complex and long-term psychiatric illnesses have is that because of that they may be denied the potential benefits of interventions that other people who are more fortunate than them can have. There is a legitimate fear that 'you are not going to do this operation because I'm depressed'. How do you respond to that?*

What do surgeons now say to someone with a BMI of 36 who comes for knee replacement?

*People are legitimately feeling discriminated against who have probably been discriminated against their entire lives.*

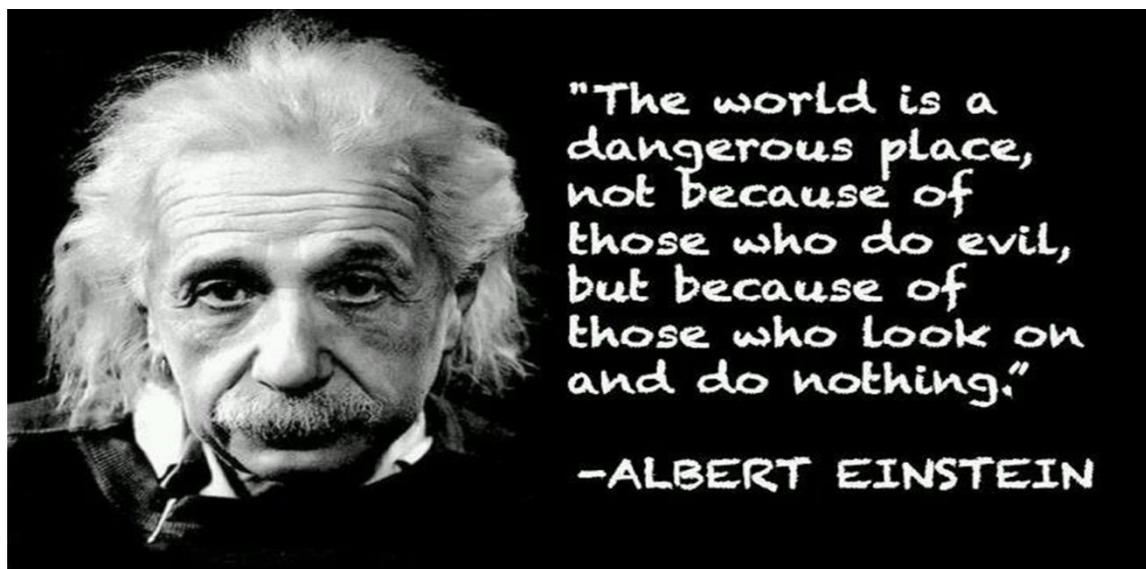
Is it right to do something that isn't going to work?

*We don't know it's not going to work. I recall working with a group of orthopaedic surgeons who got hold of some work by psychologists on stress risk assessment and they administered a scale of depression and if patients scored highly on this they were refused surgery. We know that people who are depressed generally don't do well after spinal surgery but this doesn't necessarily apply to individuals; if an individual has a nerve root that is causing problems they may benefit enormously. It may be that the 'biological' problem they have is very important and if you deny that you may make the psychosocial problems worse. I'm not saying I have an answer but we must acknowledge that it is very complex.*

The object is to optimise the outcome with the right kind of support and engagement. We are being asked to be deciders of the ration. We feel unhappy about being made to make that difficult decision or saying no. We struggle with that and may say this procedure may help so we say go ahead and in six months time we won't be in a position to pick up the pieces. At some time that individual is going to run out of people who can help.

*I have patients who respond tremendously well to intervention but I am not allowed by the policy makers to repeat it even though it lasted for three years and they have remained mobile and independent. This intervention does not work for everybody but we know it does for this individual.*

We need to build a bigger picture for that individual including for instance their support system and optimise everything that can be changed

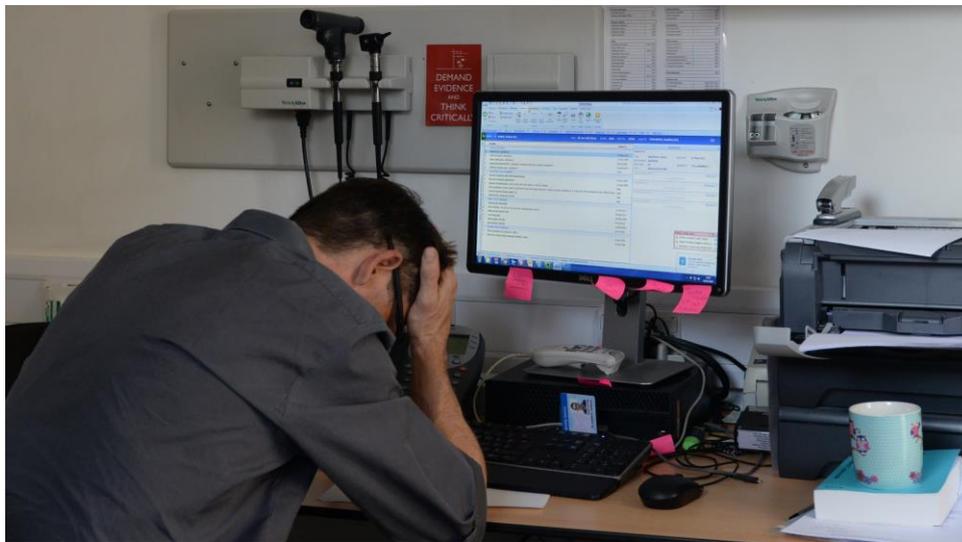


## Trauma informed care

Jonathan Tomlinson

It is the feeling of overwhelmingness [identified in the discussion of the previous talk) that I want to begin with as it's how I came to be on this journey. I'm going to talk about how we diagnose chronic pain, how we view the person in pain and get to know them and how we talk about trauma and pain.

### Diagnosis



The process often starts with the clinician in despair. I started my journey writing a blog in 2013 called '*How doctors feel about patient with chronic pain*'. The issue for me was not that I couldn't fix them – I'd come to terms with that – it was just that they kept coming back. I asked a fellow GP who works in a pain clinic what was the difference between a GP surgery and a pain clinic and she said that "in a pain clinic I get to see patients for half an hour at a time and at the end of the day I can discharge them. In general practice I only have 10 minutes and I can never discharge them. So they keep coming back to torment you and remind you how useless you are as nothing you suggest works". (But don't say why they keep coming !)

I thought I would go mad or burn out if I continued to feel like this, and wrote a very long essay about it, and got a huge response from patients, especially, who felt engaged with it and thought that I did understand how they felt and understood how I felt too. It was an incredible moment to connect with patients and I realised that I was on track.

Usually these patients have four or five computer pages of problems: the digital equivalent of the fat file of paper notes – and they go all the way through the alphabet and all the numbers; it's overwhelming and you know what it's going to be like. Here is a typical record – this is just one page out of five out of 'Debbie's' records.

	Problem	Onset Date
K	Migraine	20-Feb-2017
L	Somatization disorder	31-Aug-2016
M	Somatization disorder	14-Apr-2016
N	Helicobacter breath test positive	05-Apr-2016
O	Stress incontinence	10-Dec-2015
P	Microscopic haematuria	03-Sep-2015
Q	Eye symptoms	12-Jan-2015
R	Irritable bowel syndrome	11-Dec-2013
S	Gastroscopy NEC	13-May-2013
T	[D]Chest discomfort exercise related	2012
U	Helicobacter pylori gastrointestinal tract infection 29.A.13	28-Dec-2012
V	Depressive disorder NEC	11-Jul-2012
W	Dizziness symptom	27-Oct-2010
X	Counselling	27-Oct-2010
Y	Helicobacter breath test positive	09-Apr-2008
Z	Chlamydial infection of genital organs NEC 22.11.07	21-Nov-2007
1	Menorrhagia	30-May-2007
2	Fertility problem	19-Sep-2003
3	Dyspepsia	19-May-2003
4	Depressive disorder NEC	21-Aug-2001
5	Introduction of gamete into uterine cavity NOS	25-Jul-2000
6	Panic disorder	01-May-2000
7	Secondary infertility unspecified -9yrs	12-Jul-1999
8	Acne vulgaris	18-Nov-1998
9	Fertility problem	01-Sep-1998
	Infertility - female NOS	01-Sep-1998

... and so on. Electronic records are divided into active significant problems, past significant problems and minor past problems, and usually with patients like this it's chaos. There are millions of dots and you don't know how to join them up.

The place where you provide care matters. My consulting room is arranged so as to make patients feel safe, with a rug on the floor and pictures. When I lead them in from the waiting area I stand side with them looking at this list of their problems on the computer screen; I point out the ones that are marked 'active and significant' and ask them what they think about those, and we rearrange the problem list together, perhaps removing some or adding ones from the past. I tell them that this is a shared record and we are sharing the responsibility for curating it. You will bundle together 25 euphemisms or codes for back pain and call it chronic pain. Then we will take together all the codes that relate to anxiety or panic attacks etc. and agree to call this chronic anxiety. Likewise all the stomach pains, bloating, indigestion etc. get stuck together as IBS, and frequency etc. as irritable bladder. We preface all these with chronic as they are no longer isolated episodes - it's a long-term 'thing'. So you have a reliable record should you need to use it for the bit that's always missing: the 'social' work which is so necessary for establishing social security, the right to benefits and a life that is sustainable; it's important that you have an agreed record that you can then use when you are providing reports, instead of wading through a million problems in a patient you don't know. So it's like seeing the patterns in the stars that form the constellations: once you've curated a few problem lists in patients with complex trauma you can never look at a hundred isolated problems without joining the dots. It's collaborative.

This then is my diagnostic process for patients with complex trauma and chronic pain. I'm going to refer to them synonymously, accepting that there are some people with chronic pain who might not have complex pain and some people with chronic trauma who may manifest this in other ways than chronic pain. At the moment I have a cohort of about 40 patients where I am collecting all of the types of trauma they have had and all their symptoms to see what the relationships are.

The person in pain

You might think about them like this:



But in reality they are more like this:

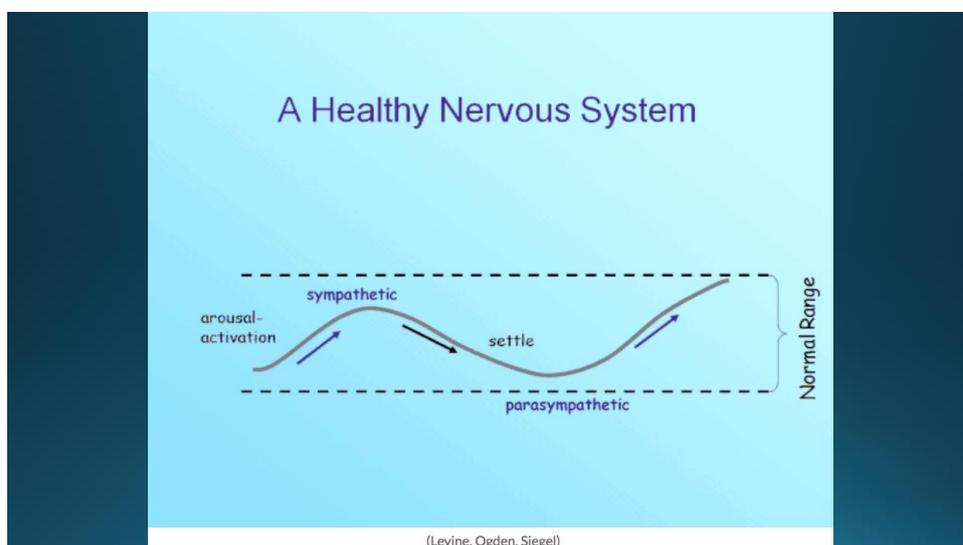


This might be the sort of problem list you have curated:

*Chronic anxiety, paranoia*  
*Chronic depression*  
 Insomnia  
 Teeth grinding  
 Palpitations  
 Breathlessness  
 Functional dyspepsia  
 IBS/ Irritable bladder  
 Incontinence  
*Chronic pain*  
*Chronic fatigue*  
 Autoimmune diseases

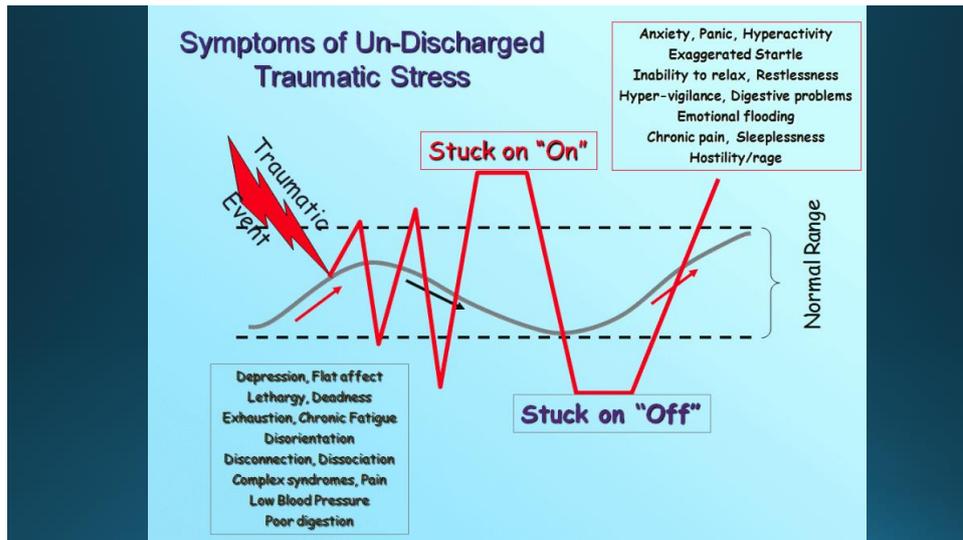


If you've got three or more of these problems you're probably looking at complex trauma. I've started at the head and worked down the body. It's interesting that incontinence, urinary and faecal, is quite common in this context. You often find that this has been diagnosed at quite an early age: the inability to hold onto your bodily fluids - a term which is often referred to as abject, stuff that fills us with disgust. This is significant as the consequence of adversity in early life is that you have this sense of shame or disgust and this is reflected in the somatic disgusting body that just cannot hold onto itself.



This is Siegal's idea of a healthy nervous system. This is 'calm' response to stress with sympathetic arousal – we're feeling excitable but it's contained. Likewise with parasympathetic - we're relaxing but not collapsing. But your window of tolerance is narrowed by adversity and widened by salutogenesis. People taking SSRI'S report that the top and bottom of the emotional range is 'clipped.'

But this is what happens with trauma:



Your window of tolerance is exceeded. You suffer from anxiety, panic attacks, inability to relax, hypervigilance, irritability and anger etc. (80% of people in prison are like this) But you can't be like that all the time and there may be days, weeks even, when you can hardly get out of bed. And you can see that someone that this is happening to can be labelled as having an emotionally unstable personality disorder or even bipolar disorder. But no, this is *un-discharged post-traumatic stress*.

In twenty years of general practice I've never met anyone with either of these diagnoses who doesn't have a history of severe trauma. I'm sure the people without them exist but I have yet met them. An image which works well is to imagine you're in a car with your foot on the accelerator and the brake at the same time – you're just going to burn out the brakes.

So what I do with patients, rather than talking about trauma I do a systems review, starting at the top with emotions and asking about anxiety, panic, OCD, trouble sleeping, palpitations, dyspnoea, pain in jaw, neck and shoulders, digestive symptoms and so on. By knowing what questions you ought to be asking and taking a very detailed medical history you show empathy because you know that these are the kinds of problems you know people are likely to have; they think; "how did he know that ...?!"

The connections between the limbic system (the 'emotional centre) and the brain stem are much stronger than the connections between the limbic system and the prefrontal cortex, so you can access your emotions through the body more easily than through the rational mind. If you tell me to stop being so emotional you're just speaking to my prefrontal cortex; you're not speaking to my emotional brain and the way into my emotional brain which is being traumatised is through my body. So by 'psychologising' problems you're not going to get in that way for most people. So this is where embodied practice: things like Tai Chi, Yoga, massage – 'unscientific' things – come in. We only call them unscientific because we haven't realised what is going on until very recently. The body keeps the scores: when we have a good story or a memory it becomes a narrative because we retell it, but we don't tell stories about the terrible things that happened to us when we were growing up, but this is embodied as somatic memory.

Other problems we see include addiction, especially to prescribed drugs; non-dependent substance abuse (at least as common as addiction) when the emotional

build-up needs to be discharged by going on a bender; self-harm including attempted suicide; excessive exercise or work (to which professionals are not immune despite their support systems); eating disorders including severe obesity; OCD, psychosis, Isolation and loneliness.

We might refer to these as means of dissociation or disconnection from the trauma and most of the drugs we use for chronic pain have dissociative properties. New psychiatric drugs like synthetic cannabinoids are powerfully dissociative. That's what people like, for instance Pregabalin. I've tried some of these things myself and they really do dissociate. So if your situation is intolerable why wouldn't you want to dissociate? Hanna Pickcard who is an addiction psychiatrist and philosopher who has a beautiful description of cycling to school on a trike with her kids on the back and the next thing she knows she is being put in an ambulance in agony with her arm broken in three places. They give her an injection of morphine at which moment she remembers her kids but as the morphine kicks in both the pain and the anxiety about her children are immediately dispelled and she thinks: "this stuff doesn't discriminate between body and mind pain – what is it we're treating?"

I look after 'Peggy' who was very seriously abused in childhood; she has SLE as did her daughter, who died having had most of her fingers and toes amputated and was covered in ischaemic sores, and who she nursed while she was in hospital in pain for two months, leaving two young grandchildren children whom Peggy is bringing up. She already had chronic pain and I remember her coming in for more oxycodone, pregabalin and diazepam. I remember asking her "Peggy – what are we treating here? – is it pain or grief or what?" She replied "I don't know - you don't know – how can you possibly tell? The drugs help; I know they're not good for me and I am addicted but they are good for all pain." She is now coming off them and has volunteered to be in a BBC documentary about addiction.

So why do we take these drugs? We are trying to keep the trauma: the little kid that was abused, the wife that is beaten – as a separate identity. So there is a healthy self trying to keep the traumatised bit of their identity separate. Kids and underdeveloped adults can dissociate by having an out of body experience. They will often describe an episode of abuse when it 'wasn't them' - they were just floating around somewhere else; observing as if they were a third party. There is an amazing book called *Instrumental* by James Rhodes who describes this very vividly.

## Shame

My own journey began with despair about pain and then I began to relate it to trauma, but there was a step along the way about shame, which was a constant presence in the consulting room but I didn't have a name for it. Then one day I saw a patient I was rather fond of and greeted him affectionately with an arm on his shoulder in the waiting room but he pushed me away because he had been drinking and only wanted to make an appointment. He said: "please don't – I'm so ashamed" - and I thought about it and wrote a blog about it which nearly 70,000 people read. I realised that many people feel huge shame when they go to see the doctor.

"Shame is unlike guilt, which is the feeling of doing something wrong, shame is the feeling of *being* something wrong."

*Marilyn J. Sorensen*

Guilt can be about forgetting to send your mother a birthday card, shame is about being a bad person to do such a thing and you don't care about her. Shame is different to stigma – it is internalized stigma and more disruptive. For instance, you can live in a society where you can be made to feel bad about being fat; you can say “I don't care” but if you yourself feel bad because you are fat you have internalized that negative moral judgment. People who have experienced abuse in early life rationalize it by saying it must have been something about *me* – it must have been my fault. That is almost ubiquitous. It's why people just don't attend or engage with therapy; they feel they are not worthy of it, or that they can't be fixed because they are fundamentally flawed. So often when people are difficult to help it's because you haven't been able to shift the shame.

“When I was a child, there were things that happened to me, were done to me, that led to me operating my life from the position that I, and only I, am to blame for the things inside me that I despise. Clearly someone could only do those things to me if I were already inherently bad at a cellular level. And all the knowledge and understanding and kindness in the world will never, ever change the fact that this is my truth. Always has been. Always will be.”

*James Rhodes*

## Trauma and pain

Trauma can be almost anything: it can be in childhood or adulthood. The symptoms may be the same: chronic pain, anxiety, self-harm, suicidarity and so on, but there are other things that go with developmental trauma which might require a different kind of approach, and developmental trauma exceeds adult trauma by about 10 to 1. Most of the earlier research was done on war veterans and has only recently been applied to childhood trauma.

What makes trauma traumatic? It's what you carry around afterwards. Not everyone carries the legacy of their trauma with them for the rest of their lives, but some people do and that is what makes it traumatic. How come some people do OK and others are left with this lifelong burden? The book *Understanding and Healing Emotional Trauma* by Daniella Sieff helped me to make the link between hypervigilance, dissociation and shame. She describes this as ‘the trauma world’: embodied fearfulness (all the somatic stuff), dissociation and the desire to cut yourself off from this traumatised self and a deep sense of shame. Two other very valuable books are *The Body Keeps the Score* by Bessel Van der Kolk and *Trauma and Recovery* by Judith Herman, which deals with the politics of trauma. She combines the roles of academic, psychiatrist and volunteer in womens' shelters and is very big on advocacy. Getting involved in the politics gives you and your patients a sense of meaning and purpose which is so important in recovery

## Talking about Pain

I don't believe in ‘screening’ for trauma, partly because it can take decades to come out, partly because people often don't want to talk about it as this can itself be too traumatic.

It's easier to talk about diseases you don't have, than the stories you do have

*Julian Hart*

That goes for clinicians as well as patients. And there may not even be a story there. People may think what happened was just part of growing up and not necessarily traumatic; whereas you may think: Oh my God! – perhaps it may not have been so unusual in Glasgow in the 1980s

Maybe it's not the fact that pain cannot be expressed but that listeners don't want to hear it; it actually hurts listeners to hear someone talking about pain.

*Joanna Bourke*

Pain ( I mean in its broad sense – emotional, developmental etc.) can be expressed but people think as soon as they do the doctor is going to zone out and reach for a prescription pad or otherwise respond in a way that makes it worse. My patients don't want to upset me – they may want to protect me from hearing how awful things were , or at most reveal a little bit at a time. These may be people I have known intimately for years.

It was impossible to explain to the healthy the logic of the sick, and he didn't have the energy to try"

*from A Little Life, Hanya Yanagihara*

## Safety and Trust

People can't rationalize trauma - I mean we can, it's our job to try and make sense of the science and stuff, but I've come to the conclusion that trying to explain trauma to patients isn't a particularly helpful exercise. I used to imagine that the scales would fall from the front of their eyes and seeing things as they are would help them to get better, but I'm quite skeptical about that approach at the moment.

So testimony may not be necessary; *safety and trust have to come first*. All patients may want to talk about is their symptoms and these have to be tolerable before you can get anywhere so medication can have a role. The patient must be in control.

Recently one of my patients took part in the INPUT residential pain management programme at St. Thomas's and the patients were made to sit with the psychiatrist who made them bring to mind the most traumatic memories that they could think of, and after that they all just wanted to go home.

Trauma disrupts memories: imagine you are trying to study for exams and someone is screaming at you and threatening you so you just can't concentrate. So you may not remember the event but still have somatic memory of feelings, palpitations etc. which will get triggered.

Testimony may be traumatic for doctors as well as patients, so any kind of trauma informed service requires taking care of the clinicians: having time to stop and talk to each other and share the burden of care and probably having supervision from a psychotherapist to care for the carers.

## Empathy

In her book *The Empathy Exams* Leslie Jamison she describes how she tried to have empathy with people for whom she found it almost impossible. The book is about her experience of acting a pregnant patient wanting a termination in an OSCE (Objective Structured Clinical Examination) when she was pregnant herself. I believe that empathy, at any rate cognitive empathy, can be taught, and Jamison's aphorism often comes to mind:

Empathy is asking the questions whose answers need to be listened to.

So when your patients are kind of shouting at you: “you’re just not hearing me” you need to help them say what they mean to say.

## Joe

Joe is an anaesthetist who had a panic attack in theatre when things nearly went horribly wrong and was diagnosed with anxiety and OCD, and three years later he is still unable to return to work. He is having psychotherapy and is on four different psychotropics. His story is that he grew up in Sheffield with a very violent alcoholic father. He buried himself in school work to avoid the situation and got to medical school, qualified and went into anaesthesia. He used alcohol and drugs to dissociate and self medicated with Fentanyl, and it was when he was trying to cut down on this that he had a panic attack.

I published this story as a blog with a lot more details and was immediately bombarded with emails from all over the country saying you’ve got to take this down because you have broken confidentiality and I know this guy and I worked with him. *But it was completely fictional!* But Joe is an archetype.

Some trauma survivors cope by overworking. One said: “for me, working all the time and being in constant motion is one way to avoid thinking about how I am feeling.” Perfectionism and burnout among medical students and junior doctors is partly to do with trying to procure approval and deal with feelings of shame and not being good enough. I tell medical students that this sometimes happens when you have grown up in an environment where you were always made to feel that you weren’t quite good enough. If I say this in a lecture, when I leave it is like a lot of baby ducks following!

With your own children, you can’t meet all of their emotional needs all of the time, you can’t help saying things that you immediately regret. Micro-traumas are a normal part of growing up. And they don’t all grow up with chronic pain. Trauma is not destiny.

## How do you make things better?

### 1 Validation and Vindication

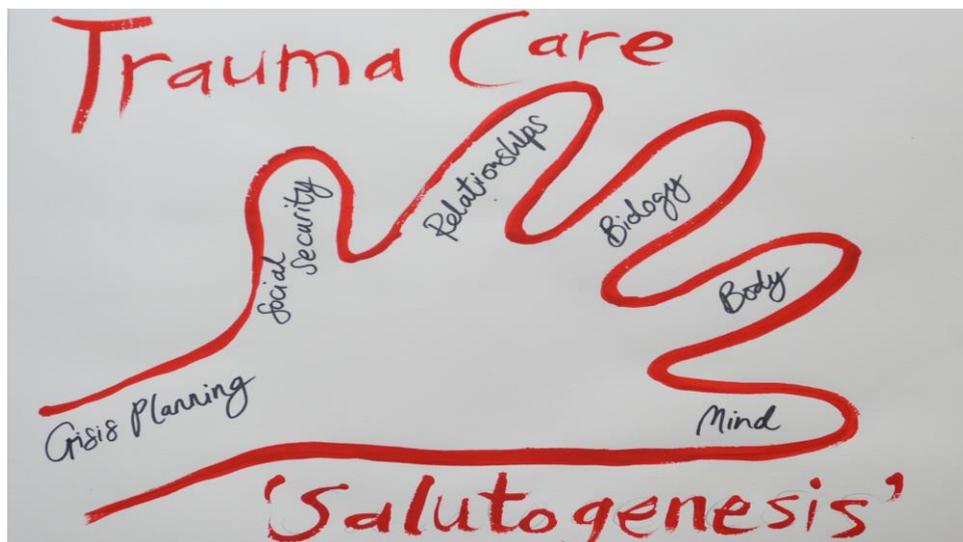
Judith Herman writes about validation and vindication. Validation of your experiences means my saying: “I totally accept what you are saying to me about your experiences, your symptoms and how you feel ... I accept you as you are.” Vindication is how we respond to shame: “*It’s not your fault* that this happened. It’s not because *you* did anything wrong that your dad used to beat your Mum. It’s not your fault that you were abused at school but didn’t tell anyone. It’s not your fault that your husband used to beat you. You’re not a bad person. We have to keep saying that over and over again. In our role as senior clinicians we are incredibly powerful. To be validated and vindicated by someone more powerful than you is very powerful therapeutically. The suggestion that these people just need social workers instead of doctors misses this point.

### 2 Reconnection

This is about commitment and dependency. I was taught as a medical student and junior doctor to be afraid of dependency and dependent patients; it's about their and your neediness which is a bad thing. But these traumatised people have never been able to depend on anybody. They have spent their whole lives being abandoned, betrayed and abused especially by people in power like us. So if you deny and reject their neediness you are recreating this abandonment. They will test you to see if you will abandon and betray them like everybody else. They will be very good at pushing your buttons and trying to make that happen, but if you are not afraid of dependency but instead step in and commit that is another powerful intervention as they are used to people doing the opposite.

## Salutogenesis

This picture is on my consulting room wall so I can use it with patients.



At medical school we spend 99% of our time learning about pathogenesis and hardly any about salutogenesis.

Often the only therapy we have for trauma involves *mind* but this is just the little finger in this image, as it is usually not enough.

*Body* can be anything: Yoga, Tai Chi, knitting, dancing, singing – anything physical so you don't have to deal with this stuff in your head. Our local psychotherapists have a therapeutic gardening group.

*Biology* involves anything that goes in your mouth: food, drink, cigarettes, alcohol, but also medication. When people ask: "haven't you got a pill for that?" you think – well we do but that's just a small part of one finger out of everything you need to be well.

*Relationships*: the strongest predictor for flourishing despite trauma is a long term relationship with an emotionally stable adult. I go through this hand nearly

every day with my patients and when we get to relationships they almost always burst into tears. Or they may say: well, I've got you! This is good but sad because I can't be that person, or at least only for the time being, but they have to learn to connect with other people.

*Social security* is deliberately on the thumb. When you make a fist your thumb wraps round everything else. You cannot be healthy or relaxed if you are living in fear of homelessness or running out of money and food. We have to be social advocates: on a practical level, by helping people with benefits and housing and stuff, but also on a political level by campaigning against austerity and the other things that make our patients sick.

When things get too much we have *crisis planning* which goes on the wrist. People need a written plan and share this with friends, family, and professionals. They must learn to identify triggers and spot the early signs of impending crisis and review their plan after a crisis to see if it worked.

Don't change medication in a crisis – if you had one it doesn't mean that the medication you have had for the last two years suddenly isn't working.

## Conclusions

We need to learn to recognise the patterns of hypervigilance, dissociation and shame. Validation involves believing patients, bearing witness and kindness. We should hold our interpretations lightly.

We need a compassion that stands in awe at the trauma people carry rather than standing in judgement at the way they carry it.

Harry Burns

This emotional labour and commitment to people is incredibly hard so we must focus on salutogenesis and be hopeful, and take care of ourselves and our colleagues.

## Discussion

[The first few minutes were spent in groups identifying points from Deepak Ravindran's talk, with which Jonathan's shared a lot of overlap, which needed further discussion, and the first few following paragraphs are the reports back from these.]

*We discussed the relationship between knowing and understanding things at an academic level and doing things practically like changing consultations and providing support. People build up huge defence mechanisms. . I spent a day with John Stone, the Edinburgh neurologist, who deals with extremely complex cases. He didn't talk about psychology or early life but he provided rehabilitation and practical measures to enable people to regain their foothold on the ladder before these more difficult issues could be dealt with ...*

... About how long would you work on the somatic before you bring up these issues?

*It's variable but this is more of an art than a robust science – which is important – but dealing with it requires multiple approaches which we have been talking about for years.*

My experience of working in the same place for 20 years is that you can have been seeing the same person for 20 years before the stories come out, which is why I am slightly sceptical about the screening approach.

*It's the way people communicate in a workplace. If two people went to a psychologist or a counsellor then that person would be skilled in the way that they talk to them but would be more likely to talk about those things?* [verbatim transcription]

There is evidence that some people get worse after seeing a psychologist ...

*... it often gets worse before it gets better because they go back ...*

*We identified the fractionation of health services and the difficulty of unifying ... working together*

*We discussed the fact that we are part of the problem because of our belief in our ability to fix things*

*We agreed that when you use questionnaires to make enquiries it's not a neutral thing; even if you are not necessarily going to provide long term therapy you are opening up old memories and associated emotions so it can be quite high risk. You have to be ready with a back-up team to take them on if necessary.*

*...and making an unexpected diagnosis...*

*Some psychotherapy patients may take two years before they will admit having an unhappy childhood; before they develop the skills to deal with emotional trauma. Before they have that they may not have ways to benefit from psychotherapy. I cannot take their pain away as that is their way of saying this is my problem, until I have given them the skills. (I am a psychoanalyst)*

*You may have to go very far back to get to the original trauma – even generations – because of the transfer of the trauma from generations. But we have to start somewhere even though we know they are carrying the burden from generations back.*

*So it can be overwhelming and completely out of your control even if it happened years back.*

*You talk about trauma informed practice: how do you create a safe space within your whole practice? ...*

Yes ... a trauma informed practice rather than a trauma informed practitioner. First of all are the receptionists who have to deal with patients behaving badly. Your 'front of house' staff who have to take the brunt of a lot of the emotional stress need to have a sense of what is going on, as do the secretaries who type up the trauma narratives in the letters. Secondly consistency: you have to build continuity and stability of relationships within your organisation, as discontinuity is part of why people become traumatised. Things have to be comprehensible; part of trauma is that things just don't make sense, so you have to work on the hermeneutics (the little video *All behaviour is communication* is a nice way of introducing that into your organisation)

And then you need to take care of all the people that work there. The psychotherapists come in once a month to talk about difficult problems. We cancelled our regular Monday meetings and now we have a meeting with no agenda just to be with each other. We do peer supervision for all our salaried doctors once a month to give them an hour once a month to talk about anything that they want to. This involves everybody, not just the clinicians.

*In your excellent talk there were bells ringing with me when you were talking about your hand and your mind; It's almost more than this because it involves a belief system, and change has to do with belief. This has a spiritual dimension which is often ignored in the world and by secular doctors. How do we fill that void? You comment on dependency ... the way that I have addressed that in my head is the image of scaffolding (which comes from my work in education): it's OK just to put the scaffolding up to support ... and just to be there ...*

I have a friend who is a psychiatrist who is very interested in this. He was aware that many psychiatrists believed that they asked about spirituality or involved it in their practice. But his research showed that the vast majority never did. If psychiatrists who think they do don't, then it's very likely that the rest of us don't either. I think that existential questions are important but I don't think that everybody is spiritual. Where I work it is so massively diverse in terms of different religions and spirituality that are represented in my patients. So I would probably think about what sort of spirituality and probably boil it down to meaning and purpose, which are part of salutogenesis. And also how feelings of guilt and shame are kind of built into some kinds of Christian and especially Catholic belief ...

*I think the best Christian response to this business of shame is just to know that you are accepted and loved with all your faults and vulnerabilities. Being fixated on the Old Testament picture of an angry vengeful God who has to sacrifice his only son to save you from your sins may only add to your sense of guilt. But although you may not even believe in God as an all powerful being 'out there' who could prevent your suffering but chooses not to, you may find the concept - the image - of God as love pervading the universe including your little bit of it immensely consoling.*

I think my patients get that a lot.

One of my patients is a woman in her fifties with very severe IBS for all of her adult life. She is otherwise very functional, not a chronic pain patient. She has tried an enormous list of physical and psychological therapies, and been subjected to nine colonoscopies. (Sticking tubes in people is often a way of retraumatizing them). One day after I had known her for about ten years she asked me: "Do you believe that things that happened in childhood could affect you ... " She was very tentative, as she didn't know how I would respond. I replied: "Completely - and I'm very interested in this area - why do you ask?" So she told me what had happened. About a year later she saw me again as the symptoms she still had were playing up. Psychotherapists report curing people by discovering it was all about the mother etc but that never happens to me - I wonder what I'm doing wrong or if there is any point in these conversations! But she said: "Oh my God you have no idea how much that helped! All these years I thought I was mad - that it was somehow my fault. It still hurts but I don't think it's because there is something wrong with me". Then I mentioned that I had seen a documentary about non-epileptic seizures and she confessed that she had never told me that she had had those as well in certain situations of intense emotional stress or after sex.

So when you look at your pain patients and think nobody's getting any better some of them may be thinking 'I'm not mad - I don't blame myself any more' It may not

necessarily be the best outcome if they are still in pain but if you've done something to make a change ...

*I had a patient who was a refugee from Ethiopia who cried as she told me that she had been tortured by being made to stand barefoot on a block of ice for 24 hours. I sorted out some treatment for her and arranged to see her again in two weeks as she was really worrying. She was a completely different woman – happy and smiling, so I asked her what had happened and it transpired that the Red Cross had found her husband and daughter and they had been reunited.*

*There is a study by a Coplin, a psychiatrist in California and his colleagues who have identified a cluster disorder and called it ALPIM: Anxiety, (joint) Laxity, chronic Pain syndromes, Immune disorders and Mood disorders.*

*If you look for joint laxity it's very validating if you find it because people's problems can be explained in terms of genetics.*

Others have recommended describing findings when doing a physical examination: "your muscles are a bit tense here ... your reflexes are a bit brisk ... etc. There are real physical things that I can see or feel in your body" ... which validates the fact that they are experiencing physical things. You don't attempt to interpret them as having a particular causative framework (you probably don't know) but acknowledge them as real. We miss a trick as doctors if we are not very hands on - there is valuable interaction in that.

*If you look at studies of the epidemiology of pain which show that one in five of us have it, you also note the group that never go to the doctor; they are resilient and they are not distressed by their pain. You only see the patients at the other extreme with all their problems and disabilities. It's obviously more than just ...*

There are a whole lot of people who don't go to the doctor because they don't want to be shamed, or have had bad experiences of this. Doctors are prone to make moral judgements as well as clinical ones, and the fear of being judged keeps a lot of people away. There are many peoples suffering who never see a doctor, but if everybody came who should come we'd be a helluva lot busier!

*A lot of people don't come to doctors not because of shame but a variety of other reasons. We did a study a few years ago which identified a lot of reasons and shame wasn't very high on the list. [perhaps because people didn't want to admit to it?! ed.] But it's very important because in the framework of salutogenesis we have no idea what is going on because we don't see the people who are successful.*

*I found your talk great and I am really impressed by your approach. I'm now retired – I was a hospital doctor, not a GP, by the way - but I am interested in two aspects of how you do this in general practice today in the UK. The first is: what proportion of the patients that you see need this kind of different approach – different to a more 'mechanical' approach to the sort of simple medical problems which we have. The other is how do you do this within the ten minute allocation?*

I work in a deprived area with lots of immigrants from Turkey and Sub-Saharan and West Africa so it's not representative of how other people work. So the proportion of patients can be anything up to 50% of anything up to 30 to 50 patients on some days. So it's a massive caseload. But I can have longer appointments in the afternoons and evenings so I can spend longer with some patients and my evenings are often filled with patients like this as I like this kind of work. But all the doctors in the practice have big caseloads. Even if [trauma patients] represent only 10% of

your caseload they may take 40% of your face to face encounters. So it is an enormous amount of work and it's very hard on the doctors, and even harder on those who don't like this kind of work or find it fascinating. As I do. We do have problems with doctors burning out.

How do we make it work? We don't usually actually talk much about trauma – we know it's there, or we have talked about it many years ago, but usually you are just taking care. This often just means checking in – just allowing people to pop in and let you know how they are doing. And that really matters to people. Sometimes people just want to send you a message, sometimes that just means ringing them back, but sometimes it needs to be a home visit. Having a mixture of ways of contacting the practice, being flexible, being aware that checking in therapeutic even if you're not being paid for it. The way in which financial incentives, which are very outcome and process driven can undermine care and govern your behaviour, is a challenge we could perhaps discuss that this week

*On a more practical level, (I do paediatric pain work) to what extent have you identified in your patients that a lot of their symptoms are manifestations of a similar ilk like pain? If they are insistent: "but now I've got a new pain and I need to be referred back to rheumatology orthopaedics", to what extent do you try to have a discussion around that and/or include any hospital based service to refer them to to help them be aware of the wider picture. We certainly have this in paed and we try to have an paediatrician who has overarching responsibility to hold these children; often the parents are shopping between multiple subspecialties because they can't believe pain doesn't necessarily mean harm or disease, but often everyone being in the loop to understand ... .. and learning that there comes a point where drawing a line is really important and saying you've had all the tests and there isn't anything more to do, rather than going round the loop again, can be very therapeutic, and helpful to say we will think of another way to work with you, or give you the option of other ways of helping you get better. I wonder how that works within your practice given that you have more of a physical disconnect between the other services who might be involved in your patients.*

The investment at the beginning of going through the problem list and a full systems review, and exhausting all the symptoms ("is there anything else that's bothering you?") from head to toe, is in itself very therapeutic, and helps to see the bigger picture. And then summarising all the investigations they've had and all the specialists they have been under, and spending some time talking about what makes for good relationships. If people are always asking for fresh opinions it might shine some light on the relationship you have already: is there sufficient trust? Can you contain their anxiety?

But I do agree with people that this list is what we are dealing with and if anything else comes up we will deal with it on its own terms. It's important not to psychologise problems. People hate to be told it's just because of your trauma or just because you are anxious.

But as regards retaining people and not referring them ... the main way is just through trust. Knowing the person you are referring to is important but gets increasingly hard the way the NHS is organised these days – if they are going somewhere else it gets very tricky – and giving them a good referral letter and hoping they read it.

*We have the advantage of being in a small area of practice so understanding what is happening in other sectors makes everyone more aware that there may be reasons why they do need help to stop them going round medicalising things ...*

I'm very keen on patients having a shared record. I always do my referral letters with the patients in front of me, and they have access to their records online.

*You have the opportunity to get to know and understand your patients but this is a problem in secondary care. Patients come to doctors at crisis point. So if we in secondary care don't understand the background but they don't want to do anything else but focus on their symptoms it's difficult to avoid medicalising everything. I understand what you say that it's better not to touch on the trauma in most cases because it may retraumatise them. But in secondary care we don't know the person and see them as isolated encounters. How do we then make sense of what we do and ensure that it doesn't change the narrative each time?*

Simple strategies include taking a full history every time and checking in on the full spectrum of symptoms as well as social problems. If you are working in a pain clinic you focus on the pain and don't ask them about their IBS or migraines or diabetes, or housing problems. How many have social workers in the pain clinic? [none]

In Oldham they have Focussed Care Practitioners working alongside GP's. If they identify somebody in chaos with complex problems they identify them as probably part of a family or social network that is probably in chaos; so they will go and visit the household and see what else is going on. They try to explain that they are not going to get better or get their pain fixed if the husband is an alcoholic and the kids are off school smoking spice in their bedroom. So they try to interview everyone in the household and try to think of interventions at that level. They have had incredible outcomes like 30% reduction in A & E attendances, 7K reduction in cocaine usage in the last year.

Perhaps there should be women only pain clinics given the prevalence of gender-specific violence.

*We may not know what the trigger is. Shortly after I arrived in Durham I saw a young man who had had an injury to his feet but as soon as I greeted him he became very distressed and made for the door. I asked him what I had done to upset him and he replied: "You're from Northern Ireland where I was blown up as a soldier". We managed to contain that and we worked together for the next four or five months.*

*There are men who might feel like that about women because they have been abused by them.*

## Going beyond the bio psycho social; the complex person in a complex environment and uncertain world

Betsan Corkhill

Preparing this talk has given me the opportunity to put thoughts that have been mulling around in my head for some time into some sort of order. I am going to attempt to offer some potential solutions to the problems but as I've learned more about pain, health and wellbeing I've realised how complex they are and how little I know.

Medical science has made tremendous progress but there is hardly a healthy human left.

Aldous Huxley 1946

( note the date of this comment!)

We have got to a stage where we need to change our thinking to create new approaches rather than try to fix, patch up or prop up current systems that are clearly not working for those living with ongoing pain or many other long term conditions.

The complexity is a bit like that question 'where does the universe end?' and involves questions that are difficult to get our heads around. So it becomes easier to simplify and safer to compartmentalise, but we can go so far down this route that we lose sight of the complexity.

Those of us who have ventured into the wider context have often met with fierce opposition from those with more bio-mechanical viewpoints.

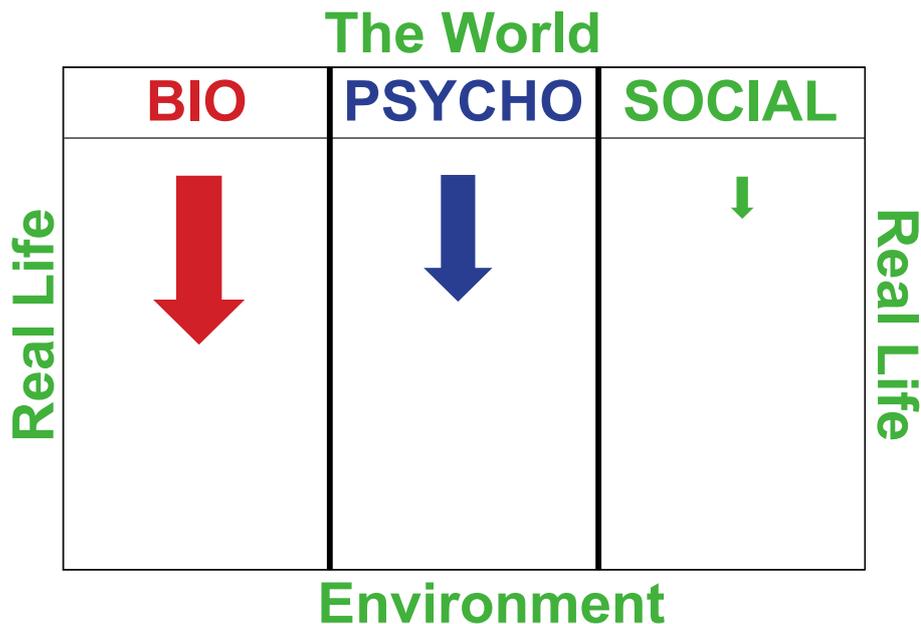
I first met Paul (Dieppe) about 8 years ago. He was giving a talk and put up a slide that had as a title: 'body, mind....' and then he added 'spirit' . There was an audible intake of breath around the room. Later he dared to use the word 'healing' and the intake of breath became a gasp.

We've thankfully moved into an era where anyone taking a purely biomechanical approach is considered to be outdated. however, even bio psycho social doesn't grasp it all.

Boundaries are often arbitrary but once some arbitrary boundary exists, we forget that it is arbitrary and get way too impressed with its importance.

Sapolsky 2017

We even do the bio psycho social in silos often without communication between the silos or linking or thinking about the overall effect.



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The bio psycho social model chops the patient into three neat packages.  
Cabaniss 2015

Approaches are compartmentalised and fragmented. Boundaries are artificial and distract our attention away from the person as a dynamic whole embedded in an environment

Humans are complex beings in a complex world. I recently became really interested in the theory of complex systems and how this can be applied to the human body and pain.

Here are some facts about complex systems:

- The whole is always greater than the sum of the parts
- If you separate out the parts, the whole will be lost – in our case life
- Emergent properties are defining qualities (Pain is an emergent property)
- You can test all the parts but it doesn't mean the whole will work
- Looking too closely at the detail can cause you to lose sight of the whole
- They are dynamic and adaptive
- To understand a complex adaptive system you need to know its history
- They are non linear and behaviour can be irregular
- A minor, simple change can cause a big response
- A major stimulus or change can have little effect
- They are characterised by feedback loops

The human body is made up of a range of complex systems from cell to whole that all interact in complex way. And then they are embedded in complex environments in an uncertain, complex world. We can't separate out the interaction between body mind and environment.

Complex systems are driven by the quality of the interactions between the parts, not the quality of the parts. Working on discrete parts or processes can proper bugger up the performance at a systems level. Never fiddle with a part unless it also improves the system.

Complex Wales

We would do well to heed this. Prescribing opioids is a classic example of attempting to address a part without considering the whole. When you affect a part you affect the whole but often in ways that are unpredictable.

slide ↯wolves

A good example of this was the introduction of wolves into Yellowstone Park. The unforeseen outcome of this was that it changed the course of rivers because the wolves ate red deer, who no longer ate the grass on river banks so it grew more which changed the flow of rivers back to more natural courses and decreased flooding.

Humans are ecosystems too – organic, dynamic systems that are constantly changing in a constantly changing background

If we take this viewpoint we can view pain as emerging in the complex conscious person (a dynamic whole) embedded and inseparable from a complex environment and wider, complex uncertain world when credible evidence of threat is perceived. (the word perceived is important)

Pain always has a context involving the past, the present or expectations. It never happens in isolation. It involves a range of factors associated with the person as a whole and their interaction with their environment and the world

Pain does not reside in a mysterious immaterial mind, nor is it entirely to be found in the blood, brain or other bodily tissues. instead, it is a relational and emergent process of sense-making through a lived body that is inseparable from the world that we shape and that shapes us.”

Stilwell and Harman. *An enactive approach to pain: beyond the biosychosocial model.*

1-10 scales can never capture this. Linear pathways of care can't address this. People and life are messy and the longer you live with pain the messier and more complex it gets. But linear pathways are more straightforward, aren't they? They have boundaries and we know where we are going so they make us feel safer when we have procedures and pathways to follow. Dealing with complex, dynamic, organic systems involves things we don't fully understand; they are hard to get your head around and the enormity of it can be scary.

“Like riding a bike, if you think too hard about complexity, you may fall over.”

John Launer

You almost need to get a *feel* for it, to get it intuitively rather than try to verbalise or explain it.

Even the way we approach exercise and rehab is very linear. For example Mark is a young man who came into my course walking and moving stiffly, avoiding any unnecessary movement holding himself rigid, but was he was very proud of the fact that he was doing physio every day. This involved doing squats against a wall and dorsi/plantar flexing his ankles. He could do 12 of these now whereas in the

beginning he was only able to do 8. That was an improvement of 4 reps in 6 months – 6 years after original injury. Yes he was ‘doing his physio’ every day but it was confined to these linear exercises and in everyday life he was getting stiffer and stiffer. The message about moving more in general wasn’t being translated across to his real life.

Every new diagnosis and changing social context is a complexity multiplier. Now we live for years with heart, brain, lung, neurological etc. diseases that once would have killed us. Evidence based on single diseases becomes ever-less certain in the face of multi-morbidity. Multiple specialists, clinics and medications add up to an intolerable burden of care. We need specialists in people and relationship-based care, now more than ever.

Trisha Greenhalgh

## Labels

This brings me to labels. People are not collections of symptoms or machines on manufacturing lines. Labels can lead to fractured care.

When we do define ourselves by one of those labels, we can get into trouble when all of a sudden were no longer that thing.

Joletta Belton

They can also become your identity and difficult to let go of.

## Kelly’s labels

Kelly is a woman in her 30s who came on my course. She had recently spent 11 months in an inpatient psychiatric unit on suicide watch. She had acquired a large number of labels including eating disorder, anxiety, depression, suicidal tendencies, OCD, chronic pain and several others. She is a geneticist - a bright young woman.

Interestingly, she’s the second young woman I’ve encountered with anorexia where failure to consider the whole person has caused harm. Her treatment for anorexia focused only on getting her weight up. So she and the other woman were both told – ‘focus on getting the calories in, not the quality of the food or whether it’s healthy, and *do no exercise*. She now is overweight, has poor eating habits and does no exercise. She leads a very inflammatory lifestyle, is prediabetic, and after 11 months as an inpatient on suicide watch has long-term pain from being sedentary this whole time. On discharge she was barely able to climb her stairs because her legs were so weak.

This is a classic example of just focusing on a part without considering the whole. At the end of our first session she took me aside and told me “horrible things happened to me from the age of nought to 21” - it didn’t take much to learn this but she had had no trauma therapy in these 11 months in crisis care.

Four weeks into the course she had an appointment to assess her pain, and, surprise, surprise, she was diagnosed with fibromyalgia. So she acquired yet another label – another ‘life-long’ condition to deal with. No-one explained to her that this is all part of the same problem. As a result of acquiring another life-long label she emailed me to say she couldn’t come to my course any longer because she was

back under the care of the mental crisis team. She had tried to take her own life four times in the week since her fibromyalgia diagnosis.

## Trauma

We've heard a lot this morning about the long-term effects of trauma. Trauma comes in many forms.

When Ben was at school (he is now in his fifties) his teachers had told him that he and his then future wife were thickies. They never thought they could learn anything or change their life. They were both in the same class; they have been afraid to socialise, and were convinced that they were re unable to learn or do anything apart from keeping their heads down and not interacting with the world. They both had long-term pain.

There are six teachers in one support group I set up. All had suffered bullying at work. All have fibromyalgia, some alongside ME and pelvic pain.

Low income, austerity, poverty and cuts to services are traumatic. They can make people sick. But it goes deeper: the effects of trauma can be passed down through generations by what is thought to be 'epigenetic inheritance': the baby's systems are programmed to enter a hostile world.

Pain and the impact it has on peoples' lives loops back and becomes an ongoing threat they can't escape from. When you can't run or fight to escape trauma or threat you go into freeze or flop mode; perhaps that is the case when we label people as unmotivated.

So what can we do about it?

I want you to hang on to these suggestions:

- Complexity can bring hope; because lots of things go into complex systems it gives us lots of avenues in to make changes
- Small changes to one aspect can trigger a big overall effect. Simple things can have a big impact

## The possibility of recovery

One of the biggest barriers we face is the ingrained belief that nothing can be done for long-term pain. All that is left is managing or coping with it. That's a pretty depressing thought to live with. I think that that belief in itself can drive ongoing pain. But change *is* possible and it's not just the person living with pain who needs to believe this. We need to start believing that too.

I thought the best place to start was to try to find what recovery looks like because some people do recover after many years of pain and we really need to be asking them what it means.

So I thought I would ask some people who had recovered what it meant to them and these are their answers:

“I’m living a happy, fulfilled life. I still have pain but it’s just ‘normal’ pain now. The normal aches and pain that everyone gets from time to time.”

“The fear has gone. I’ve found me again.”

“I’ve found my meaning, my purpose. I’m me again.”

“I’ve moved from pain-centred living to living my life.”

“I’ve reconnected to things that matter. I’ve connected to life, other humans, to Me , and the world again.”

“I do have pain from time to time but I don’t ‘have’ pain. I’m not *in* pain.”

“ I needed to figure out who I was without the labels.”

“I have a sense of agency again.”

“I consider the pain I have these days ‘normal pain,’ not the next level shit I experienced during my darkest years when my world was upended, my identity was lost, and my future was sheer terror.” Joletta Belton

(I recommend reading Joletta’s blog <https://www.mycuppajo.com>)

What these responses have in common is that people are finding who they are: in finding their Me the meaning of pain changes and they lose fear. :

Recovery is not simply about function and the activities of daily living, but about personhood, identity, self-worth. So often in current healthcare the focus and attention is on functional improvement.

Margaret Hannah: *Humanising healthcare. Patterns of hope for a system under strain.*

So finding out what recovery looks like can help us to think about what we’re aiming for. But how often do we ask ourselves: in our pain clinics and Pain Management Programmes *what are we actually aiming for?*

## Fight, fix or cure?

It’s not about fight, fix or cure. As soon as you talk about fighting or beating you trigger a stress response. We need pain to survive: if we suddenly discovered a way of fixing or curing pain tonight we would all die and the human race would have died off long ago if we didn’t feel pain.

Having an understanding of this is the first small step to thinking of pain as a protector and gently nudging that mindset away from pain being harmful or destructive.

Systems are no longer capable of recognising what’s actually dangerous and what’s not and respond inappropriately.

Vessel van der Kolk: *The body keeps the score.*

Perhaps instead of reducing pain as our prime focus, we should be looking at ways of resetting and recalibrating our protective systems.

But before I get on to this I want to take a look at how we set the scene and create the right environment for this to happen. The relationship between you and your patient is key. Even before you've opened your mouth you've made an impact and set the scene and the context; you've affected a person's anxiety levels and expectations. What makes the difference is the interaction and understanding between you.

If you look at this from the complex system perspective you can possibly think of it as two complex beings engaging, connecting and interacting and making sense together to enable emergent change and meaning that would not be possible if they were acting alone. This relationship can in itself become a powerful tool to create change as we focus on building relationships of mutual trust, respect, belief and kindness and equality

Trust is especially powerful. As Jonathan [Tomlinson] says: "only once trust is established do the stories behind the stories come out."

Building this kind of relationship involves looking after your own wellbeing, and treating yourself with self-kindness, because when we are stressed it comes across in our approach, through our body language, the way we speak and little things that people pick up on.

### Tai Chi Movement for Wellbeing (TMW)

I have just qualified as a Tai Chi Movement for Wellbeing teacher. One of the things I've had to learn is *teaching through transmission, not instruction*. This has been so valuable but really difficult because as a former physio it was the complete opposite of what I used to do. It involves *embodied presence* which invites mind into body so your mind and body are in the same place at the same time, so you are fully *present, aware and receptive*. People pick up on this, they sense it.

That can make a difference between moving towards a shared understanding of issues rather than simply being a source of a prescription. It involves recognising the humanity of the person in front of you who are people who have complex problems, not difficult patients, and who want to be seen as a person, not a list of symptoms.

People are people we sometimes call patients.

Anon

We are all people who sometimes become patients

Kieran Sweeney

I would highly recommend that you watch a YouTube interview by Kieran Sweeney, a GP and academic who died from mesothelioma in 2009 which was recorded shortly before he died. <https://www.youtube.com/watch?v=3TignNvHNx4> I'll warn you will need some tissues. It brought tears to my eyes because much of what he said resonated with our experience when my husband needed urgent surgery to repair a severely damaged mitral valve. Dr Sweeney discovered he had terminal mesothelioma at his kitchen table. We learned that my husband was in heart failure, after valve surgery, at the kitchen table.

Sweeny describes medicine as:

Being with people at the edge of their human predicament

and talks about how the inadvertent small humiliations can add up. My husband describes being wheeled backwards along a hospital corridor with an open backed gown on but feeling too weak to do much about it, and being instructed to 'take your top off and get on the bed' with no introduction, smile or humanity. All these things add up to traumatise and humiliate a person when they are already at a low point

Sweeny also warns that –

What's routine for you will be a big life issue for your patients.'

We learned that the hard way: Steve's valve surgery was more or less shrugged off as routine by the surgeons. To both of us it was huge....they were going to cut open his chest, stop his heart and then cut into it.... that was *big*.

So it is really important of recognising a person's humanity and their fear.

## Othering

It's not about 'us and them'!

Bronnie Lennox Thompson warns us against our predilection for 'othering'. We must recognise the fact that we can all end up in the pit given the right (or wrong) circumstances. Don't kid yourself that you could never end up there.

## Professional boundaries

I'm not afraid to say that I do cross the more traditional professional boundaries. Many of those who have attended my wellbeing programme will hug me and I hug them back. *Touch* is powerful in building relationships of trust. It also helps by sharing a little bit of yourself to move away from an us and them situation. You can trust that your clinical and life experience will guide you in this. Building relationships of mutual trust and respect helps here because they will respect you.

When Steve needed surgery the knitting group and wellbeing friends support group I started supported me. A lady I'd helped to get back to walking through 'walk and talk

sessions' said "come on, you're coming for a walk with me today. My turn to help you!"

## Shared decision making

The key is to remember that the word is *shared*, not devolved. Patient autonomy should include the absolute right not to have autonomy, if that is the patient's preference today.

Perhaps one of the key skills of any doctor is knowing how to determine a patient's preferred consulting style, and also recognising that those preferences may change from day to day, and from illness to illness.

The turbulent sea turned out to be enough to bear without the burden of navigation too.

David Haslam and Nishma Manek: *Whose illness is it anyway?*

This is a conversation between my husband Steve and a doctor at his one year post op check (which actually happened at 16 months). He'd been called in for a routine echo and this was to have the results.

*Doctor:* What can I do for you today?

*Steve:* I've come for my results

*Doctor:* but what do you want to take from this consultation?

*Steve:* to know the results of my echo

*Doctor :* In an ideal world what would you like the outcome to be today?

*Steve:* for you to say i can come off my medication

*Doctor:* Well, I can't make you take your medication so I'm happy to stop it. Let's do that and we'll check you in one year's time, and if things have deteriorated we can put you back.

*Steve (and me !!):* but is that safe? what does my echo say?

*Doctor:* Evidence is not conclusive for this drug anyway

After this conversation we had to ask him to actually look at his echo which showed that he had made a complete recovery.

## Validation

Patients long for doctors who comprehend what they go through and who, as a result, stay the course with them through their illness. A medicine practiced without a genuine and obligating awareness of what patients go through may fulfil its technical goals, but it is an empty medicine, or, at best, half medicine.

Rita Charon, *Narrative medicine: honouring the stories of illness*

To understand a complex adaptive system you need to appreciate its history. The most valuable information comes from the patient's story.

It is more important to know what sort of person has a disease than to know what sort of disease a person has.

Hippocrates

What does *their* world look like – what does *the* world look like from their perspective?

The German word *umwelt*, literally environment, means in the present context the sense of an animal's lived, phenomenal world, the world as it presents itself to that animal thanks to its sensorimotor repertoire. An individual creates and reshapes its *umwelt* as it interacts with the world. People can have different *umwelten* even though they share the same environment.

I like to make the analogy of using a filter on a camera lens, which people seem to understand, and try to explore their filter on life. What are the things that have shaped their world? What really matters to them?

Consciousness, the world, and the human body as a perceiving thing are intricately intertwined and mutually engaged.

Merleau Ponty

When you get to know peoples' stories you begin to get an understanding of why they are in the place they're in; and actually in many, if not most cases, a realisation that, within the perspective of their systems, they were behaving logically in response to life events helps us to better understand the decisions people make. Finding what lights their spark stops you making assumptions about their lives.

I was talking to two young women in their 40s in my support group about why they get low and immobile over the winter months. They told me they can't afford to heat their homes so they stay in bed or lie in thick sleeping bags on the sofa.

When dealing with complex systems we need to learn 'not to shape the results as the craftsman shapes his handiwork, but rather to cultivate a growth by providing the appropriate environment in the manner a gardener does this for his plants.

Friedrich Hayek. *the Pretence of Knowledge*. Nobel memorial lecture, Stockholm 11th December 1978.

And in order to do this we need to know the story – the history



Some people carry heavy life loads and we need to know what they are. I think people are – often telling us ‘my life hurts’. Sometimes all you can do is to help them to find as much sanctuary, as much safety as possible within this context, and helping to ease the load or put it down for a while. Bearing in mind that relieving suffering may not always be the same as relieving pain.

## Bringing about change

I’m going to look now at some things that I think can influence change. This change need not necessarily be in intensity of pain but in other areas of life so their relationship with pain changes over time. Firstly security and safety.

If you feel safe and loved your brain becomes specialised in exploration, play, and cooperation. If you are frightened and unwanted, it specialises in managing feelings of fear and abandonment.

Bessel van der Kolk, *The Body keeps the Score*

If there is credible evidence that the person as a whole embedded in the context of their environment is in danger or under threat, pain is experienced.

Mosely and Butler

Take the example of fibromyalgia which I have defined as a condition where all your protective systems, including your alarm (nociceptive) system, stress, sensory and immune systems, are on high alert and sensitive, producing experiences such as pain, fatigue, generalised aching and a range of other sometimes strange feelings that can be quite scary. (Note that I am not using the term pain system. I don’t think it’s correct. Pain is an experience that emerges from this process. It’s your alarm system that becomes over sensitive)

So it makes sense for lots of reasons to consider how we can improve feelings of security and safety.

For our physiology to calm down, to heal and grow we need a visceral feeling of safety.

Bessel van der Kolk. *The Body keeps the Score*



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These are just some of the issues people living with pain fear and drive ongoing pain

Fear, feeling unsafe makes it impossible to recover or heal and we need to think of this across the board from the environment of the surgery and waiting area, the posters on the walls, to the way we greet and speak to people. All these things form part of the picture and can change the way people behave and react. When we approach people with a smile in an open, friendly way it promotes feelings of safety.

I went to Steve's consultations with him and I'm still amazed how many clinicians don't introduce themselves, turn their back on you, don't smile, don't seem to grasp how big a deal this could be for the patient.

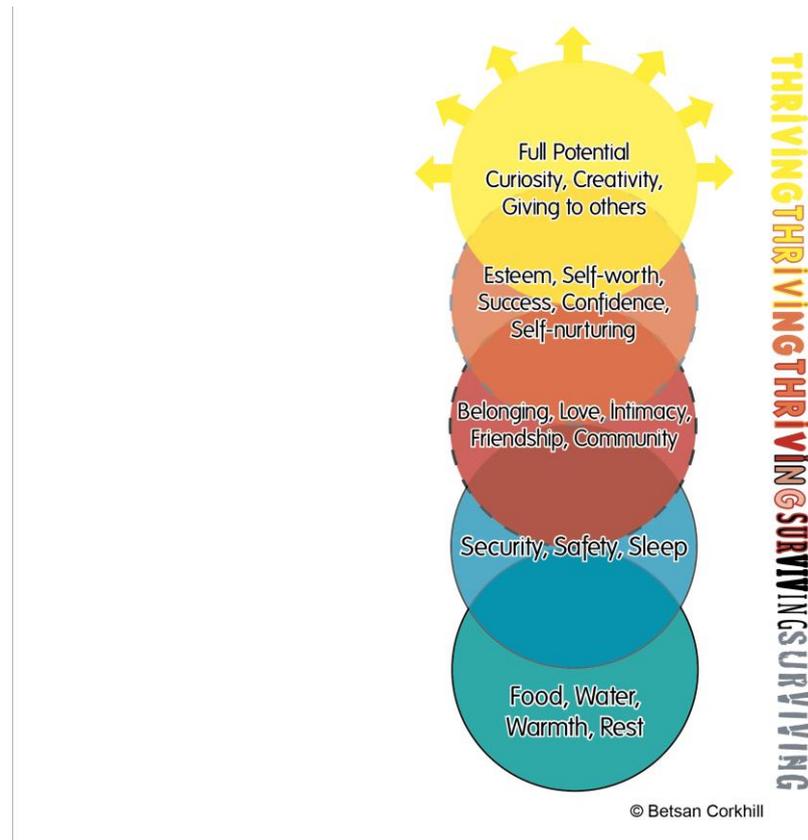
People are also afraid of getting better. How many times have I heard something like this? :

" I'm frightened of getting better of allowing myself to feel I'm improving because my benefits will be taken away. If that happens I will lose my home. I haven't worked for 15 years; who's realistically going to give me a job?"

Nocebic messages from health professionals and social media are all sources of fear and threat. We have to be careful not to provide more 'scaffolding' for their pain.

Improving perception of safety, security is fundamental to change. There are some things that we can't do anything about as individuals and that can be a source of great frustration

## My Maslow



I had a bit of a play with Maslow's triangle and as you can see it's no longer a triangle!

Housing, a living income and good nutrition are key. Benefits and social care systems create an uncertain unsafe environment and make people sick. Current systems deter recovery. Peoples' pain levels go up two or three months before they have to go for assessment. Being unable to see the same GP who knows your story .or the same psychotherapist or psychologist so you have to retell your traumatic story over and over reinforces it and prevents you building relationships of trust and respect.

Poverty, austerity and cuts to services are making people sick. I'm sure we all have powerful stories that illustrate this. I don't think it takes much to realise that these cuts will cost more over the longer term in every way. It's not just this generation – it will impact future generations

Poverty has a psychology and identity all of its own.

From *Low Born* by Kerry Hudson

Disabled women who are on low benefits or have been turned down by the benefits system are working in the sex trade. It's called survival sex. Life is made most difficult for the most vulnerable people

This is where we need national and international organisations like the BPS and the IASP to raise awareness on a governmental, global level.

But there are things we can do to promote an increased sense of security and knowledge is the key to this. I have found that people are really receptive and eager to learn. Those who have recovered say that understanding the biology and the complexity of pain was important as it gave them hope. Knowing the how and why of their biology helps them to understand at a deeper level and they need this deep understanding for change to happen. It is particularly helpful for them to know that change is possible and that plasticity is a biological fact.

Learning about stress and how it works also helps

I've realised all my symptoms are down to stress, not pain. and I can do something about that."

Course participant

## Calming the primitive brain

This involves communication at the deepest level. We can try it from the top down, the bottom up, or both at the same time but if you're in a crisis trying to do it top down, for example through meditation, is very difficult if not impossible. You can't instruct the mind to 'relax!' or 'calm down!' but you can show it how good it feels through experience. We can recalibrate protective mechanisms through *experience* of safety i.e. from the bottom up, which then often results in the effect of both the bottom up and top down approaches.

**Rhythm** is one way of doing this. Most of you will be aware of my research into the therapeutic benefits of knitting. I have accumulated many stories from people who are unable to meditate or practice mindfulness (top down) because they are too stressed, busy or distressed, but can still knit (bottom up and top down) and achieve a meditative-like state. Rhythmic movement seems to be important in this.

Tai Chi is another means to this end. Two of the core understandings of Tai Chi Movement for Wellbeing are that:

- The body reflects the mind
- Gestures have an atmosphere that make a difference

So rhythmic bodily movement can change the atmosphere of the mind and this is somehow unifying mind and body again

Examples of rhythm include rhythmic movement: dancing, tai chi, yoga, knitting, rocking, walking and running, but also singing, poetry, laughter, music, drumming, breathing, stroking a pet and listening to the purring of a cat, and watching waves. The brain likes rhythm because it is predictable. It makes the brain feel safe. I recommend using a rocking chair to those with complex pain or traumatised states

where any sort of movement is difficult. (Perhaps our grannies who knitted in a rocking chair with a cat purring on their laps were on to something?)

**Movement** is closely tied in with our sense of safety. Immobilisation increases our sense of fear because in evolutionary terms a sedentary being is more likely to be attacked and isn't safe. But at the same time movement can feel unsafe because of a belief that it is harmful. Knowledge is important here: learning that it's not only safe to move but it's therapeutic. Movement nourishes the body.

Tai Chi Movement for Wellbeing does this through embodied presence and moving within soft limits ( a much kinder expression than 'pacing') to give the experience of movement feeling nourishing, caressing and flowing.

So we can change a person's perspective from one of movement being harmful to one of it being beneficial and nourishing through *experience* rather than *instruction*, which doesn't tend to work. So you as a whole being learn that it's OK, it's safe to go against what your biology is telling you.

We can make movement safer by changing the context within which people move, remembering that pain always happens in context, but also bearing in mind that someone who can walk in the safe environment of a physio department may not be able to walk well outside or in on a crowded street because the context has become more threatening. When people are ready we should be giving them experience of moving outside in nature and in social groups, and think about moving for general fitness. not just to exercise the body part that is painful. We need to get away from a linear, biomechanical approach to movement.

Todd Hargrove in his new book *Movement through Play* advocates this as a way of influencing our complex system. Play involves exploration, fun, risk taking, uncertainty, variability and creativity. Fun, play and laughter are all ways of promoting feelings of safety. I have a session playing with Lego which works really well. People get to the end of the session and they realise they've had fun, laughed and haven't thought about or felt pain at all. I learn a lot about them through this.

**Laughter** is rhythmic, contagious and emotionally bonding.. I show contagious laughter videos and it doesn't take long for a room full of people with really complex pain conditions to all be laughing out loud. It's heart warming and sometimes a shock to them that they can do this. In laughter they find the sudden realisation that there is nothing to fear in the moment. Learning that they can still have moments of enjoyment is powerful

**Gratitude:** I've found that asking people to keep a gratitude diary really helps them to refocus on the good things in life. to re-tune their brains to picking up this information. The brain can get into the habit of focusing on threat; keeping a gratitude diary over time can improve feelings of safety and help to recalibrate those systems. But most people find this very hard at first.

Piglet noticed that even though he had a very small heart. it could hold a rather large amount of gratitude.

A.A.Milne

**Sleep** is included in this section on safety because good sleep is closely related to a sense of safety. Your brain will only allow you to go into deep restorative sleep if you are safe, because you can't run or fight when in deep sleep. Other animals go into unihemispheric sleep where one side of the brain stays alert for danger. This has a

cost to the brain and humans have evolved away from it as our environments have got safer. But we have retained the ability to keep one area, the left cortical default-mode network, vigilant and alert when we're in a dangerous or new environment. In these circumstances part of the left hemisphere is not sleeping as deeply as the right one. Many of us will have experience that first night in a hotel or strange place where we are unable to sleep. Learning that sleep is about a lot more than that moment when you get into bed can be hugely beneficial

Within this you can look at establishing **routines**. These provide a background rhythm to life and the brain likes routines because they're predictable and safe.

**Belonging, social relationships and loneliness** : although I have given these a separate heading they are very closely tied to feeling safe. Going back to evolution - we feel safer in a tribe or herd. Lone individuals will be singled out by predators so everyone needs a tribe. We too have to find our tribe. (Our group is a good starter!)

The feeling of loneliness puts your brain into survival mode, on the constant look out for threat.

John Cacioppo

As a result of loneliness our mode of interaction with others, our verbal communication and body language, changes. This impairs our ability to communicate, make friends or read a situation. People who are lonely can often come across as rude as a result, so we need to bear this in mind. We know too that loneliness increases inflammation and is highly detrimental to health and wellbeing in many ways.

**Compassionate Communities** are being created to address this problem. This has been done very successfully in Frome, a small town just outside Bath. The Frome Model of Enhanced Primary Care was set up by a GP, Helen Kingston in 2013. This project, which is run by the Frome medical practice, aims to reconnect people to their own local support networks that support basic activities of life, such as help with shopping, gardening, looking after pets and transport and provide an extensive range of community activities. It has reduced emergency admissions to hospital by 30% over three years.

Rather than configuring all health services around deficits and illness, this frame grows an economy of wellbeing, configuring recovery and aspiration through quality relationships.

Margaret Hannah

**Social prescribing**, if done properly, can significantly ease the pressure on clinicians who become guides with ongoing support done in the community. It needs to be done with the same diligence as prescribing any other treatment. We should always be asking: 'will this change this person's story? Will it have side affects? Is there anything in his person's story that will interact with this, beneficially or detrimentally? An eight or eleven week course won't heal a life time of problems and ongoing support groups are important to leave pathways of communication open, to support people on their ongoing journey of improvement and to provide a safe haven for those who cannot escape the trauma of their lives where they can forget, laugh and enjoy the company of others, even if it's only for a short time.

**Social Activity Groups** move participants' focus onto the activity. They can help those on margins of society to find friendship and integrate into the community. They can provide a place to learn new skills and knowledge, a safe rich form of social engagement and the opportunity to 'just be' in the company of others - a gentle, safe way of helping someone re-connect with life, under the radar of those protective systems.

**Space** can range from an environment where people feel safe to share who they really are to a safe sanctuary in the home, car, garden shed. It can mean finding a safe space within you when the world is falling down around you. You can find moments of safety in your breath or through meditation or just counting from one to ten.

There are other aspects of space that we need to consider which is why I've included it as a separate category. It is important to put space between the you that is you and your medical condition. People who have recovered from pain or who live well with long-term health problems will say "I've found *me* again!" A programme that focuses on improving wellbeing nourishes them as a person and helps them to do this

Shinrin yoku translates from the Japanese as 'forest bathing' You can find space by being out in nature which is beneficial in many ways.

"If you look closely at the natural world, you may begin to see patterns amid what seems like chaos – unexpected connections thrumming everywhere around us."

Hannah Fries

Just being in nature can help us to begin sorting our own chaos. Patients at Oslo university hospital have access to a custom-built woodland retreat within the hospital grounds.



Spending time in nature helps to reawaken awe; it can put things into perspective.



I experienced this intense feeling of awe on top of a mountain on the South Island of New Zealand under a dark sky. I've never felt anything like it. At the same time as feeling a deep sense of connection with the universe there is a feeling of having your place in the world.

Enjoying space in nature re-awakens curiosity. I sprinkle my wellbeing programme with interesting facts that are designed to create interest and awe in the world again. I ask people to come up with interesting facts or think about what they would like to learn next week.

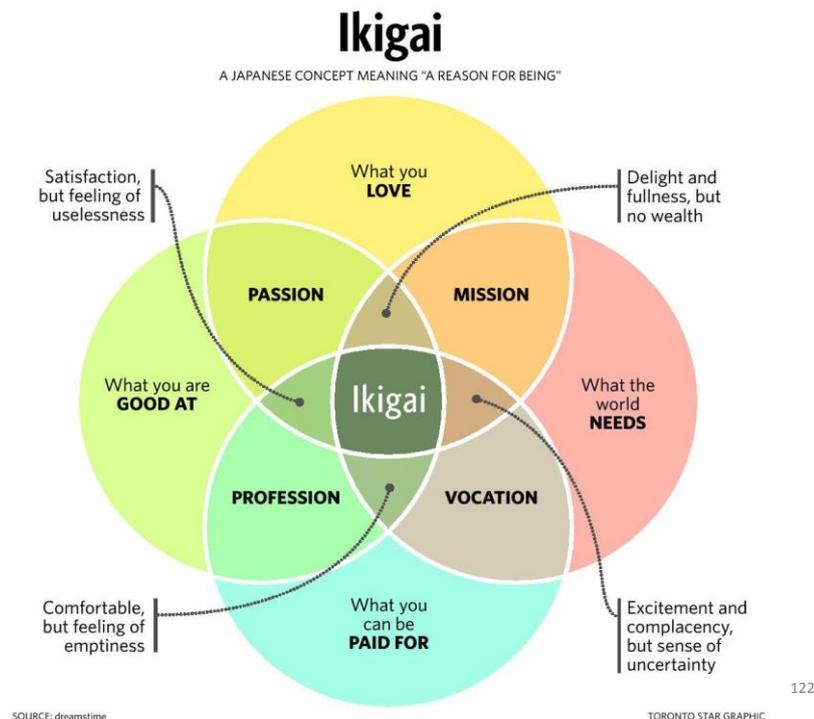
**Creativity:** rediscovering creative ability, can steer us gently away from life's problems and relentless negative thinking patterns. Social creative activity groups can be hugely beneficial for wellbeing. If you're thinking creatively you have more options open to you so it's important to nurture this. Creative activities are *constructive* in what can seem a *destructive* life and world. They may be the first *constructive* things people have done in years.

Creative activities are colourful in what can seem a dark, grey world. They can open up an avenue for giving gifts, helping charities and volunteering. Moreover they have the potential to create feelings of anticipation, excitement – the awakening of lost emotions. They can provide means of enjoying flow, learning new skills and even a way of enjoying moments of solitude to help people deal with loneliness. All these things can get under the radar of protective mechanisms and bring back meaning and purpose.

Creative activity groups also reintroduce the concept of 'being successful'. Many people we see have nothing in their lives that they feel successful at and experiencing success can have a powerful effect and change your personal story. It creates a desire 'to do', a springboard to other activities and the restoration of hope.

All these things help to lessen the load on people and enable them to put their burdens down, to develop interests outside themselves and rediscover something to live for.

**Ikigai** is a Japanese word which roughly translates as reason for being, for waking up in the morning and getting out of bed; the motivation for living life well. Most of the people we see will have lost this. In fact many of us may have lost sight of this under our burden of work.



## Wellbeing

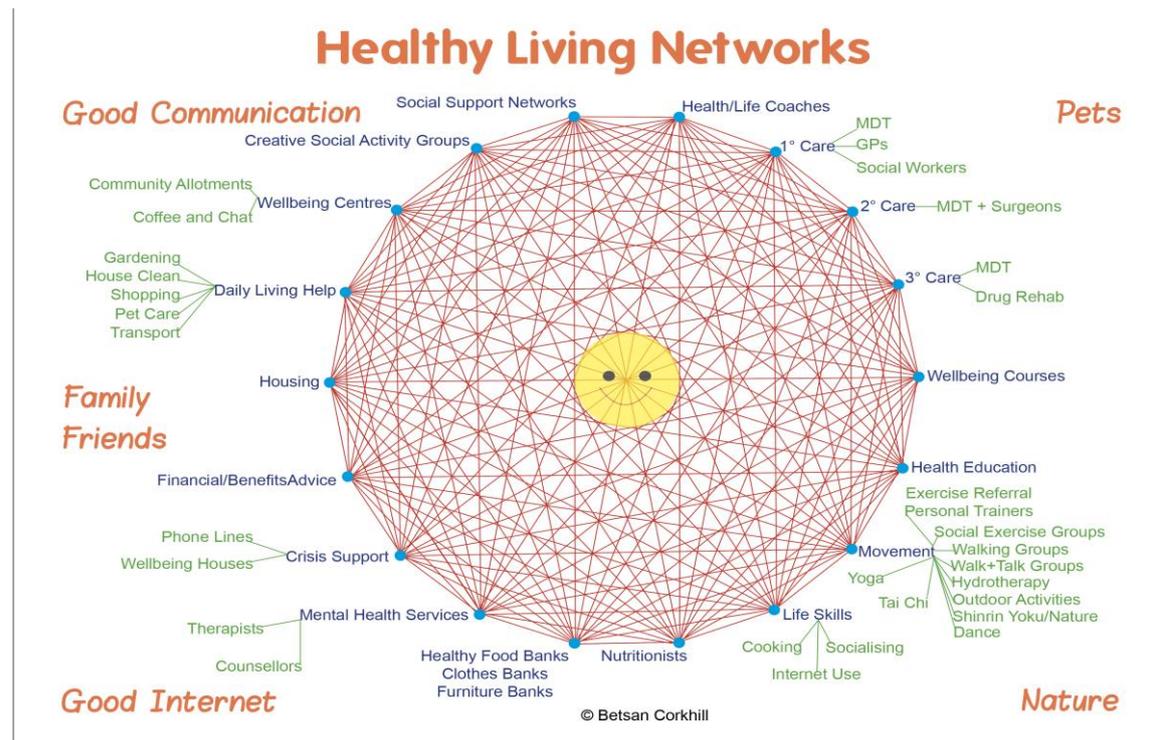
Wellbeing courses that focus on improving wellbeing rather than focusing on symptoms work really well. As well as changing that focus away from symptoms to what people *can* do, they give hope for meaningful change. They can trigger a move from survive to thrive and encourage measurement of success in ways that don't focus on pain.

Within such courses you can share knowledge about living a less inflammatory life and such things as the importance of light and re-setting your body clocks, nutrition and hydration and nurturing the gut biome. Body clocks are not just about sleep. They affect the sequence of physiological processes, so when they are out of sync can throw you into chaos. Many people who live with pain, stress and fatigue consume nutrient poor high sugar diets. (This makes sense from an evolutionary perspective: if your body thinks it will need to fight or run you need quick calories) We know that altered gut biome can alter the experience of pain and opioids can change this.

## How can we ease the load on clinicians?

No one can do this alone. The big drawback of what I'm doing is that apart from a wonderful clinical specialist lead physio I have no local support, yet I get people with some of the most complex problems who have been turned away by secondary or tertiary care because they don't fit linear pathways. The consequent load on GPs is unsustainable.

So we need to develop appropriately trained community resources to provide ongoing support.



This is a 3D network of mutual support with multiple entry points and the person at the centre, creating relationships of trust and respect, reaching out and educating people so that everyone is singing from the same song sheet. (Note that I have included surgeons in this!) The aim is to ease the load by spreading the load. All too often I hear stories from primary care where pain clinics have been seen as a problem, but we need to be cooperating and supplying mutual support and education.

We need networks that support healthy living, healthy relationships and aim for cohesion and continuity, minimally disruptive medicine, shared decision making, values-based practice with no hierarchy or linear pathways. They must have multiple entry points and confidential communication pathways.

This has wider implications because we are all connected. We are also part of the complex system that is the world. Our behaviours affect our wider communities and the world, and that is a constantly changing dynamic

**Ubuntu** is a Nguni Bantu word meaning *I am because we are*. It is:

“a word that captures Mandela’s greatest gift; his recognition that we are all bound together in ways that are invisible to the eye; that there is a oneness to humanity; that we achieve ourselves by sharing ourselves with others and caring for those around us.”

Barak Obama

Those who are struggling to survive don’t have the energy for the wider issues. Survival is their primary focus. They can’t expend energy on climate change or eating a sustainable diet. When we nurture individuals we nourish communities and the wider world.

To conclude: four thoughts for making complexity work.

- Complexity gives hope
- Always consider the whole
- Never fiddle with a part unless it also improves the whole
- Problems in complex systems often have simple solutions that have wide ranging benefits

## Discussion

*There is an ecumenical organisation called Healthy Healing Hubs whose remit is to give churches and Christians the resources, networks and confidence to get back to basics and become places of health and healing for the community. We have more churches than general practices so why don’t we make more use of them?*

I think a lot of such things exist. But people don’t know how to access them, and they aren’t linked up.

*In Berkshire the CCG has taken upon itself to create a directory ..... of the third sector, voluntary groups, charities; all their phone numbers are made available in an online directory which is also available to GP’s . The problem is that this may become another prescription form and that isn’t what the patients want. If it gets too complicated they don’t want to be navigating it along with making decisions. Sometimes they just want to have their hand held and be told that’s what we need to do.*

*My second question is are we better focussing on shared understanding than shared decision making?*

... well, both really. Shared understanding of the issues is really important

*How do we get buy-in from sceptical commissioners, politicians and decision makers who are looking for evidence? What counts as evidence in such complex systems? Trisha Greenhalgh says that multimorbidity is evidence based medicine's nemesis\**

I find the only way to get people to listen is to argue it from a financial perspective. There could be a financial case: the way we are going about it now ... we are seeing more and more people getting sicker and that is costing the NHS and the social care system a vast amount of money. If we could have social networks providing ongoing support systems where clinicians become sort of guides, rather than people coming back all the time for consultations or new referrals ... I don't really have the answers.

*One of the problems is that there is an increasing lack of community in our society. Loneliness is on the increase as more people live alone.*

That is what compassionate communities are doing through the social prescribing network. Social prescribing in NHS Wales much more advanced in Wales than it is in England.

*My practice in Wales has been set up with OT's in order to forge a link between primary care and the community. They have done a really good job in bridging that gap. There is an organisation called the Artisans Collective in Prestatyn who do all sorts of different activities in community centres etc. and collaborate with the OT's to expand what they can offer by directing people into that wider ... it needs to be expanded.*

\* Evidence based medicine: a movement in crisis? Trisha Greenhalgh et al. [BMJ](#). 2014; 348: An essential read

On my Tai Chi programme there were eight referrals from personal trainers working for NHS Wales. They run a range of community exercise programmes from walking and talking to Nordic walking to a six week getting off the floor programme – all sorts of things that GP's can refer to. Tai Chi training is available free from NHS Wales.

*First I wanted to say that your presentation was terrific and what you are doing is fabulous and that this is a real model of how to go forward. I have to say that I have reservations about diagrams like that as a way of explaining things and I would caution you against taking that to the commissioners!*

*I wonder if you have come across the Whole Health Initiative in the USA?\* It seems to have some echoes in this and perhaps something we as a group ought to pick up on. It has been developed by the Veterans Administration. As I understand it the emphasis is in a sense around wellness and salutogenesis but it revolves around the concept, instead of saying what symptoms have you got and what can we do about them, of exploring with people what they enjoy and why they want to be well – what would you like to do? And then go forward in that totally positive mode rather in the negative mode of illness and symptoms. That seems to echo a lot of what you are doing and it might be worth making a link with it.*

*I was talking to a taxi driver the other day and he said he had bought one of these retirement community flats which are supposed to provide a big social network. I asked him if he was any happier and he said no: everyone just stays in their own homes.*

*... conflict of people you are treating or are involved in your group with further issues – we heard this morning about people with health concerns and other things wrong with them. It's very easy to do what you are doing if the health concerns, undiagnosed pathology for example, are out of the way and people are fully on the side of rehabilitation. Certainly in our Pain Management Programmes we get people arriving with unresolved anxieties. Is that something you find difficult to deal with?*

[reply not clearly audible]

*...occasionally you're half way ... and get a neurology appointment that was arranged nine months ago and that has just gone through and that raises a whole lot of other problems and that can be very disruptive*

We try to look at all the labels that people have acquired.

*Another issue that concerns several of the people who have spoken today is that many of the people who present in the pain clinic, who have trauma in the background and have had very difficult childhood experiences and often abusive marital relationships as well, actually strike me as being very strong people. They have battled the circumstances; some of them have been brought along by a very supportive partner, and in that situation they are very stable and secure. We have talked about the alarm system, and I just wonder if when things quieten down in a more supportive relationship whether you start to hear the alarms more whereas before the amount of stress has blocked that. It always surprises me how much adversity people have had and yet ...*

... yes - these are some of the strongest people, who have learnt to live with a huge amount of life events that would sink a lot of people ...

*\*<https://www.youtube.com/watch?v=UINFbJLuSPg>*

*... this morning Deepak talked about people who were psychologically 'frail'. Although there are vulnerabilities this is not a word that springs to mind when you hear what they have had to cope with.*

*When I said frail what I meant that if you are going to put people through an unknown surgical journey, should we be doing something more to keep them safe on their journey? Frailty is a current topic within perioperative practice with regard to elderly frail people and in that sense people are definitely strong but the fact that they are in health care - seeking help for problems that we cannot be entirely sure are entirely structural ... if there are structural things that our surgical colleagues want to change, can we modify that journey to make sure that the outcome is optimal?*

I haven't found them unmotivated - a lot of them are highly motivated but going down the wrong path. For instance a lot of people with ME are on very restricted diets like rice and chicken and nothing else. They may have spent thousands of pounds looking for help because they are not getting the help where they really need it.

*I like to think that we are scientifically sound even though we have to buy in to things like Tai Chi. There is a dark side to the wellness industry such as crappy wacky diets and enemas and stuff which is flourishing because people will go for it in desperation. There was a recent court case of a guy who had a very serious head injury who wanted to go for some extraordinarily expensive and obviously bonkers treatment*

*in [?] and the court ruled in his favour. So how do we distinguish between stuff that we all believe in but can't really prove that its sound while saying something else is nonsense? Scientific integrity is important but you are also involved as a patient advocate guiding them ... 'that's probably worth a go and that probably isn't.'*

*It's a different sort of science. Qualitative phenomenological science, not counting things, is the way round your problem.*

*It's also something intrinsic in us as humans to go for the gesture. There is a story in the Old Testament about the Philistine who was told to bathe seven times in the Jordan to free himself of leprosy but didn't want to try it because it looked dirty.*

*I enjoyed this talk Betsan as you raise some interesting points regarding complexity and simplicity. The idea that simple inputs or interventions may create a cascade of reactions may be heartening or illusive depending on how we view people as objects or as complex interactive beings perhaps. Communication and interaction seems to me to be more like a game rather than an objective fact driven pathway? Neuroscience seems to be shedding light on why and how trust, empathy and hope, for example, may lead to changes in the neurobiology of a person. It's more than the dichotomy between the tea and sympathy brigade vs the needle jockeys. Benedetti covers these points well. As a physiotherapist myself the inner game of tai chi movement you describe and demonstrate may, if you look at the philosophy and just do the movements in a jerky type of manner, be something that sounds a bit ridiculous and what you gain very little from. However, approached with a different mindset and engagement the process may feel very different. I feel the bridge between these practices of slowing down, feeling and also understanding some of the effects (via neurophysiology) may allow us to communicate between patients and care providers a little better. I suppose that this requires an interest to look at these kind of things; safe spaces, communication and movement in a different way, for example, than handouts of exercises*

... There is a lot of evidence for the benefits of social contacts and exercising in social groups. When I was a community physio our job was to go round houses visiting people who couldn't come in to a physio appointment for whatever reason and I was absolutely shocked to find how many people there were behind four walls that we never see. I would be asked: "Mrs Smith can't get out of her chair – will you go and show her some exercises." Now the likelihood of Mrs Smith doing them was zero. *The problem was that she didn't have a reason to get out of that chair.* So I thought maybe helping people to do the exercises in a social setting would be a better use of my time than seeing five or six Mrs Smiths in a day with travelling in between. And I was only be allowed to see people three times and expected to make massive changes.

*I think you have answered the question. It's about misidentification of the problem. If you believe that the problem is that Mrs Smith doesn't exercise her knees enough you're going to come up with the wrong solution, evidenced based or not. But if you identify the problem as one of social isolation and lack of connection then whatever you do to answer that need will help.*

*That is why salience is important. We do have to make the powers that be aware that disconnection, and trauma are issues that need to be looked at. The patient*

*may not need to hear about it in every context but everyone needs to be aware that this is what we have to deal with rather than medicalising things at every opportunity, which is what we do in secondary care when we do the same medical things again and again. If more people say that this is a problem of disconnection commissioners may say what can we do about that; how can resources be used better.*

*Does cost make a difference to the way commissioning is done? For example with interventions: we are told now that there is no evidence for facet joint injections but has that changed anything? People still do them because there are anecdotes of patients responding well and they carry the narrative. You have a place in Milton Keynes which does them for £350, one in Reading for £800 and another in London for £2000. At what point does it become economically suitable to say that two facet joint injections a year to keep people functioning ...*

*... the lack of evidence misses the point - the whole point of that facet joint injection is multidisciplinary. My physio's ask me to do them on certain patients so they can get them exercising and that is what gets them better...*

*... That is the same for Tai Chi and any complementary therapy: we know that it works within a context. So if we can present them within a better cost base would that make them more attractive ...*

*... but my suggestion looks at the action. Just injecting joints won't make anyone better. It's this plus exercise that does.*

*In China, every evening at 7 the amplifiers start up in the street in every town and village and all the old ladies line up for the Tai Chi session*

I ran a therapeutic knitting group linked to the pain clinic for twelve years. It didn't take long for the stories to come out. People changed as a result: some had been attending the pain clinic for 15 years and the clinicians had no idea of their background. They were really profound things that had happened to these people. Little things too – like the woman who used to be locked away in a cellar when she had done something wrong when she was a child, and she needed the lights on in the consulting room to make the consultation more effective. Those stories could come out in an unthreatening environment where they had complete control over simply participating in the activity without talking unless they wanted to.

It's also important to realise that when you know a person's story some people don't want to let go of their pain because there is a link to something important in their lives. Like a lady whose 15 year old son had muscular dystrophy; they knew his life was limited but one day when he was relatively well she found him dead in his bed. She described this as a physical blow. She describes her back pain as resulting from caring for him and this was her connection with him; although she didn't want to be in pain she was reluctant to let go of that link. The only thing I could do for her was to provide a safe space every week where she could enjoy an hour ...

*I am a director of the Shoreditch Trust, a local charity which has developed a series of programmes under the umbrella term community connections. It sees the importance of connections in everything that they do. One of the things I am particularly proud of is that if somebody is referred to them - isolated people with complex problems – and they invite them to a group and if they don't turn up that they see it as a sign of trouble and instead of sending them a stiff letter, ring them up and go round and knock at the door or ask the neighbours. They are very proactive and regard not attending as a sign that someone is too ill or too afraid or*

*whatever. The NHS often treats the most vulnerable people in a punitive way: 'if you don't turn up you're not interested' etc.*

*One of the groups that we have in Durham that patients have told me about is ? NANS ? . Some patients get a lot out of it but a lot would never go again because all they see is what I'll be like in three years' time. It's almost like a disease prophesy group ...*

*... it's the same with some Parkinson's groups ...*

*... exactly. They expect to get someone to understand them – a specialist nurse – but actually, because it's complex, what the patient sees is quite different from what we intend.*

*Often in fibromyalgia groups there is a subgroup of patients who very much appreciate the camaraderie of people with shared experience, perhaps as a form of validation from peers.*

I run a group providing ongoing mutual support for people who have been through the programme which is very positive because they call it the Wellbeing Friends. I do pop in whenever I can ... I was warned against that because it is peer support group which they run themselves but I'm not going as a clinician and I learn a huge amount from that group, just having a coffee with them, and it's just like checking in which they appreciate. But I have found that FM groups tend to be very negative. The group they ran in the Bath pain clinic was called the positive living group and there was nothing further from positive living. It was just comparison of symptoms or drugs all the time.

We never focus on symptoms at all - rather on knowledge, wellbeing; we do talk about problems and pain but it's never 'down there in the pit' and their minds are focussing on keeping as well as possible. They meet twice a month but they may go out together from time to time, for a walk or to art galleries and all sorts of things. It seems to work.

*About four or five years ago the rheumatologist and I got together and started a community support group for people who have completed the PMP. There is some evidence ... [not clearly audible] ... at the end of the course we tell them about the group; a few patients say they don't want to be part of a group but there are others who say the group is my life – I want to go every month. Sometimes they just want to meet over tea and talk about their pain and compare symptoms, other times they want to go out together for a river trip. Sometimes they want to know about some new technique they have read about in the paper and ask me to talk about it, or questions they can't ask their GP so I go along for an hour or so every two or three months. They also raise money for charities and get speakers every month. The numbers vary but it needs about five or ten people to keep it going.*

Do you think if you have a support group linked to a pain management programme people will get together to discuss their pain management? Should we be steering away from that?

*In the PMP in Durham on one day we took them out to the local leisure centre ... [not clearly audible] ... at the end of the programme we introduced them to the support group. Some went for a few weeks and then said they didn't want to be around people who are talking about ..... so the support group never grew.*

*There is a group called [?Face to Face?] on Facebook; younger ones like the electronic bit and the older prefer to com face to face for tea and coffee. It's not linked to PMP or mandatory that they should have completed a course*

*I have learnt a lot about the way a lot of their problems go back – things that they couldn't tell the physio and the psychologist on the PMP. It's useful to have that kind of feedback.*

We spend a lot of time in the knitting group asking how do you feel etc but it's all done in a positive way ... "who here can help?" ... and they work things out together. Another thing which is working really well is to get students from Bath University Health Psychology Master's course and others to sit in on my programme and the wellbeing programme. It works because it is a nice mix of people learning together.

*There is a GP I heard giving a talk recently who has addressed the problems people find in filling in DWP forms and medical reports to get their Universal Credit or PIP (Personal Independence Payment) People with pain or mental health issues sometimes don't say the right things to the ATOS people or whoever and get refused which makes them even more dejected and frustrated. So he has set up something where he fills in the forms and the functional assessment for them in the right way so it gets the point across; so they get their funding and that in itself changes the way they view their situation and their ability to cope.*

*It's incredibly unjust and entirely dependent on where you are registered. Some GP's have the same side-by side method. Some practices employ an expert social worker but others will do the most minimal useless report and their patients will all fail and go to appeal and will be charged £50 for an equally useless appeal letter...*

... I had one lady last week with problems with her hands who was turned down because she could pick up a cup of coffee... another because she had a manicure and didn't look 'unkempt'.

*...80 to 90% of people with mental health problems will fail at the first assessment so they all go to appeal ...*

*...I reckon 90% of my group fail the first time round...*

*... Almost all succeed on appeal but that depends on finding someone to help you who...*

*... [several people talking at once]...*

*... it says tribunal on the letter so people think they are going to court ...*

*... benefits stop with immediate effect so in a couple of weeks you get letters threatening you with eviction, and you have three to six months having no money – begging from friends and family, living in fear of being made homeless – and your pain or your diabetes control will go through the roof...*

*I have a patient who was an ATOS examiner and getting death threats...*

... Realistically if you have someone in their fifties who hasn't worked for 20 years ...

*... If you've been unemployed through illness for a year you have no more than a 5% chance of ever working again, so bashing away at those guys is absolutely pointless and a waste of money.*

*A GP wrote to the BMJ last week about the injustice of the benefits system and I responded by asking what we could do as professionals - to present a united response in a cooperative endeavour with patient groups about the injustice and the enormous cost in increased attendances at A&E and peoples' health falling apart, the time I takes to recover, the lost time ...*

*One of the problems is that there are different levels of incapacity benefit or PIP and the level of mobility allowance you get depends on how immobile you are, so there is a natural tendency to try for the highest level. Inability to work isn't the same as disease. If you haven't worked for a long time, with the current vocational rehab system, you're unlikely to. In this situation the benefits are potentially life-saving but in order to get them you have to demonstrate illness and a high degree of immobility – for instance so that you can get a car to drive the children to school.*

They talk themselves into being in a worse condition on that day and start believing that - it becomes their story

*The whole system provokes disability*

*Is it Finland that ha a universal basic income?*

*They experimented with it for a year or so but the politicians stopped it. The introduction of UBI was deemed a failure but they didn't do it right. It was done in a scattered fashion including the whole population when UBI is meant for certain stepped classifications. The next level is being introduced in parts of India. There are a couple of trials in Africa and they are doing it in a much more careful fashion.*

*You talked about community based work in this country. When I was listening to you – I have used some of those vehicles too - I was thinking vey selfishly about myself. What could I do to get improved social contacts and so on. .Because if we are not embodying the health we want to give to our patients what are we going to give them? Are we working ourselves to death ...*

... It's very important that we look after our own health ...

*... and then we are an example. It occurred to me that when we talk about the [...] space should we study more about what is health? What are the things that define it? What do healthy people do? When we see unhealthy people we need to think how do we increase this rather than giving them medication. I know from those pain patients who just relate to their coffee machines – that's their social network because they don't know anybody. So it's a very limited world.*

We also need to look at people who recover.

*It's not only British people who stay in their own homes and community places. Even when we [in Norway] are in a social situation we don't talk!*

*I like the idea – in NLP (Neuro Linguistic Programming) there is a thing called future pacing, so you start to look forward without worrying how to get there, what you are going to look like when you feel confident and strong; and you get people to have a really strong visual of that – you hear it, you smell it, you feel it – it's like the opposite of feeling yourself down a hole. It can create motivational thinking because your mind is going oh yeah – how can I get there, without having to really cognitively figure it out.*

*That is very like the Whole Health approach which I really think we should learn from...*

*... AXAPPP Healthcare have started a whole health insurance...*

*... brilliant!. It's a form of evidence too; the government will begin to think quite seriously if the Americans are running with it within the VA which is the nearest thing they have to an NHS.*

*..... mindfulness for treating depression from Canada but when the Oxford GP's tried to put it into place it failed because all they had done was import a process. They hadn't done the mindfulness courses themselves. I look at what I do in a clinic and there are some days I sit all morning ... I listen to people and there is a huge almost toxic overload ... We have to be compassionate to ourselves because if we're doing that then what authenticity is there for what we're doing ...*

You need to go into a diabetic clinic to actually see nurses giving out advice to diabetic patients and they are probably about 20 stone ...

## Integrating the Art of Healing with the Science of Curing

Paul Dieppe

Much of what I want to say echoes what Jonathan and Betsan were saying yesterday, but it's just framed rather differently.

This may seem a pretentious title but I feel reasonably safe here to talk about healing - I don't feel so in many of the medical audiences I talk to – but you are enlightened – or are we?

In yesterday's outdoor Yoga session with Gillian we were encouraged to feel the energy flow in our bodies, but when we come inside we put that all away and go back to our science; we make obeisance to the god of science and make comments like "we need more scientific evidence to support this sort of stuff" and keep these parts of our lives separate. That's a very weird thing to do. It's like we're living in two separate worlds: we have our very clear scientific one, and our messy one that is about human experience. The first is dominated by our materialistic positivism and the other messy metaphysics. Even though we are relatively enlightened compared with many we are still struggling with this problem. It's a conflict between our belief in science and our everyday experience of what it is to be human. We do have confusing experiences all the time, and Betsan alluded to this yesterday when she talked about what I think would be called a noetic\* experience; one of those moments of sudden understanding of the connectivity of the whole universe and our connection to it. Moments often of pure joy and delight which most of us experience occasionally in our lives. These get dismissed by our science as 'suggestibility' or some psychobabble nonsense of that sort but they are very real and powerful experiences. But when we come to our medical world and our medical praxis we dismiss this as nonsense.

### The Healing Project

This project is in a sense trying to bring these two worlds of the metaphysical and the materialistic together. I deliberately put the messy metaphysical one in front of the materialistic scientific one as it is its rightful place. There is a group of us working around this project: myself, Sarah Goldingay who was here four years ago; Sarah Walber, a primary care doctor in the US who is also trained in North American Native healing; Emmylou Ratz who is a social scientist by background and was here two years ago; Natalie Harriman who is an extraordinary polymath and others. We have been funded by the Institute of Health in Baltimore, although only Emmylou is paid.

The project is trying to understand what healing is and ways of integrating it within our current scientific approach to medicine. I sometimes get accused of being anti-scientific but I'm not. The science of medicine has been fantastic in many ways but it's also rubbish about some things such as many of the issues we were discussing yesterday such as chronic disease and multimorbidity, and people for whom we need to integrate the art of healing which of course has been around a lot longer than the science of curing.

\*Of or relating to mental activity or the intellect. OED

I want to start just by talking a wee bit about the difference between healing and curing. My own ideas about what healing is about are evolving all the time and my present position isn't in any sense final. It's a journey of understanding. It has moved a bit since the last time I spoke to you. When I talk to medical audiences I find they can't get their heads round this difference.

It's reasonable to say that curing is about pathology; our obsession with pathological processes and the need to get rid of them so we can restore the body and mind to its previous state or something we strangely call normal although I don't think anyone knows what that really means. But it is this sort of mindset of – oh well, if you've got pain or some other symptom there must be something driving it and which we can attack with our science.. Healing is completely different: first of all it's not just body and mind: it is soul as well, and it is about a journey to a different to a different state of integrity. It's not about restoring normality, it's about moving to a different position. The soul/spirit thing some people find tricky but for medics one of the ways of best understanding this when you deal with people with severe dementia. If you've got this, your memory and your reasoning go; we all define ourselves by our memories and our ability to reason so the mind bit has gone. *But they are still in there* and through things like music and approaches one can still make contact with that person, and the essence of who they are – their soul – is still intact. That is a powerful reminder that we are more than body or mind.

You can die healed or be in chronic pain but healed. Thomas Egnew defines healing as transcending suffering. It is also an experiential issue which again makes it tricky for our scientific approach to life. I have been fortunate enough to have experienced healing in both directions, so to speak. My first experience was going to see a healer I had heard about, a lady who works from her front room on recommendations, not for money, just to help people. When I told her I wanted to learn about healing she said I would have to experience it and asked if I had any problems which I did and she healed. That was a bit weird but a few years later I was with a group of healers at a meeting in London and one said she was a horse healer; I expressed a little bit of scepticism so she invited me down to the stables a few weeks later. She showed me a big horse and said "OK Paul, I want you to heal it". So I healed it. And that was kind of weird, but for me there is no going back. And that is the power of those noetic experiences: you can't go back or deny them. You have to incorporate them into your ontology and your way of thinking about the world.

We have been exploring what other people think it is all about in a variety of ways. We use qualitative research within a phenomenological framework. We ask all sorts of different people to tell us what they think healing is all about. Doctors find this tricky particularly when they are in groups when they generally won't play, but if they are on their own they often will. The group dynamic of medicine doesn't generally allow people to accept healing. We have a number of techniques and I want to try one on you - a simple game. It is one I have used with medical and lay audiences: complementary medicine, and where we have shown exhibitions about healing in hospital for medical staff.



Your word will probably be in there. It includes lots of words that were being used by Jonathan and Betsan yesterday. I was very surprised that medical people had love as their biggest word. How often so we talk about love in medicine – in medical schools – in our clinics?

Another technique we use is to ask people to tell or to write stories. It's tricky to share this as most of the stories I have are long. Recently, my wife and I were in Finland doing an exhibition and we recorded some of these stories for audio use while looking at it. There are three elements in these stories which are very common to descriptions of healing events by energy healers (In this country there are a lot of healers who call themselves this, or spiritual or Reiki healer. In the US it's often called healing touch although it doesn't actually involve any touching but it's all much the same thing.) Firstly It's very strange; experientially it's very strange. Secondly, people often describe becoming 'a completely different person'. This is not about getting rid of pain; it's not returning to normal – it's a complete change. The third thing I wanted to pick out is the energy in the patient. Healers commonly say: "it's not me – I'm just a facilitator of energy change. They talk about energy in a variety of different ways; it is obviously a difficult concept for those of us who like to be able to measure things.

We also use pictures a lot and I think this is the most powerful instrument we have for helping us to understand what healing is about. The words are from medics, the stories from healers, but the pictures are all from members of the public accosted in various places such as museums and the Eden Project, but not in medical settings. We ask them to give five minutes of their time to help with our research. If they agree we give them crayons and paper; ask them a question and if an image comes into their mind we tell them to try to draw it straight away. We say: "don't try to analyse the question, just go with whatever image arises." So we ask: what does the word healing mean to you? We record them so they can talk it through and get signed consent at the end (not at first as that would 'prime' them so they would start analysing the word.)

Common themes in these pictures are healing from a great external source of energy illustrated by, for instance, a drawing of the sun: healing coming from other people with images trying to convey some sort of concept of an interchange between individuals. Hearts are a common image of love in your heart or something that comes from within, and the idea that you heal yourself from within through love and compassion. Some people tried to express rather more complex ideas like healing as a growth towards wholeness which requiring energy transfer from a great source outside the self. And a journey from chaos to order or from fragmentation to integrity. Some people draw circles and say it is about wholeness

Emmylou Ratz has analysed all these data and recently published it (We had great difficulty in getting it published). There are three interacting themes: healing coming from externally, healing about connections with people and healing from within. Many people have a sort of composite of that which brought together those three strands. Some people described it as an outcome rather than a process but most were on the process level.

We think that the language of healing is metaphor because it is experiential and difficult to explain and understand; and drawing pictures is the best way of expressing the metaphors that mean the most to you.

## Healing in Clinical Practice

The next section brings us back to the subject of my title. If the foregoing gives us an idea of what healing is about and what it is: this concept of assisting people on a journey to a new state of integrity, of transcendence of suffering, and wholeness of difference, and is understood by the public in spite of all the tutoring they get that all they need is more research and stem cells - if that is how it is, then how can we facilitate this in our patients?

What does the literature tell you about this? There is, actually, and some people find this weird, a hell of a lot of literature and a lot of it has been written by doctors including John Scott in the USA, Annemarie Churchill, David Schenk and Eric Cassel in Canada who have written beautifully about healing and the practice of healing in their clinical world. There is also a huge amount in the nursing and sociological literature. So the subject is not without proper study; there are loads of RCT's to show healing intention works not just in humans but also in animals and even plants. But that somehow in general we don't go there in our approach to medicine. And nobody takes any notice of evidence unless they believe in it!

“A man convinced against his will / is of the same opinion still”

Dale Carnegie

You can have as many RCT's of healing as you like but people will still dismiss it as nonsense because they can't understand it.

What then does the literature say about healing in our patients and our clinics? Actually it says pretty much all the things that Jonathan and Betsan said yesterday: safety, being present in listening, body language that conveys caring, and being human and caring. It involves the polyvagal stuff and the importance of high parasympathetic tone not only in enhancing a feeling of safety but because it affects your communication system; the way you speak and what you hear. If you say the word 'cancer' you get a high sympathetic charge and people don't hear anything else. We need to pay far more attention to the spaces in which we practice.

Being fully present is hugely important. We are very bad at this in medicine and don't properly prepare ourselves. There is some evidence that doing mindfulness exercises before seeing patients improves their outcomes. So there is actually data to suggest that we in the right place ourselves so we can be present in the consultation.

Body language is another important matter: maintaining eye contact, touch, smiling, finding something to love, not judging – the things that Churchill and Schenk identified as facilitating healing in clinical encounters.

## Validation and invalidation

I want to give you a slightly different take on validation and invalidation. I think it was presented slightly wrongly yesterday as a feature of *us* validating (or invalidating) people but it's not about that; it's about the patient and *their* perspective. There is a

lot of talk regarding compassion and empathy which again is about us, but the important thing is what the patient thinks about what is going on, not what we think we are doing. Validation happens when the patient knows that the doctor understands them and cares for them, and invalidation is the opposite. When we are being compassionate and empathic we can often invalidate people. A classic example one of my PhD students picked up in her research is when a doctor says "I don't think it's anything serious – it's nothing to worry about", that can be very damaging because it's very serious to them. They think: "it may not be serious to you, doctor, but it's bloody serious to me and you obviously don't give a shit". Maddie Harris (the student) and I wrote a paper about this some years ago and showed that damaging through inadvertent invalidation is five times more powerful than validation.

So I think we should concentrate on the nocebo effects of invalidation more than placebo and validation because if we just stop making people worse as medical professionals the world would be a better place.

In the context of being human and sharing it's very important for us to be able to switch between the professional, expert mode to just being another person in the same confusing world.

What do healers say? I have interviewed many healers and what they think is pretty much the same. Few of them could give a monkey's about evidence or literature; it's all experiential – it 'just happens' - for them, and find it very puzzling that I want to try to understand it. But if you try to pin them down they seem to think that the same things are important. My sort of summary and analysis of what a large number of healers say about how to achieve healing is that it is focussed attention with good intention, unconditional love for the other, and making sure that your ego is not present. The last is a crucial one we don't talk about much, and it's the one that personally I find the most difficult because my ego is all over the place even when I am seeing patients. And that makes me anxious about trying to be a healer myself. It's part of our background, our education and our way of thinking - a lot of this is about us, and healers tell me that if it's about you it's all over. Some of them say they have had to give up their healing practices once they found their ego is getting into the room.

All of these are important. The concept of unconditional love may be a difficult one for science to deal with but all these things are necessary to allow people to heal.

So, in sum, healing is real, it has good evidence behind it, it's relatively simple conceptually and fits with what we would regard as good clinical practice, and we should take it on board and incorporate it fully into our practice. The problem is that we can't understand it so we reject it. But the science of non-locality gives us a potential way of understanding it and bringing it all together. I think it's about connectivity. Non-locality was introduced from quantum mechanics some time ago but is now gaining ground through neuroscience. It links with Ubuntu which Betsan mentioned yesterday, a Nguni Bantu term meaning "humanity." (or "*I am because we are*") but which is often used in a more philosophical sense to mean "the belief in a universal bond of sharing that connects all humanity." That idea has been present in every community since Adam was a lad until science booted it out. The essence of non-locality is that the universe is consciousness; that is the primary thing in the universe and the physical world is a product of consciousness. That was actually said by Max Planck, the originator of quantum mechanics. I don't quite understand what it means but that is the idea: this table, me – we are all products of consciousness. Our brains don't *produce* consciousness but they help us to *connect* to it. The idea that

our brains produce consciousness is a relatively recent one which neuroscientists like us to believe in but not only is there absolutely no evidence for this but there is quite a lot of evidence against it. There is quite a lot of evidence that we connect in different ways with each other through an external link to consciousness and not by the brain producing it. Neuroscience is now catching on to this. For me this is helpful. People yesterday were saying how helpful they found the development of ideas about traumatic childhood events in thinking about peoples' problems, and this concept has for me been extremely helpful and freed me up. If you are keen to read more about this I would recommend two books both by doctors. In *Proof of Heaven* Eben Alexander describes an extraordinary experience: he is a young American neurosurgeon who developed a bacterial meningitis and was dead for a week. Because he was a doctor they kept him alive for too long but they were just about to turn off the machines when he showed some signs of recovery and he recovered. During that week he was in the heart of consciousness. Near death experiences are very interesting; they are much the same whoever you are or whatever culture you come from and the stories are very similar. Eben Alexander being a neurosurgeon decided that one of the things he would do with his experience was to destroy the physiological theories. In *Proof of Heaven*, he goes systematically through the reasons why his near death experience cannot be explained neurophysiologically. He is now, like other people with such experiences, devoting his life to the understanding of consciousness and connectivity in the universe and has given up neurosurgery, and his second book is about that journey. Larry Dossey is a Californian physician who has been researching and writing about healing and paranormal phenomena for decades and edits the journal *Explore* which is devoted to the science of healing. His book *One Mind* is about how the individual mind is part of a greater consciousness and why it matters. It is still a very good introduction to the concept of non-locality as a way of helping us to understand healing phenomena.

*Healing Matters* is the title of our website which is about to go active

## Discussion

*You talk about the medical profession and healers, Could you say a little more about the connection between the two. I presume there are medics who are also healers? Is that something which could be promoted?*

I made a differentiation but of course there is a huge overlap. Many GP's that I have met have a profound understanding of healing and use that within their practice of medicine. Very few hospital doctors that I have come across are in that mode. When I talk about this to mainstream medical audiences I get given a bad time so I tend to be a bit defensive and make this unnecessary division between medicine and healing. I think people are a bit frightened of it. But individuals, generally GP's, will side up to me when no-one is looking and whisper "I think you're right and what I think is...." I have in fact formally interviewed a number of GPs who are very insightful about all this and from whom I have learnt a lot. And nurses as well - a lot of them and palliative care staff completely get all this.

The difficulty is that it is not in our educational canon; it's a bit like combining homeopathy with medical practice, and I actually think homeopath is one vehicle of promoting healing.

*I wonder if it's necessary to have the vehicle ...*

... I think not - it's about the intention and love for the other person....

*I have colleagues who I don't see very often but I would say that they are healers: their approach and interactions ... and probably love ...*

Guys like Churchill and Schenk, who I have mentioned, are definitely healers.

*Perhaps there is a lot of that going on within families in an informal way? If they care about the person very much and are around ...*

I agree entirely. In the word cloud of the public perception of healing family and friends are rated as important as healthcare professionals.

*Can you have anti - healing through ill intention?*

That's a really interesting subject. Gillian probably knows more about this than I do but the answer is yes. The one that is often quoted is Voodoo death.

*You don't need to look so far for anti-healing. Something I come across in my daily work with jail-birds: people who have been sentenced by the state to something which is going to harm them. And then you have prison doctors or people like me who are ostensibly there to heal them, so you get this weird working across ... you're in prison because you have done a terrible thing and society is trying to harm you but at the same time you are going to need to say you are too sick to attend court or too depressed to be sentenced ... so there is this very odd division between your role as healer and your role as agent of the state which is trying to harm them, which is very uncomfortable.*

*What was wrong with the horse? – if that wouldn't reveal anything confidential!*

I don't actually have the horse's written permission! ... I had actually been to a course on training to do energy healing and there are certain sort of rituals you go through: centring yourself and connecting to the universe and then involving the other person into your orbit with good intention; I had learnt the rudiments of how to do that. This woman took me to the horse and told me to do what you were taught in the course. It was stomping around and snorting; I did all this centring and connecting stuff and ... *and I was at one with it* in a very profound way. It stopped stomping around, it relaxed, its ears went up and its behaviour completely changed. Then I started to get terrible stomach ache. But I stayed with the horse until it looked as if it was about to fall over and the woman told me to disconnect, which I did, and its ears went back and it started stomping around again. And I was left with the bellyache and a very confused experience. I told the woman about this and she said "ah yes, I didn't tell you that the horse had digestive problems." It was a very profound experience. You can't ignore that sort of experience or go back from it.

*I had a similar experience with a horse; it was locked in a garage and it was awful ... I just stood for a while and tuned in to it, and it was just like you said ...*

*I was interested in your connection of the sceptical world of science with the world of spiritual healing. Healing horses and having transcendental experiences is probably the high hanging fruit, and maybe the low hanging fruit is to just stop invalidating patients. Are there any other experiences of low hanging fruit that we might focus on?*

*There is a really good book called Healing Conversations which is all about the conversation that goes on underneath the one you are actually having on the surface. If you tune in to that it really helps with the connection.*

*I am thinking about my role as a medical educator and leader in my practice.*

The most important of the low hanging fruits is simply the power of caring.

*[partly audible] ..... about 40% of the improvement after psychotherapy is unexplained. I believe that this has a lot to do with the patient – the patient's ability to get better with or without any psychotherapy, but especially with a caring person being there as a [?... ?] object..... Another quote I was reminded of when you talked about how we can facilitate healing by being fully present and listening: Wilfred Bion, a psychoanalyst, gives an instruction to psychoanalysts to attend every session without memory and without desire so you are fully present, you don't remember what you have learnt or know about the patient or have any desire for them - you are just there for them, whatever they need. That is a good illustration of being fully present without the ego.*

*... I went into medicine because I thought I was a good kind empathic person ... I find that if I have an understanding of a person may be the way they are I am less judgemental ... unless I understand that they are caring for their Mum who is ill and that transforms that situation ... for me the understanding is not so much about me helping the person, although it sometimes helps them to be compassionate to themselves, it about helping me to give them that space and to recognise that my understanding is limited, and therefore there are things which I do not and will not understand, but I have to give that space and not jump to judgement.*

One of the things in the literature that health professionals write about healing is the advice never to judge someone else because we never have sufficient knowledge of them to make a judgement. I have to admit that when I was still seeing patients I found that very difficult - because we do it all the time, even just by looking at someone in the street with no knowledge of them at all. And to try to rid ourselves of that mode of thinking is important.

*There is always more going on than meets the eye*

*Regarding the possible harms involved in healing etc.: I grew up in South Africa where we had traditional healers. When I was working as a houseman we would tell someone they needed surgery for their breast cancer and they would ask why have they got it? - and we would say we don't know, so they went to the sangoma for an explanation. In that role they had a wonderful traditional function, but probably because of the confusion between healing and cure we see tremendous harms because they start interfering. Probably part of the traditional scientific approach sees the interface between people who don't understand the difference between healing and cure. I had a brother-in-law who was a healer and he probably didn't understand it and I used to say to him why don't you go to the paraplegic ward if you can do what you claim? But that was in terms of cure rather than healing. There is that sort of blurred ... are we romanticising ... the scientific evidence is the pinnacle of what our approach should be in terms of healing.*

There is no doubt that healing can be harmful if it deprives people of medical interventions that would save their lives and a lot has been written about that. It is one reason why healing and healers get given a bad time by the medical profession. Without doubt that happens but I don't think it happens very often in this country.

There is a lot of use of healing for a variety of a forms of complementary and alternative medicine in addition to Western medicine and that is the usual model and I would encourage those of you in practice to ask your patients who else you are seeing. You have to ask specifically about healing as people are often too embarrassed to admit going to a healer but they often are. That can open up that conversation beneficially to both sides.

*Sometimes people aren't interested in cure - they're on a different path.*

*Can I illustrate with a patient I saw a couple of years ago that made me feel profoundly queasy. She is very happy for me to share her story. She was a woman who was an extremely spiritually engaged person and a serious Yoga practitioner who developed breast cancer about 15 years ago. She declined surgery because she felt it was violating the integrity of her body, as she would describe it. And then she declined oncology treatment or radiotherapy. She continued to decline treatment as she deteriorated and developed local chest wall and distant metastases. Her pain was difficult to treat because she declined morphine because of the sugar in Oramorph and Oxycodone. She continued to use her Yoga and her chanting. And then she died, but not before I had a conversation with her about whether she would agree to my sharing her story with audiences such as this.*

*I felt profoundly ambivalent about this particular case for three reasons: the first was that she was a kind, generous and spiritually open and available person with not a shred of the kind of hostility that you will occasionally encounter in people with those kinds of convictions, but described without rancour her continuing feeling of being sacked by her oncologists and even her palliative care physicians because she couldn't accept the treatment that they were offering, so her feeling was one of rejection. The second thing was ... I find palliative care in the community - despite what the palliative care movement says how manageable everything should or ought to be - my experience of managing palliative care patients in the community is always like landing a WW2 bomber that has been shot up - things constantly go wrong and it demands every aspect of your medical skill. But she was by a long way the least complicated palliative care patient I have ever looked after in that her pain was less pervasive, her fear was less pervasive, her open-eyed ability to navigate her own death was unlike anybody I had ever met - possibly because she had thought a lot about death over the previous ten or fifteen years. The dose of morphine some of which she was spitting out was only about 2.5mg qds for her advanced breast cancer and this was knocking her squiffy. It was extraordinary how little she needed my medical intervention. I am not in any way advocating on her behalf because I think it is possible that had she had treatment 15 years earlier her outcome might have been different: she might have lived for longer and her morbidity considerably less. But it really made me rethink everything I thought I knew.*

She arguably died healed...

*... although she was way off being cured.*

One of the things that most shocked me when I started this research - I did start by talking to some of the doctors and GP colleagues who were interested in healing, and I would ask them to tell me about a case of someone you have worked with who you would describe as having been healed. And within the first ten people I interviewed two talked about someone who had died healed which I found very surprising. One of the stories was not a million miles from the one we have just heard.

*I was struck by what you said about moving from chaos to order and fragmentation of integrity. I would say that people who struggle with long-term health conditions are in chaos, and everything in their lives is in chaos. But when they become healed then there is somehow a unifying where before they were somehow fragmented. But I can't explain how or why because other things in their lives haven't changed very much. It happens within them.*

I can't explain it either. The person who drew the picture illustrating the move from chaos to order told me that was the story of her life. I didn't get any more information as when we do this sort of stuff we are not doing formal long interviews or getting a full medical history, we are just spending five or ten minutes with a member of the public. This was not the only person to have articulated this concept using a variety of words - the words are tricky with this sort of stuff.

*My observation, which may be right or wrong, is that not only are they not living in their bodies, they're not living in their heads either – they are living outside both. When that healing happens they somehow connect to themselves as a person again.*

I was also struck by something you [Betsan] said yesterday: that people say "I'm me again", and that somehow nails a lot of what healing is....

*... and being really comfortable with that ...*

*... a politician ... talked about her mother who had really bad hip arthritis and went to a healing service and the pain went away and never came back. About ten years later the other hip started playing up. She saw a surgeon who said this hip isn't too bad but the other hip is terrible!*

*The other story is about a London surgeon who wrote a book about some of his experiences; one was about a memorable patient who was dying. It took him a moment to pluck up courage to tell her she was going to die and probably wouldn't go home. As he was about to tell her she smiled and said "I'm going home!" He replied "I'm afraid not – I think you're going to die" and she said "oh no – I'm going home to heaven!"*

As you know I have been talking as an ex-rheumatologist who used to take a lot of interest in pain from osteoarthritis. One of the first observations that took me in the journey I am on from being a fairly conventional academic mainstream rheumatologist to someone who dabbles in the weird world of metaphysics was that peoples' joint pain had no correlation to the pathology in the joint. That does disturb the given order of things.

*I still can't weigh all the different cognitive biases, especially tradition bias. I have smashed my knee up several times and I am very aware of how pain comes and goes. The injury is painful but the journey afterwards is unpredictable. If someone comes along and says I've had healing and feel better then tradition bias suggests it must have been the healer but the fact is pains do come and go. That's the nature of it.*

Of course that's absolutely right. Part of our work on healing has been in Lourdes. None of our group are religious or have a Catholic upbringing, but it is still fascinating to see what goes on there which is a very powerful healing experience for many people. Again there is this confusion there between healing and curing. All the stories are about miraculous cures of which there have only ever been 72 out of the six million people who come every year looking for a cure. But the number of people who get healed is huge. The attribution issue became very clear to me when we were

working there; if there was a change it was almost always attributed to the Virgin Mary, whereas you and I would have attributed it to something else.

The attribution issue is a real one but it doesn't alter the phenomenology of people getting better in a way that we don't understand. You, or the people in Lourdes, can use whatever attribution you or they like, but I prefer the attribution of connectivity with the universal consciousness. It's up to you what ontology you want to work with here. What does bother me, however, is the arrogance of biomedicine in saying that there is no other way and no other explanation. That's what I get angry about and why I may seem to be dissing medicine.

*The marketplace of alternative healers is not a benign, caring field of goodwill and compassionate kindness. It's an absolute snake pit of scams ... getting people out of their homes...*

*There is a potential to understand how both might be relevant. When we heard yesterday about trauma and how that results in alarm systems going off. If you look at some of the basic science of pain and analgesia studies you come across conditioned pain management, which is where if you have a pain problem and introduce a pain somewhere else in the body, for instance by blowing up a blood pressure cuff, the normal body response is to produce analgesia and alleviate the original pain; but in people with fibromyalgia for example you get the opposite response so introducing a pain somewhere else makes the pain worse. It doesn't take much to think that that is perhaps happening by the trauma causing changes within the body and altering such a fundamental response. This also may explain why old people respond better to pain than younger people. So there are connections between healing and the biomedical stuff, and we should be looking at those and trying to understand them. The idea of integrity makes a lot of sense.*

*... That works on both sides as there are a lot of challenges around ...*

*... it's about how we value ...*

*In her book Knocking on Heaven's Door Lisa Randall, the theoretical physicist, who writes in terms of science and reductionism, particle physics and quantum mechanics, makes the point that if there are energy transfers [involved in healing] we should be able to measure them; if you've got a kinetic effect or actually implanting something you should be able to measure it. But obviously we can't measure those things because they haven't been found. And then she talks about religion being in the realms of philosophy where we attribute whatever and so it's not measurable; it's the way we ask not what is actually happening but why or how. That is the difference between science and metaphysics. So churches shouldn't be pronouncing on this stuff. In my own mind I can separate out the two and I don't have a need to try to create some other new energies some other alternative realm.*

*Have you talked to neuroscientists about this or are they among the ones who are arrogant and won't believe anything if they can't measure it?*

Yes, but then there are a lot of neuroscientists who are working on non-locality and doing some very cool experiments with MRI scanners showing that people can connect across space. A lot of them are taking on the concept of generalised consciousness and trying to use things like functional brain scanning to show that.

*We have also moved away from natural intuition or instinct which is a shame because what you actually need is 'but'. I feel that learning to get in touch with that part of yourself is vital because that informs you on all those things.*

We could actually do an experiment during one of these meetings. There is one quite simple one on the power of good intention which is to sow two lots of cress and fire good intention on one and bad intention on the other and see how they grow over the three days.

*... back to what Tim was saying about recovery and people who have recovered but still have pain: they changed as people and have found their 'me' again ...*

... yes ... absolutely. We recently did some work with a group of people who were identified as having been healed from disease by their general practitioner in the US and we found exactly the same: that they had integrity and wholeness and were 'me' again. Their diseases hadn't gone and they still had symptoms but it was OK. That is an important part of the understanding of this. And this could be so powerful in pain medicine. It's a bit like morphine – you still have pain but you don't care. In a sense, healing seems to be a bit like that: you still have your symptoms but they don't matter so much ...

*... Less 'bothersomeness' ...*

*... it's relief from suffering ..*

*It took me an awfully long time as a pain clinician to realise that it's not actually about pain, it's about people coping with their pain. What we are seeing is the reaction, not the stimulus, and so much of what we are taught about and programmed to try to do is getting rid of the stimulus, the pain.*

*It's very much like that with treating psychotics. The psychiatrist comes round the ward and asks "are you still hearing your voices?" and if the answer is yes they just put up the dose of the antipsychotic. A patient of mine was in a ward and this was happening and she was getting more and more out of it, and the woman in the next bed said: "You've got that all wrong – you've got that all wrong; you've got to tell them that the voices have gone and they'll stop doing that! So she did that and they reduced the dose and the voices weren't bothering her! They weren't listening to her ...*

On interesting thing I have learnt in talking to healers is that they hear voices and see things and connect with other people in ways that are very disturbing for them. I managed to connect with the horse ... it's very powerful ... I have connected with other people a few times in my clinical career, but healers who work with this and trade on it an train themselves how to do it are very sensitive to other people; they can 'switch in' to another person very easily; they hear the voices of other people and see things. So in a way they are schizophrenics; they don't like to talk about these things to people like me because they think that they will get they will get Largactil as well . They are genuinely quite frightened of revealing their experience of the world.

*I was wondering about your encounter with the horse: you explained that you had stomach ache without knowing that the horse had it: how do you explain that and what role did that experience have in the healing of the animal?*

I have no explanation. I don't mind that I have no explanation, and I have no idea if the horse's stomach ache changed.

*In psychoanalysis the phenomenon that you describe is called somatic countertransference and it gives you information about the body - in this case of an*

*animal that can't tell you about ... but when there is a person there we can hear behind the words and hear what they cannot tell - which is not in their conscious thinking - about early trauma which may have occurred even before they developed words. So that is a skill but it is also scary and a very difficult experience.*

*Healers talk about that commonly and in the context of physiotherapy those reactions are very common. I understand it a bit from reading about it but never had any education about dealing with it. It's a very difficult subject to communicate to other people, first of all to colleagues but also to people you are trying to help*

We did talk about that and the emotional stuff and they [healers] will say that ... I have had so many weird experiences with healers ... they will suddenly stop themselves in a conversation and say "I can feel you're not happy with this". They will pick up on some emotion you may have and express it and you think ...bloody hell, they can read my mind!

*The low hanging fruit that Jonathan was talking about has been cracked to huge effect. In a hospital environment we've got lots of people with very longstanding complex problems and all this big cakemix going on. Without a private space to practice in it's very difficult to create this safe space. This is a very practical matter that needs to be addressed.*

For us mere mortals ... the healers don't seem to care about the space. They care about their presence, not it's environment. Actually that's not entirely true; some of them do this business of clearing medical images out of the space they are working in before they start.

## The Future of Pain Management

David Laird

The psychologist I worked with for many years said to me that it was not events that changed us but our response to them. I hope that my words will be true, may inspire, be necessary and kind. Shakespeare said the past is prologue, but what is the future for pain management? (as it has also been called palliative care for those who are not dying) We have here a gathering of experienced specialists - mostly doctors but psychotherapists and psychoanalysts and others: a great meeting of minds. What is philosophy? Literally it means the love of wisdom. Bertrand Russell said it was that which occupies the state between science, with its empirical nature, and religion. What about ethics? That is concern about something or someone other than ourselves. We know that medical ethics is first about non-malevolence: first do no harm; next beneficence: be good, promote autonomy by maintaining agency, looking for justice, being fair and offering equality.

When winter walking in the Scottish hills it is imperative to know where you are before setting off to where you want to go. So I thought first of all we would explore where we are before looking at the potential future. Each pain service is different locally but some things may emerge. I thought we would apply the assessment model I use for patients where we apply specialist knowledge to identify the patients' needs and condition, and are aware of appropriate therapy and can negotiate advance plans for treatment .

*The audience was then invited to divide into twos and threes and chat about their local pain services, about what is effective and ineffective in its function and process, whether its structure is fit for purpose. Are there dynamic factors which are continually changing? What about accessibility, outcomes, staffing, resources? What is the value of their input into your hospital*

So what sort of things were came out of this exercise about effective functioning? Points from the audience included:

- Integrative working with local primary care or secondary care within the hospital – or with tertiary care so you can refer onwards.
- Are we competent? – supportive? – responsive to needs? Do we make a positive impact to the trust, our local health economy while caring in an empathetic and compassionate way?
- Are we tough?

( a strange word, but when three astronauts were burned to death on top of the Apollo 1 rocket the then director of NASA put up two words on the blackboard: competent and tough. By the first he meant their ability to do their job well, and by tough he was admitting that a lot of people were aware that they were taking short cuts; it was a dangerous situation and nobody had spoken out or pressed the red

button to stop the elevator. We would call that government but sometimes we just keep going because it's a big project and affects so many other people)

- Examples of ineffective functioning – being isolated or rigid.
- Poverty of resources, time or agency: great ideas of moving forward but no way of implementing them.

There is a gap between our actual identity and our perceived identity and when that gap is within limits that helps to drive our growth as adolescents grow into tremendous gaps and develop. But if the gap is too wide that causes tremendous problems. Are you regarded? – do you have an appropriate sense of self-worth or are you marginalised with low morale in your unit? Is the trajectory growing or static or even sliding? I speak as someone who was involved in building up a pain service from a half time clinician with two sessions of psychology to ten people really working together seeing 800 patients a year, combining with a neighbouring clinic together seeing more than 2000 new patients a year ... and then three years ago it started to change: the CCG took away our four psychologists and put them into the community; we were outbid by a private health contractor and it all changed within a year, becoming fragmented and less effective, with the loss of good staff.

So things change rapidly. At my first meeting of the Pain Society it was still called the Intractable Pain Society and it was hosted by anaesthetists; it wasn't even multidisciplinary. They got together for mutual support. There was very little hard science.

There are red lines of sinister pathology in where we are locally: fractures, toxins in our system. Do we have problems with our afferent, processing system? – our efferent system? Do we know what we are doing and what is going on? What about nourishment: human and financial resources. Trusts want more for less; there is pressure to do more things that are countable: the CCG says “only things that are value based please” so there is huge clinical dissonance between what we know we could do and what we are allowed to do. Managers seem to change every two or three years so when they get the hang of it they go – that's not always a bad thing. We are told to ‘obscure’ colleagues: that is code for ‘use cheaper resources’ . You lose support and things change. You are told to give shorter appointments, make the PMP shorter ... Nationally we have got private interference. I'm not just talking about commercial companies: Connect, Virgin etc. but also commercial factors for us as doctors. How much of an influence is the golden nugget around the corner? Have we got an invasive bias? We know as neurosurgeons, spinal surgeons radiologists and anaesthetists, that if we can identify a target with a long needle and local anaesthetic or electrical stimulation we say lets go for it. And of course electricity must be better than LA and steroid which must be better than tablets which must be better than ... *listening?! By applying that philosophy we induce iatrogenic problems. Yet ethically we don't want to do any harm. We reinforce surgical problems, we treat the results of investigations that we didn't expect clinically; we have a silo mentality in different specialities, only seeing what we expect to see. People may be attending clinics in different hospitals, may have had private MRI scans which are not available to us, all of which leads to fragmentation of care for the individual. Our patients read the papers: ... “Why do doctors still not understand chronic pain? ... learning to live with pain ... exploring the future of pain management ... neurostimulation ... stem cells ... nanotechnology”. From one glossy “What doctors don't tell you: how to really get rid of pain”. ... *There's nothing here about listening.**

Iatrogenic problems abound: our primary care colleagues with little time to listen to patients; consulting with an interpreter present; not recognising that what patients come with and what they really need may be two different things. In research conditions oxycodone is shown to give 'enhanced surgical recovery from knee surgery' and junior doctors think "that must be a wonderful opiate – better than morphine because its in that research protocol". So they prescribe it for everybody and the patients go home with it; and before long we have tripled our opiate budget, and that before we acknowledge that we have an opiate problem just like the US. And we can't use NSAIDs because they rot the kidneys and cause strokes and heart attacks. Gabapentin and Pregabalin are the coming epidemic: SSRI's just make everything grey. We have been using amitriptyline since I was a boy and guess what: in this week's JAMA we see 'Cognitive decline with anticholinergics.' And how many of our patients are on amitriptyline? That's most of the drugs we use. Abnormal [patient] behaviour is reinforced by our abnormal treatment behaviour. How enmeshed are we in what we do and can we even acknowledge that we are part of it, because unless we do we will continue to push that.

## Yellow flag alphabet

A and B are for Attitudes and Beliefs. When we talk about 'Locus of control' – are we talking about the doctor's or the patient's? For you as clinicians, is it the trust limiting your formulary? Is it the CCG determining what you can and can't do? What about our other attitudes and beliefs? Rheumatologists have access to these DMARDs (Disease-modifying anti-rheumatic drugs) and look how much they are paying for them.

We push ourselves to the limit; every day I am at the limit of my competence and skills. We wouldn't ask that of our patients. What are my drivers? Is it my belief in being superman? Because I am doing the job does it mean that I am the right person to be doing it? Are anaesthetists the right people to be running pain clinics? Let's look at our behaviour: are we effective? Do we cause harm? I see many conditions I probably learnt about as a student but do I know enough about them to be the caregiver for that patient? Am I identifying patients for injections or some other therapeutic pathway? Are we there to provide symptom control or help to increase function or to enable a person who is in need to define what they want from us?

C is for Compensation – money! I am invested in my job – maybe with kudos or research or other things but it keeps the roof over my head.

D is for Distress: the internal distress of [?...?] working. We know what happens if you stress people in a closed working environment: if you starve them of resources they start eating each other. Are we experiencing an autoimmune flare-up nationally as well as locally? The BPS has been witness to that in years past.

E is for Emotion: fear of loss of professionalism and autonomy as doctors. I think I am a pessimist and inclined to focus on the hurdles and will hit them. We know that an optimist with clear goals and energy can achieve things but sometimes the future appears very foggy and there are a lot of icebergs out there.

F is for Family - our wonderful anaesthetic family, locally regionally and nationally... ... pick up all the pieces. What about other medical specialties including palliative care? I used to do a lot of this and voted against it becoming an independent specialty because I thought every doctor should be doing it. On my first day as a house officer I signed three death certificates. I went into pain medicine because of

trying to help a man in his forties with terminal oropharyngeal cancer and thinking we must be able to do more. But now the inclination is to say this isn't my specialty. We don't know how to move people out of our consulting rooms without getting an investigation, referring them on to somebody, writing a prescription or putting them on our waiting list. And yet our colleagues expect us to sort out their complex patients: the surgery that did not go well, the unexpected response to a drug.

Work for work: we have more patients with more diverse demographics: increasing age, increased survival from cancer; more complex problems and greater expectations of the drugs and treatments that we have introduced and have steadily grown over the years. Conditions like diabetic neuropathy with a shortage of speciality and psychiatry - we can't get mental health care.

What is the ethos of focussing on pathology to treat? - rather than improving factors that can promote health like understanding, sleep, healthy nutrition and social support from family and friends, and positive employment experience. (We know that employment for a lot of our patients consists of things like call centres and shift work.)

That I think is where we are and each of you will have your own perspective.

*Let's just pause for a moment and look at the windows which have wooden panels at the side. Let your eyes go round one of the panels and when you get to a corner breathe in and as you are going round the side you breathe out. Repeat this several times with each lap becoming slower and slower.*

That is a technique I often use with patients just as they come with me. You can do it anywhere to focus and encourage the parasympathetic nervous system as opposed to the 'wind-up' sympathetic system.

How can we be compassionate to ourselves? What does compassion mean but being alongside, having a deep concerned sympathy and a strong desire to alleviate pain or suffering.

## The Future

As we look to the future let's just revise at the ethics of what we want to do: to do no harm, to do good, to seek autonomy and justice. The future is uncertain: internationally, climate change, wars, cyber objectives, natural and man-made disasters. Nationally we have a divided country, divided families, many tensions. We will have a reduced GDP and less money and resources. There may well be austerity. Social care, the need for which is exacerbated by pain, will be less supportive. We are losing community resources such as libraries and social cohesion. In the NHS many trusts are in debt; Brexit will exacerbate staffing shortages, as will early retirement and lack of recruitment. There is fragmentation. We embrace priorities we may think appropriate but are either traditional or bright-and-shinier versions and hold promises for which there is no prospect of fulfilment. There is increasing dependence between providers and trusts, and increasing potential threats - or opportunities - from the private sector. And the patients themselves who will increase in numbers, needs and complexities. So how can the Philosophy and Ethics SIG - who are interested in wisdom and have a concern for others - how are we going to address that? Keep doing what we have been doing?

Keep getting what we have been getting? Are we going to make incremental changes while doing our busy everyday jobs? Are we going to improve our therapeutic networks: educating colleagues, incorporating pain patients in the future, addressing the social as well as the psychological and biological?

Or do we have to be more radical? Do we have TV screens going on at seven o'clock bringing us out in the streets to do our Tai Chi? Or are we going to have Jon Snow's to turn the tap off? Are we going to change direction? Are we talking about *us* changing because we are the people that can make that change for ourselves, or are we going to expect and require other people to change, with a focus on salutogenesis? People have had enough of rolling the boulder up the hill – are we going to soothe that? Are we going to be compassionate to ourselves so we can be authentic and compassionate to our patients? Will we look at new ways to educate and resource our colleagues rather than just saying send us more people? Are we going to change how we deliver in our local networks? Are we talking about mapping resources? A tenth of the money in the drug budget in County Durham – just under a million pounds – could make a huge difference in employing someone to map our resources and help others to navigate them. We must utilize universities, business studies, schools, teams and families to change what we are doing. What about using our patients – those who are skilled, and skilling them further? I had a vision a few years ago for our local further education college: sending people there to learn about their condition, if it was diabetes for instance, and ways of coping; but also to be a substrate for other students in the college to learn how to help someone with a painful neck, or for them to learn computer skills and to discern which websites were appropriate or not. Do we take some of those people and enable them to teach others, because we may not be the most appropriate people? Because there won't be the money, there will be the chaos and complexity.

Repairs on a mechanical watch whilst it is ticking would be a relatively simple and mechanistic thing compared to what we may have to do, which is changing a complex condition in complex people - ourselves as well as patients – in a complex and changing healthcare environment.

This has been a tremendous meeting and the one thing I shall take away is that if we simply stop making people worse the world would be a better place.

*The audience at this point was divided into groups of three or four and given two sheets of paper, one orange for NO to write down some of the things we need to stop doing, and the yellow for things we maybe should start doing, either as individuals or nationally.*

Here are some of the points:

*More yellows than orange ...*

*.... We only got yellow ...*

*GMC recognition of an individual specialty ... recognition ...*

*Stop prescribing for non tissue-based pain*

How do you know it's not tissue based?

*Chuck pain clinics*

*We [in pain clinics] see the same people as you [in GP] but have the luxury of more time*

*Divert funding for pain into the community and transform general practice to 'trauma informed healing organisations'*

*Fewer one on one consultations - a very inefficient way of delivering care for things like chronic pain.*

*No epistemic privilege (valuing one form of knowledge over another) Apart from this meeting you never ever get generalists talking to specialists although pain more than anything is a generalist issue.*

*Less social injustice, less austerity, less bullying of people on benefits, less invalidation.*

*Improved social architecture for health Better transport links Better community services not just for health and social care but more people fusing together.*

*When our Regional Medical Officer (for the North of England) spoke at our hospital recently he was asked "What do you think would help the health service?" and he replied "close the hospitals, take the money and put it into education!"*

*We've got renationalised school playing fields – the ones that Margaret Thatcher sold off for building speculation - 40% of them have never been built on –*

*Stop voting in Conservative governments! (July 2019) ...*

*... We're getting political! ...*

*... We have to!*

*Social justice is also a feminist issue. 90% of pain clinic patients are women*

*Stop invalidating. This cuts across so many of our present ills ..*

*... How many investigations do we need to show that something is normal - another way of invalidating ...*

*Profit free healthcare*

*If I paid you £2000 a year to cope with your pain or give you the operation or a spinal cord stimulator ...*

**Further discussion**

*We also need to think about what we are doing; we want *them* to stop - we want *that* organisation to change. How is it going to affect us?*

*It's a huge challenge. We should be doing something as well as sitting here coming up with the problems. When we have money being sucked out of the NHS by private enterprise, opiates being forced down peoples' throats by big pharma ...*

If we don't do it who will? Is there any other group in the NHS – in the UK – thinking about this?

*There probably are ...*

*... but they may be coming from a different perspective ...*

*... people looking at profit-free healthcare, and a lot of things flow on from that.*

*But the question really is what can you and I do about that now? And that is quite difficult.*

*... start from here ...*

*But that is very passive –*

*It actually takes a lot of energy to not protect yourself against these stories of misery and be open to ...*

*Should I apply this to my spinal stimulator colleagues?*

*The modern mantra is 'be happy' which is so vacuous and unachievable, but kindness is possible and it's focussing your energy in a quite different way from trying to be happy- a lot of people get very unhappy trying to be happy but you don't get unhappy trying to be kind.*

*One problem is the increased managerial interference which prevents us from practicing in the way we want to as professionals who profess a vocation. There is a double whammy - there is the moral case that you can't do your vocational work ... a lot of doctors are getting increasingly burnt out because of this.*

*When we had less interference, did we achieve more?*

*You have a lot of different voices in there. You have ... from your own perspective and you're looking to correct it although they can be quite forceful and it can be quite difficult unless you do have that opening of, then I don't see how you can make that progress.*

*The guidelines from NICE on the management of chronic pain are supposed to be out soon. I don't know what those guidelines are going to show but I think they will indicate that not a lot works for chronic pain; they will look at the evidence that most of the interventions we use for chronic pain – I am speculating here - don't work and we should not be doing them - and therefore they will not be commissioned.*

*A lot of that is because they are not done in a multidisciplinary setting; while the injections don't in themselves 'work' to cure chronic pain, when combined with physiotherapy they can be very effective...*

*It's the healing approach somewhere along what we are doing ... if there is healing going on, however that happens ... perhaps that is something that should be made clear to NICE and the people that are formulating those guidelines. It's a big opportunity but also a threat to them. It may disenfranchise a lot of people and make a lot of people angry and disgruntled which may be counterproductive.*

*It sounds like it will invalidate the pain clinic.*

*Is there really no evidence that injections work? – or have they just evolved?*

*The problem is that there is indeed some evidence that some work, and those will probably be prioritised and all the others stopped.*

*Are there placebo-controlled RCT's?*

*Some but it is very difficult ... when you think about the complexity of pain and you try to assess whether a simple treatment works for a complex condition ... you end up with some equivocal answers. It's the whole management that works but individual bits of it may not. It may be that all of the things we do for pain merely act as a vehicle for the healing process. I see healing physicians working around me using procedures that are probably of purely placebo value.*

*That's still good.*

*Can we get together something from this meeting to present to the BPS? ...*

*...or to NICE...*

*We could publish something in Pain News*

*If you want to do something you can - you have agency – you have some time - you have a meeting of minds*

*I did send a rant*

*With respect I don't think writing articles in things like Pain News makes a scrap of difference to anything. It's about action.*

*You're right. The profession as a whole has been very meek and reluctant to interfere with practice and it's time for fresh ...*

*We need a 16-year old Swedish girl!*

*But she is selling a very coherent and easily understood message that everybody gets. The problem here is that there is no such clear message emerging and you can see a flavour of what that message might look like: that there is something deeply wrong with the way we conceptualise pain and how it is treated and that has broad social implications but we haven't actually done the work yet to say what that thing is. We still need a strong and coherent message.*

*We started yesterday talking about trauma and then today we have been talking about healing which seems to be what it is all about. But even our speakers this morning have had reservations and concerns and questions about the healing process. That is the essence of what we should be promoting but we are still struggling with it.*

*And if we each had a two minute conversation in the lift with whoever had authority in this country how many different messages would they get?*

*Helen Salisbury who writes in the BMJ had an article last week called Doctors' duties in a fractured welfare state, calling for a united voice against the harm that is being done by the benefits system which involves assessment by someone at an*

*outsourced assessment company where they have to discuss and demonstrate what they can and can't do, which is difficult, unpleasant, and undignified. These are often the same traumatised people that we are seeing in our clinics. So we need a united voice, an act of solidarity with our patients, which includes patient activist or disability groups about these social injustices.*

Are there specific concerns about medication? I was phoned last week by the chair of my CCG, a GP, who asked: "I've got a patient who is on a bit of Fentanyl and seems to be allergic to it, so can I change it?". I said "certainly – how much is he on?" "200mg per hour." So I thought - if we are this far down the road with opiates, where will we be when controversy about Amitriptyline actually emerges, because that is another blanket that keeps all that sympathetic nervous overactivity dampened down. We had a patient last year, who ended up as a coroner's inquest, on 250mg every night. When she came into hospital three months before she wanted a good night's sleep so she took six. They called the anaesthetist at three in the morning; he queried if she had had a head injury and she had a CT scan and the next morning she said she had taken all her tablets to help her to sleep. We allow our patients to have their medicines at the bedside. It's cheaper for the hospital and they provide continuity of care despite the fact that these are people going through turbulent times and we are expecting them to navigate as well as go through what they've got.

*We had a patient die from a Pregabalin and morphine overdose*

*Do you have any problems with antipsychotics like Dothiepin?- randomly prescribed for sleep (it's off label)*

*It's used for emotionally unstable personality disorder to dampen down emotional flares*

We may not come to any conclusions as a forum but I hope I have provided some stimulation which will continue. I do some mentoring with non-medical students in the university where I think my role is to stimulate curiosity rather than to provide answers. We do need to be stirred up.

## Striving for a truly holistic pain service – the journey so far.

Jamie Watson

I have wondered if this journey would ever end as the questions seemed to get more and more complex the more I think about it. Over the last couple of days we have been thinking about new pain services involving primary care.

My story itself starts back on the 13<sup>th</sup> November 2013 with a happening that sparked the interest which has stayed with me ever since. I was a second year physiotherapy student at the time, in the first week of my first ever clinical placement with a spine specialist, who, for a couple of days, I watched assess and treat various patients. On the third day he brought in a lady called Sarah who was very much like the Debbie's that we have seen at this meeting. She was asked what we could do for her and she replied that she would really like us to loosen her back off. So my teacher asked if I would like a go and I thought at last I could do something instead of just watching. So I identified the L4/5 gap and as I touched her back with my thumbs her whole back went into spasm and she screamed. I jumped back and looked at my teacher, thinking I was in trouble, but he just rolled his eyes and gestured to me to crack on. So during that session she let out several noises. After she had gone I asked my teacher what that was about and he said she was just exaggerating - there's nothing we can do for her. During my five week placement there were a lot of patients who were 'exaggerating' so I was left with the question: are they all exaggerating? Is there anything we can do for these people?

Some of us have been forest bathing this afternoon; while I was enjoying this I was thinking of a metaphor I could use about how they could change. One image was of a figure in chains



Focussing on the part can blind us from seeing the whole picture. We miss the individual and we miss the context.

It has been good to see that everyone here is on that page and our challenge is how do we get more people thinking like us.

It took me to the end of my second year to appreciate that we needed to look at something other than the 'part' , when my former director of studies Dr Cormac Ryan, who is a hilarious Irishman and a very charismatic speaker, gave us a whole week on pain, including peripheral and central sensitisation and I began to realise how light touch could be so painful. He introduced the biopsychosocial model which opened doors and avenues we could go down to help people.

So what does holistic actually mean? According to the Oxford dictionary, in philosophy it is characterized by the belief that the parts of something are intimately interconnected and explicable only by reference to the whole, and in medicine by the treatment of the whole person, taking into account mental and social factors, rather than just the symptoms of a disease.

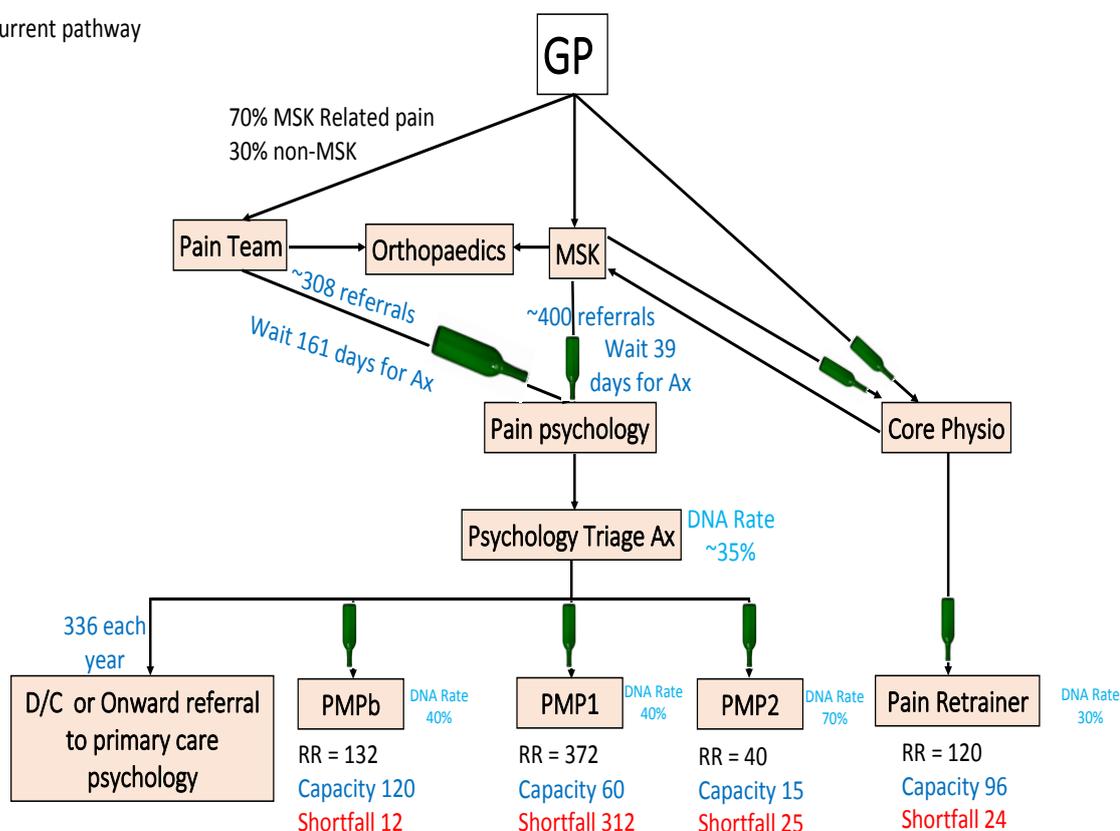


we have 43,000 fewer jobs than we did last year, with little prospect of it's getting any better. The North East had 'the least favourable general health' of any region. There is a lot of poor health literacy and poor health choices. If Stockton was a village of 100 people, seven would have diabetes, 4 heart disease, 16 raised Bp, 3 cancer, 1 dementia, 1 severe mental illness, 7 asthma, 2 would have had a stroke, 20 long-term illness. We have also been a national outlier in relation to the number of opiates prescribed in relation to the local population, being in the 96-99 percentile of CCGs nationally over the past 5 years at a cost of nearly £750 per annum. As with all trusts we are having to save money and do more for less.



So I am going to describe our current pathway and the problems we have with it and present our new model with the hope of getting your feedback.

Current pathway



Currently, when a GP refers a patient they either seen by the pain team run by an anaesthetist with nursing support. About 70% of those patients have MSK

(musculoskeletal) problems and 30% others, and have the usual procedures: injections, acupuncture and TENS. The GP can also refer to our MSK service which can act as a gateway to orthopaedics to stop too many procedures being done. Patients with MSK conditions are screened by a physio or a podiatrist so they can be sent for injections, nerve conduction studies, refer to orthopaedics if appropriate or to core physio (which is where I currently work in a community outpatient setting) to which the GP can also refer directly. Both the pain team and the MSK team can refer directly to psychology, but Core physio have to refer via MSK. They host the Pain Management Programmes. The wait for psychology for the pain team is currently more than five months but only about a month for MSK. The psychology triage is a face-to-face 45 minute assessment which is mainly designed to screen for risk of self-harm or harm to anyone else and to assess eligibility for a programme. They don't follow one to one. The is about a 35% DNA rate from this, probably because people have had to wait so long. There are four options for triage: discharge or onward referral to primary care psychology; a brief Pain Management Programme (PMPb) run by two assistant psychologists for three hours once a week for six weeks (which a recent audit suggests doesn't work; it is very much a didactic lecture style format with little behavioural work)

*Are these long-term pain problems?*

This varies from a few months to 30 years. Some of those reaching core physio have very entrenched and complex problems and we have the feeling that we don't have the necessary skills to deal with them as we would have wished and need more support. PMP1 is a weekly three hour session for nine weeks run by one qualified psychologist one MBT therapist with input from me, a nurse and a consultant, and PMP2 for patients with highly complex issues, with a long wait.

*If you were to design a system for passing patients around so you could lose them in the cracks, what would that system look like? [laughter] Difficult patient---> don't want to take responsibility--- >pass it down the line---> back to the GP ...*

*Why do some GP's refer all the patients, and some none?*

*Why is there such a high drop-out rate from PMPs?*

There is a shortfall of capacity to referral rate of 12 for PMPb but 312 for PMP1 and 25 for PMP2 . So there are bottlenecks everywhere with a wait between 12 and 18 months for PMP1 and 18 months for PMP2

We are seeing more and more of these patients in core physio and know that it can take between one and two years before they get any support (if they turn up). So we are left with the question: do I continue to treat this individual on my own in a ten minute slot behind curtains ? – or discharge them and say there is nothing more I can do? Where I work we go from one extreme to another with everything in between. So I have set up a Pain Retraining Group which is essentially a Live Well group: brief, three hours long, and runs for four weeks. It used to be for heterogeneous chronic pain where the core physio doesn't know what to do other than something they are going to have to wait two years for. But there have been some changes regionally; rheumatology is a vulnerable service in the North East with huge wait times so rheumatology patients get referred to MSK who become a screening gateway to the rheumatologists, and try to manage low level problems like fibromyalgia. So that meant that there was increased number of patients with FM referred to core, so that my group is just for them.

*... exclusion is one of the common experiences of a life lived with trauma: you are excluded from school, you are excluded from workplaces, from A&E thrown off GP lists, out of pain services ...*

*[partly inaudible due interruptive noise] ... it's interesting how that chart illustrates ... trauma and powerlessness is creating the problem in the first place ... destructive life events that create the problem in the first place: stripping of agency, anonymity, abandonment ... lack of personal connectivity...*

*... also meaninglessness ... someone has decided you have FMS ...*

*... there's no professional ... no human being ... having responsibility to you ..*

I concede the issues here. There are pockets of really good practice in a system which frankly – stinks.

If I have a really complex patient for whom I need some support I book in some time with a psychologist

*In the first talk this morning we had a sketch of what a virtuous circle might look like ... the person who is able to create a healing environment; the words love and compassion were thrown around. These virtues are instantiated in a person who is able to create a space in which virtues can flourish. But virtue can only flourish within a certain kind of ecosystem. If you don't have the right context virtue dies. This is an austere environment – it's just a parking lot. There is no possibility of continuity of one-to-one contact, responsibility or connectiveness – or love.*

*The fractionation of health services is ...*

So to sum up so far, we have an increasing population with an increasing complexity of problems; people get older with multiple co-morbidities. The waiting list is growing but our funds are shrinking.

*Waiting lists make the professionals feel needed*

We are in a fragmented system with pockets of good practice. I never speak to our pain consultants.

*In terms of modern pain medicine this could be regarded as negligent.*

*Doesn't all this make you angry?*

The good news is that it is all changing. A year or two ago it felt as if I was banging my head against a brick wall. I was working with a really good psychologist who left the service because he felt he was burning out and not getting anywhere.

At the moment it is so fragmented we don't really have a pain service.

What then are the key elements of a holistic pain service?

*Some years ago there was a BPS proposal that pain teams should come and visit each other and learn from each other and garner support at every level.*

A bit of work I am hoping to do is to bring clinicians from over the region together to form basic connections between both services and individuals to provide informal support ... and formal links ...

... may I ask what volume of patients are going through your spinal surgery aspect?  
– you had links into orthopaedics ...

Not many through the regional pain pathway

[several people talking at once ... integrated pain services]

I have here the IASP definition of an [ideal] pain service: 'Multimodal treatments, multidisciplinary teams collaborating in assessment and treatment using a shared biopsychosocial model and goals, working closely together with regular team meetings face to face; agreement on diagnosis, therapeutic aims and plans of treatment.

Before this got so bad the commissioners finally started paying attention to the changes going on in terms of what the Trust can charge for with the NICE guidance for injections. They told the pain team they should be doing fewer but when they didn't conform they reallocated some of their funding to try to build a more integrated team

So we had to think about what the key elements of a holistic pain service were and came up with these:



Patients should be partners not just within the clinical consultation but also through helping to design and run the service. The Newcastle pain service had done some really good stuff in terms of integrating patient views.

An integrated multidisciplinary team needs to actually be together, to talk to each other and share one another's resources and skills and knit together the fractured care which is going on.

Links to social care: to use Deepak's metaphor, if we are just at the bottom of the waterfall can we go further upstream ...

*... How do these links work – through individual social workers or ...*

That will become clear. These were our thoughts about the key elements when we were considering how we wanted to redesign or service

*[inaudible question]*

MSK and physio are separate services but the same team . Pain psychology are really on board with this, but we have really struggled to engage our [medical] pain team. They have been invited to every meeting of the steering group with various stakeholders ...

*Primary care is not involved?*

No – we should have done

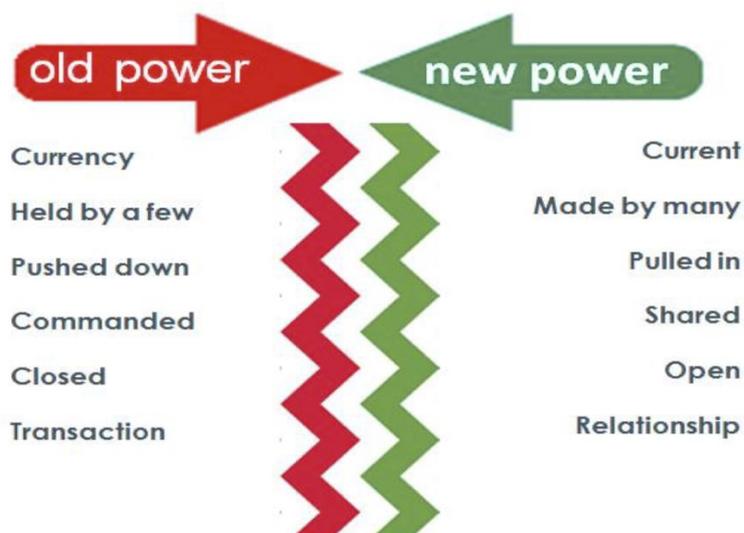
*It's critical because one of the things that is so obvious from the perspective of primary care is that chronic pain is not a thing in isolation; it is part of a spectrum of what misery looks like. So people with chronic pain will also have depression, obesity, IBS, polypharmacy, substance abuse and have suffered from unemployment and divorce. Misery comes as a pack, and to try to reify chronic pain as a thing which requires its own specialist team, is, I suspect, part of the problem. People perform their suffering under a prescription. People perceive and act in their lives according to the prescriptions that are available to them. And if the prescription is a mental health problem, or suffering from chronic pain, that's how they will experience their suffering and perform it. And so having a system which is elsewhere, expert, inaccessible, hard to get, valuable, means that people perform and experience their suffering according to that script that is offered to them. But you have this unavailable complex system which is expert and expensive, it's going to make this epidemic worse. That might sound outlandish but it is terribly obvious from the generalist perspective. All of these things like food allergy, obesity and mental health require specialists but it's all the same thing: anguish and suffering.*

*That's a very provocative thing to say and you may not agree ...*

*....You are going against what has been the dogma of the last 15 or 20 years, but having been here for the last day-and-a-half I think you are right. We may have been looking at pain as 'the thing' when it's a symptom...*

*... We have short memories: this isn't new. I'm in my mid-fifties, and this [?chronic pain and specialised but fragmented pain services?] didn't exist when I was a newly qualified doctor. Now it is pervasive and everywhere. It's not that it is a virus, not that people have suddenly developed chronic pain or that suffering is new; something has changed and I suspect that peoples' suffering conforms according to the prescriptions that are available to them. Who is offering these prescriptions? It's a social thing as well as a medical thing. Do we offer the prescriptions under which people perceive and act? So we need to be very careful of the diagnoses and the words we use. The chronic pain story is not terribly useful. We have demonstrated that none of our drugs work; we have ideas about how agency and the relationship with an engaged person works in all kinds of suffering, not just in chronic pain.*

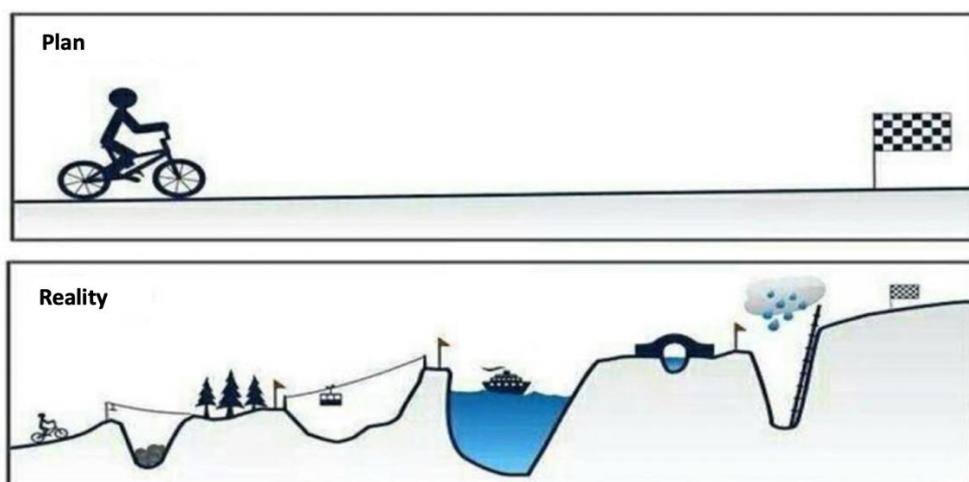
So let's pause for a moment to reflect on the words in the last slide [above] before we move on to considering how we can share our insights regarding changing things.



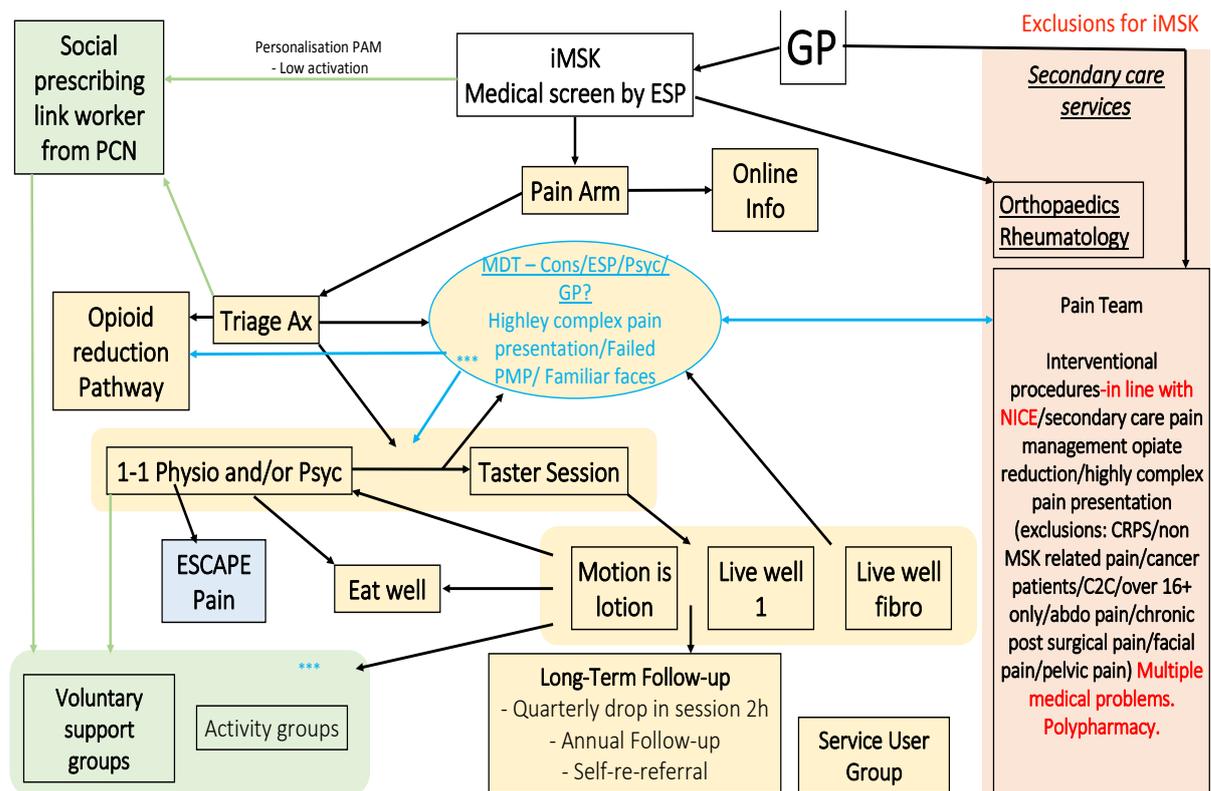
Jeremy Heimens, Henry Timms [New Power: How it's changing the 21<sup>st</sup> Century and why you need to know](#) (2018)

I was introduced to this concept by Kathryn Perera, the Head of Transformations for NHS Horizons, who gave a very powerful talk in Leicester last year on power. We need more of the New Power, which is essentially an open shared relationship between the many, rather than something held by the few, if we are to move forward.

## Striving for a truly holistic pain service



Plan and reality are of course different! This is our current proposed model.



The initial screening is by MSK, orthopaedics or rheumatology. Patients will be sent to PAM which is a personalisation measure of their activation. If they score low on this and are not very health aware and not very activated at taking ownership of self-managing their condition, they are sent to social prescribing. So as part of the long-term plan there is probably funding to be made available as part of primary care networks to employ a linkworker who will be able to refer to voluntary support and activity groups. They will help people to navigate through the jobcentre and the benefit system. Primary care networks involve groups of general practices coming together looking after between 30 and 50 thousand patients and they will employ a linkworker. That is the social arm.

The criteria for referral through to the Pain arm which have yet to be decided will determine whether someone will go to pain, normal physio or elsewhere. We are hoping to develop online information. Trusts like Cumbria have really good online information – whether it is useful for more than a minority of patients we don't know, but it looks good.

They then will get through to a triage assessment which used to be just done by a clinical psychologist but could also be done by a physio. At that point they could be referred back to social prescribing if something comes up that hasn't been revealed by the initial assessment. They may go through to an opioid reduction pathway. One way we are trying to get additional funds for our service is to undertake to reduce the opioid spend by 10% within our locality year on year.

From the triage assessment they can be referred to an MDT, so there is a multidisciplinary assessment of which the specifics remain to be decided but will involve consultants, .ESP psychologist and GP, plus or minus family

As for highly complex presentations, failed PMPs and 'familiar faces' we have no clear plans.

From triage assessment or from MDT they can be referred to the next step of one-to-one psychology or physiotherapy where actual therapy will be done, or back to MDT if they are not progressing. One of the issues we have with our programmes is the high DNA rate from the start so the one hour Taster session is to try to eliminate people who are going to drop out of a 12-week programme and waste a place. (But those are probably the people we need to get) It aims to introduce the whole person approach and explain why it may have been suggested that 'the pain is all in your head' or FMS is not real. We give them a taste of relaxation.

From this they can be referred to one of three groups: Motion is Lotion which is or brief intervention (90 minutes for six weeks) run by a physio and a psychology assistant including education and exercise. Our idea is to have a patient specific functional scale recording activities that are important to them that they struggle with, and give them specific exercises to deal with these. Live Well 1 will be nine weeks, three hours long run by physio and psychology; there will be an exercise component in this but how big is to be decided. Then there is our Live Well Fibro group: it may be questioned whether we need two different ones but this one will have shorter more frequent sessions for people who are easily fatigued. My initial impression is that this group have bonded better. There will be long-term follow-ups: a quarterly two hour drop-in sessions with a physio and a psychologist. This provides a lifeline so they can be re-referred back in to the service if they need. Questions that come up are sometimes about new interventions they have heard of or whether certain activities are safe for them. There are always things coming up in peoples' lives which derail them and we aim to help prevent this. We are not sure of the value of an annual follow-up ....

*Do you have a graduation ceremony? – and then you could have a re-union to help confer a sense of achievement ...*

One of my groups did suggest that it would be a good idea to meet up and support each other like going to the gym with each other ...

*How do you stop that becoming a meeting space for symptom generation?*

We would ideally want them to move into social care and engage in some form of activity like art or ... They can go back into one-on-one - we won't have the capacity for more than a few – but they may benefit from some education on a specific topic. They can go back to MDT

Eat Well is one hour session with a dietician when she will go through the links between weight and pain, diet myths, antioxidant foods and the components of a healthy diet. She will have time for questions and develop recipes which are quick and easy, and not only nutritious but integrate antioxidant and anti-inflammatory principles.

Escape Pain which is run by core physio is NICE recommended for hip and knee pain.

The Service User Group is inspired by Patients as Partners for people who, ideally, have gone through a programme and can hold us to account and tell us what they think about these changes and have them at the table of our discussions, or preview documents, educational hand-outs we are producing.

*Have you looked at other models around the world? Obviously yours has to be locality specific but have you looked at available models that work well?*

We have looked locally; Sheffield, Cumbria, Leeds and elsewhere. I have travelled round and had days with their teams to try to get to grips with their models and bash something together. But we haven't looked internationally. That would have been a good idea.

*[Australian model inaudible name led by Chris Haines have publishes data on their remodelling and outcomes ]*

*... CRPS ... I do a lot of pain reduction all the time [in General Practice] ... It's the classification that really bothers me ... the idea that you need to be an expert to do any of these things ... somebody with relevant experience, broad-minded and understands the nature of the problem could very well manage a very wide range of these things which is just as well ...*

*... you and I probably never refer to a pain clinic, but there are lots of GP's who are on their knees: they see these patients and cannot bear it; their hearts sink and they think this isn't for me. So either you are the sort of doctor that can engage with this level of distress or you are not.*

*I do think there is a place for people to go who need longer time ... people get stuck and we can support them and contain in primary care but we don't have the time to do some of this ...*

*... I agree but I have listened to you for an hour and I believe strongly that you could deal with every single one of your problems. It's having time and space to do that.*

What you will see is that ... I don't agree with everything in the model above ...

*I have a problem. There is a whole scope of medicine called Pain Medicine. It's like me saying I could do cardiology. So are we not valuing the scope of pain medicine as a discipline? In that [scheme] you probably should have a specific dedicated pelvic pain service. I have my doubts that any system can handle all that.*

*How can you show that this is a good idea?*

We are thinking of some good outcome measures and as well as numbers and data do some long-term qualitative work. I would like to get each component of this and go deep into how we can make things better ...

*...the trouble is that is incredibly expensive and difficult to do.*

*... maybe it's more hope ... but I have been assured that whoever gets the physio role, there will be time for them to do some element of research audit.*

*Have you looked at financial issues? – the costs of the various elements in comparison with the previous model.*

No – we haven't done a cost comparison. We know how much the whole model costs but not yet components. That is work to do.

*I wonder where employment and getting back to work is here. That does seem to be one of the fundamental issues for the patients I see with chronic pain. I do often find that patients who do get back into work find their pain gets more manageable.*

*The barriers are with employers; anybody who has been out of work for more than two years, even if they'd successfully completed a PMP - people told me that if they admitted they'd been out of work for back pain the employers wouldn't bother to send them an application form.*

*The problem that I have is that employers say to their employees "don't come back until you are your pain/mental health problem/stress or whatever is completely sorted out". But they know and I know that they will never get back to work because work is part of the solution. That suits the employers because they are trying to shuffle that person out; the employee doesn't know that and they think that the employer is being nice. It's a horrible economic trap. I am concerned about this or any model that one thing we all know is that once you've been off for a scarily short period of time with a functional pain disorder your chances of ever getting back to work sharply go down. So these people need to engage with their employer at a very early stage of their illness.*

Purpose is something that so many of these people lack. Part of the Social Prescribing arm will provide support into the jobcentre. How helpful that is I don't know. It would be my long-term ambition to do a return to work programme of some description.

*At one site in Glasgow they employed financial advice workers to work alongside GP surgeries and increased the level of benefits accrued in one year by £850,000. This enabled people to take less medication and go the doctor less frequently. The stress of being skint and homeless makes your pain worse. So if you truly believe in the biospsycho-social model you have to pay attention to what social means; getting back into work, having enough money to live on, not being homeless, not suffering violence, not having shit at home ... I don't see the social here. There are wonderful examples all over: I mentioned yesterday Manchester ... a practice where a person in distress is seen as part of the unit; and there is probably chaos at home. They have reduced attendances by 30%. No-one has been able to do this with any other scheme. You have got to do this kind of social work: you need homelessness advisers, financial advisers, social workers, health visitors  
A lot of people in pain are women who are either caring for or being cared for by other people...*

My understanding is this: it's a linkworker or care co-ordinator who will signpost towards voluntary and support groups. They will work with an individual for between 8 and 12 sessions on how they can engage more in the community. That may involve taking them to places if feel they are confident enough, helping them to write applications for benefits ... it's not perfect but ...

*Clinicians can't do everything. You can set up this kind of service but have close links to other services in the community*

*People who can work voluntarily and can cope with that ... taking them to appointments ...*

... giving them purpose ...

*Regarding measurement of outcome: across Australasia there is an initiative called eCOA. (Electronic clinical outcomes assessment): a whole standard set of psychometrics. They can measure at six weeks, six months and a year across all pain services. It has massive research backup.*

*You have got to piggyback it [your service] on to initiatives that are world-wide and successful or otherwise you end up trying to forget about 200 years of history. If you want to achieve greatness it has to be on the back of other people*

The digital stuff isn't just because of this new service; our trust has been working with a company called Health Call on digitising that stuff. There are issues due to IG differences between different trusts and countries and different rules and regulations.

*One of the difficulties we had when we introduced our MP service was with capacity. The backlog of patients currently going through, some of them stuck ... you had designed the thing for what you were hoping would go through – and then we had a launch which invited more patients ...*

That is a rain-cloud which I can clearly see in the distance. We are getting some additional funds from the CCG to employ 0.8 of a psychologist to help clear some of the backlog, but that may only move people further down the system. But that is a very real threat. This is better than what we are currently doing and we do have some increased capacity but we could get flooded out and the wait times go up. We will need to measure our success and prove that what we are doing is having some effect and then go to the CCG and say these are our outcomes and the only limit is our capacity so give us more.

*Will GP's be able to refer to the Live Well group?*

No ... well, some GP's yes, but a lot of them in our locality will just write 'low back pain' on the referral with zero information and a lot of them don't even do an assessment or any examination. Some have only had a telephone consultation. They are massively short of time and they know there is an MSK pain service that will do it.

*What is the waiting time for that?*

Currently about four weeks. But we are predicting that one of the risks of this new model is that that will be extended to six to eight weeks. We have asked for an additional 1.5 practitioners to cope with the expected influx.

*As a GP I find that so upsetting and horrifying. We could deal with so many problems upstream if we assess our patients...*

*... the NHS is on its knees – rolling into the ditch ...*

*When you are referring very often the referrals are screened by an anonymous agency*

*I live just over the border in South-East Scotland; General Practice in my area is not great but I don't think we allow this to happen – I'm not sure what the difference is ...*

It's certainly not all GP's – some letters are great with loads of information – but others ...

*... they're overwhelmed ...*

*Our headache clinic was overwhelmed with referrals, so I audited 100 of these and they were hugely varied, from “? Head” to a detailed narrative. So we ran an education session for the high referring practices who were providing little information. I talked about the patients who had died after a misdiagnosed headache and how I dealt with my own fear of headaches and the psychology of it, and the neurologist to talk about the biology. The referrals went down by between 50 and 100% after that in these practices. So you need an experienced trusted GP to look at all this to see what is going on, and it can be quite a help if people are struggling.*

*It’s an interesting power competition here. On the one hand what comes across is that you have left GP’s out essentially because you don’t see them as part of a useful service (I’m overstating and putting words into your mouth) From a GP perspective, I’m kind of doing the same thing about the chronic pain service. I know they won’t be seen for a zillion years; it’s like punting that patient into a black hole, and more often and not they come back on Tramadol and Gabapentin anyway, and I have to stop those, so what is the point. That sounds incredibly cynical but there is this terrible mutual incomprehension and caricaturing of the other.*

*Given all the DNA rates, and given that you do all this group work, explaining what the service is and what it offers, what about a video patients and doctors can look at if they are considering referral?*

Yes. Initially this will just be information but a longer term project is to have patients’ stories of what it is like to go on that group.

*Have you considered the use of any CAM (Complementary and Alternative Medicine) interventions? One of the recent American guidelines for chronic pain puts acupuncture at the top at its suggested list of interventions. There is good evidence for the effectiveness of that. I have been sitting in these meetings for several years and I never heard these things mentioned. Why aren’t they among the possible options? Picking up from the previous conversation, giving patients choice and being prepared to say that there are other things out there like acupuncture which may help is very important. So why isn’t it on your screen?*

Because NICE said no.

*I gather NICE are probably going to change that... but just because NICE ...*

*Commissioners won’t pay for it*

*Private acupuncturists get excellent results*

I’m told that if I offer acupuncture I have to explain the NICE guidelines that it doesn’t work and shouldn’t be done

*You can do it if requested. You could also offer it to help people with opioid reduction*

*(Who will run opioid reduction?)*

There will be one or two consultant sessions and one nurse)

I’ve had mixed responses – it works well for some people; like any short-term complementary intervention it is useful as an adjunct but probably not in isolation.

*A friend of mine who runs an academic centre in Zurich is teaching patients to use acupuncture themselves. You don't need a big set-up for this. It gives them something to do for themselves and take control of*

*We have taught partners to do A/P*

*I think your comment about using it in isolation for complex patients is very valid but as part of a package – why not?*

*My experience is that by the time people get to a tertiary pain centre they've already tried it*

*That's if you're looking at a short term course – six sessions or whatever*

*Thank you for your presentation which has left me deeply depressed! [laughter] because I work within a system like that and I don't even know where I work! It hadn't struck me before how ludicrous it is. Someone talked earlier about 'patient pinball'; comparing what we heard yesterday and what we have been talking about I can't see that this is at all patient centred. I think I may have had some noetic moments – it has set me back a long way.*

*This conference has been about caring for the carers as well as caring for the patients and any trauma-informed service organisation has got to build in care for the people who work there. How are you going to do that?*

*The psychologist will provide supervision for all staff ...*

*Will you have regular conversations with your consultants because you will build in such opportunities to your service model - either formally or networking?*

*You said you hadn't really met them previously and for something like this to work ... I work in a system like this at the moment but at least we do all have lunch together and are all working in the same building ...*

*Will you have weekly or monthly case conferences? ...*

*It's very important to have the right space, the right environment for that integration and those informal conversations over lunch. But I hope that this will at least bring us formally together, and that is a start.*

*I went from a situation [as a physio] in a GP surgery where I would see a patient within in two weeks and get to know them in their environment and liaise with the doctors really well, to the waiting list going up to four months because they had introduced a centralised system where measurement, algorithms and flow charts and all that had changed things in a detrimental way. I also worked in a secondary pain clinic situation and I will take what you said about your colleague mentoring you at the start and saying 'this one is not for us and these are'. And I have gone from the pain clinic specialist environment to feel that my role should be at the GP primary care end where we can be most effective as a service; making good strong links at the entry point.*

*A very good point. The diagram focuses on complexity. Perhaps you should get rid of the diagram and focus on the tea-room. Any complex system will work if the people know one another personally: the basis, the relationships, a little about each others' lives. If you start with the tea-room, 15 minutes every other day for the*

*relevant professionals to get together and build the structure from that point. In my practice we meet every morning for ten minutes; everybody comes and we talk about cases. When we have a new person offering a new service, if we don't know her face she won't get the referrals, but if she comes along she can get integrated.*

*In your diagram almost anyone can go anywhere, but if you start off in the tea-room and everybody knows everybody ... this is presumably something that is designed to go on a computer system and monitored and logged . We mentioned backlog at one stage: words like that are so depressing for the patient to have a system where we have a backlog. I'm not suggesting that I have any answers.*

*If you can say to your patient "I've spoken to the psychologist this morning over tea and she really needs to see you next week", that is massively different from "I don't know what to do with you so I'm going to send you to the psychologist". It's the difference between anonymity and integration. You have to start with integration.*

*Penny Campling and John Ballat wrote the wonderful book Intelligent Kindness, reforming the culture of healthcare a few years ago, which is all to do with organisational psychology. Their question was: what has happened to kindness in the NHS? If you take Paul's idea of healing and ask: what makes a healing organisation? What makes an organisation kind? - it is the quality of relationships within that organisation. If you start from there you will win, whatever else you do.*

## What does pain tell us about our nature?

Peter Dorward

I'm going to take you on a walk around pain and the philosophical problems stitched through the way we think about pain. Pain is unexceptional in medicine in a sense in that it is full of philosophical contradictions and incoherencies which scientific rationalism leaves completely in the dark. After I qualified, in the three months after I started, my first job as a house officer in medicine, I had it nailed. My knowledge was second to nothing; my technical skills were fantastic; I got an A\* in communication skills - I could communicate with a stone! I went into the wards with the bright light of scientific materialism illuminating everything in my path ... but I kept on bumping into stuff which was in total obscurity.

This is the unexamined philosophical side of medicine: the stuff we keep alluding to, about values, feelings, passions, stories and narrative, history, culture - all that stuff which is stitched into everything we do. But unless we have that sensibility we will bump into it like a blind person in a crowded room

I'm going to take you on a walk around pain. It's not long or particularly arduous but it's going to be cold, wet and uncomfortable and it's going to hurt like hell. But before we set off, a wee run through what we all know about pain – what we can uncontentionally say about it. It is everywhere; in my day to day work as a doctor

probably the commonest thing I saw last week was pain. In this uncertain, difficult, fraught, contested world the nature of pain is practically the one thing we can all agree upon; it's universal. There are obvious, intuitive things we can say that we understand about it:

It is felt.

It is instantly cognitively available; it's not something you need to cultivate or work hard at being good at.

It is a thing to be avoided.

It is subjective. It is experienced by a self but yet -  
It is universal

It's a perception, not an action. It's something that you feel, not something that you do. It is passive in its nature.

It has an evolved, hard-wired function to warn us of damage or hazard or harm

It feels horrid—it's the worst thing that you can have!

You know when you're in pain. You can't be wrong about it: pain is incorrigible. I can't tell you that you are not in pain —*you know*.

If were a medical student or a scientist I might take comfort in the thought that pain looks something like this:

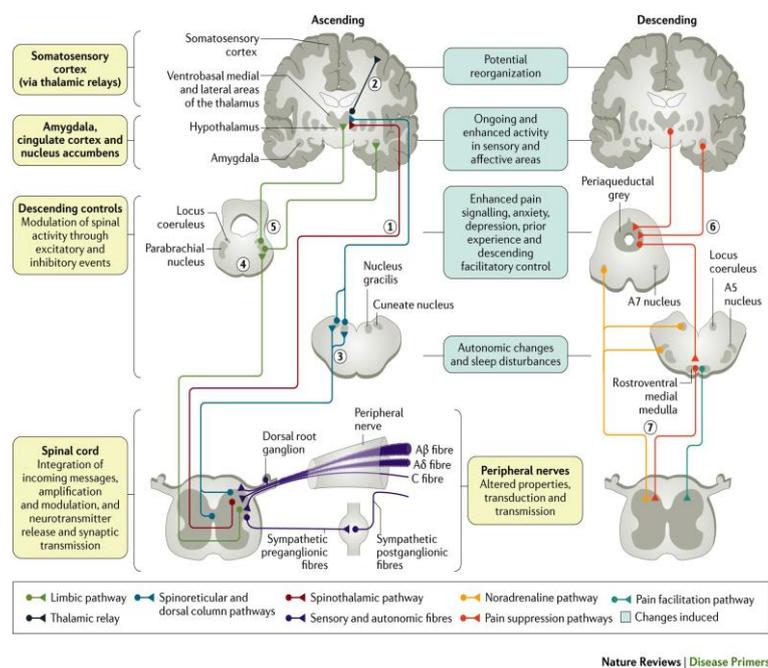


Fig.1

Don't look at it too carefully; it's just a lot of coloured boxes with grey for brains and lots of coloured lines connecting the boxes to represent the things that go on in the brain. It's very complex but it is out there and a thing you can look at, determine and control. It makes it look like a technical physiological challenge. In the brief moment before I abandoned practicing my talk this morning I had a sudden thought: what does that picture remind you of? Jamie's flow chart? [of movement through a complex pain service] Isn't it interesting how the structures that we create to manage this thing conform to our mental representations?

## My pain story

I'm going to tell you a story about something that happened to me a few years ago. It's something that underlies all of my assumptions and taught me a thing or two about pain. One January morning we set off at crack of dawn on a mountain walk. It was a cold, crisp beautiful clear day. We had been walking for hours and were warm and confident. We ascended the final ridge in that satisfying rhythm of ice axe and good grip for our feet and reached the summit. But the sun was getting a little low in the sky, it was getting colder and the weather was blowing up a wee bit. And we could see that the descent was going to be longer than we had anticipated and we would be coming down in darkness. But after the initial descent there would be an easy path down to the road. As we start down the sun has gone behind the ridge; it's getting colder and the wind picks up. My companion is not quite as gung-ho and confident as me so I harness him up and rope him down. When I am half way down I realise that my rope is stuck and as I turn to retrieve it I catch my crampon in my trouser leg, and suddenly I am falling. Anyone here who has ever done any climbing will recognise immediately that this isn't a story of heroism; it's a story of incompetence and stupidity. It's a story about making a bad decision and putting

somebody else's life at risk. It's a story about humiliation and that aspect of it is important for everything that happened afterwards.

To illustrate what I mean about heroism versus humiliation: I had a patient I used to look after a couple of years ago, an old guy with an adoring grand-daughter – this old guy came in with the grand-daughter who wanted him to have his blood pressure checked. So I said “OK, put out your arm” ... and his forearm was missing. So I asked him what had happened to his arm. “It was in 1944, a couple of days after the D-Day landing. We had just come ashore and I was with my platoon. We were running along a path with high hedges on each side. There was a blinding flash and I dropped my rifle. I picked it and my arm up with the other hand and run to the base and present myself to my CO and he goes white and says “Jesus Christ, Jock, your war's over”. So I went back to North Berwick for rehab.” I asked him what that involved and he lifts his stump up in the international drinking sign and says “Rehab - ye ken doctor, rehab” ! He told the story with pride and satisfaction; it was a heroic story. Not so Ted, another patient. He is twenty-five years younger than the other guy. He is pretty far gone in alcohol to the distress of his wife. He comes to see me constantly about the terrible pain and ringing in his right ear. Ted was in the RAC in the 60's and 70's when the troubles in Northern Ireland kicked off. He tells a story about being on patrol with his partner and being called to a trivial event: a child's school-bag had been thrown over a lamp-post and was suspended from the cross-bar. His friend tries to unhook the bag. He notices that everybody moves back including the child; he calls out to his friend but there is a blinding flash. He is knocked to the ground and picks himself up and finds the remains of his friend. He sees that the child whose bag it was is laughing. He still has pain and ringing in his ear. He's telling the story and looks at me and says: “Are ye all right doctor?” – and I'm not, because something about Ted's story has resonated with something in me. My mouth is dry, my heart is pounding and I feel sick and terribly anxious. I'm finding that I am suddenly right back coming down the mountain; the ice is hard and you feel like you're in a washing machine. You use your ice-axe as a kind of rudder to keep your head up and slow you down but it doesn't work and the rocks are coming up towards you. There is a terrible crack and a red flash then you are lying there in a strange awful silence. There are things that I remember vividly: I remember shame; I remember fear. I remember something very dark off-stage waiting on the other side of the hill. But though I have tried I don't remember pain. I have a vivid recollection of things that stand in for pain: its resonances, its echoes and representations. The distress in this recollection comes not from anything that you might call pain.

So my first thumbnail sketch of pain is immediately, obviously incomplete : emotion is missing. Affect is not something that is the frame of pain; it has something to do with the nature of how pain is experienced. I don't know if anyone is familiar with the extraordinary book *Achilles in Vietnam – combat, trauma and the undoing of character* by Jonathan Shay, which is about PTSD, not pain. Shay is an American psychologist physician working with Vietnam vets who developed the theory that the determining factor as to whether a bad event is perceived as heroism or trauma is how someone experiences the world: whether they see themselves as an agent, that is an empowered, virtuous, competent heroic actor in a morally coherent universe, such as my D-day veteran. If you are such, according to Shay, then you experience yourself as a hero and withstand the harms that the world throws at you. If, on the

other hand you are in Vietnam and of the character of Achilles: these are the parallels between Achilles, hero, humiliated by his pain, goes back to his tent and sulks and allows his best friend to go out and fight in his armour and be killed. Achilles goes berserk and fights in the river and commits atrocious war crimes; disgraces himself and his civilisation – and everybody remembers this case of PTSD. Shay writes about Vietnam vets as being people who felt that when they were there

that they were not agents, they were humiliated, disrespected, looked down upon by their own people who had sent them there. They were angry, and perceived themselves as passive, fearful foolish and blameworthy. If that is how you experience the world: if you are passive in a morally incoherent world, then your resilience is in effect stripped away.

And I wonder – I'm clearly not the first – whether something similar is happening with pain. We are human beings; we are not plants or fish. We ascribe meaning and value to everything. And when I remember my accident – and try to recreate that perception in my mind – what comes back most strongly is not pain; it is embarrassment and fear – the opposite of heroism. It's not pain I remember but its meaning.

However, all this theorising is a long way in the future, as right now I am sitting on a windswept icy plateau. The sun is skittering slowly along the horizon, the temperature is dropping, and I am contemplating my options. When I intend to move my intention isn't translated into any actual movement. I intend to stand up but I simply can't. I know that you all know what is going to happen next: I'm going to crawl for the next three days over the ice, down the side of the mountain dragging my severed limb behind me back to base camp where my companions who were about to leave strap me to a mule and take me to the nearest village ... and I'm going to write a book about it and they will make a film and I will become rich and famous. Actually it wasn't quite like that. The pain exerts its function below any level of any kind of conscious intention: I simply can't move. There is just no question of moving. It's as if the threat of the pain precludes that possibility. So if pain can be said to have a function, in this instance it seems to have performed it in anticipation without actually existing in conscious perception in the sense we usually understand it. It's as if I was a jellyfish or a plant and just responding to a noxious stimulus. But I still haven't actually felt any pain – only its premonition. So it seems that my number one statement about pain: that it is something that is felt, is not necessarily true. Pain is not necessarily something you feel. Maybe that is all that is important about pain: maybe it is just a function. Maybe we can describe the world in terms of function, mechanism, as if we were jellyfish. Perhaps all this talk about pain is just some kind of illusion. Nothing seems more implausible to me than that.

On the other hand, if it is a function, it's not in this instance performing its function very well. Sitting still as I am, freezing, I am overcome by a sense of drowsy warm languor. I discover, and this is my recollected testimony, that freezing to death, provided that you are left on your own to do it, is not really that bad. It seems better than the alternative. As I sit waiting for death ... but first a little more theory. The way I thought about pain before I went walking in the hills that January was, as I had learnt as a student, a matter of boxes connected by coloured lines as in fig 1 above. It is out in the world, objective and has a function and can be represented as a circuit diagram. We can make the circuit diagram as sophisticated as we like with boxes for memory, meaning, emotion, all the different colours and flavours of pain; a box for culture. But even if we introduce a quirky back-door route to how we might even enjoy pain. This idea of pain as pleasure is not quite as quirky or foolish as you might imagine. If I were to fast forward a couple of years from my accident, I'm back one January walking in the hills with the same companion on a much easier route. We come across a little knot of people, and among them a middle-aged woman is sitting saying: "I can't believe I have been so stupid – I've sprained my ankle really badly". And sure enough she had. What are we going to do? There's no telephone signal so I run down the side of the mountain and find a bar with a signal and call the emergency services, run back to the woman and reassure her, run halfway back to guide the rescuers, help with the Entonox and walk back down ... by this time my ankle is swollen throbbing and painful but my goodness, it's the pain of recovery. It's the pain of someone who has run up and down a mountain to save someone's life.

It's a mindful pain – it's a pain of recovery, vitality, agency. There is pleasure in that pain, like any pain you get with severe physical exertion and fatigue. There is nothing quirky or unusual or outlandish about that at all. It is something we are all familiar with.

Notwithstanding, the most perfect functional representation of pain (like fig 1) – of every aspect of pain that you can possibly imagine – I would still say that that is telling you as much about pain as the music score on a page tells you about the reality of the perception of that music. The word phenomenology is trying to capture those phenomena, those human experiences which are as objective and real as that music, but cannot be captured through descriptions or communicated. And when we talk about phenomenology as a philosophical discourse, it is about trying to bridge that gap between those things which are as real as eggs but can't be described in those terms.

However, I can't escape this thought: that my recollections, my feelings, my thoughts, all those colours and cracks in the world, all these stories and metaphors that I have been using to talk about my pain are simply representations of it. They are not pain itself. I can only access my pain through those representations of it that I have formed: stories, memories all of which are inflected by meaning and emotion, and of course the experience of telling you my story today. But the thing itself, that I believe myself to have experienced, is as inaccessible to me now as if it had happened to someone else. That is to say that something that had happened to me is something that is constructed by stories and representations.

It seems now, however, that I am to be rescued. Andy, the rescue guy, is suspended from a helicopter, has jammed his axe into the ice and is skittering across to rescue me. So I am sitting there spread-eagled on a ledge and he comes over like a spider. He shakes me and says words like 'wakey wakey!' He looks at my injury and says "Oh bloody hell! – we need to straighten that out." So now I have learned in the starkest possible way this absolutely critical life lesson: if you don't experience the pain; if you avoid the pain that is to say that if you sit immobile and do everything possible to escape it, it will creep in and find you out anyway. But if you just sit on a mountainside you will freeze to death. Pain, it seems, is the gateway that I need to pass through if I am to be alive. So is pain always something to be avoided? - in my case, no. It is something I need to go through in order to be alive. This resonates powerfully with my clinical practice. I have so many of these patients who seem to be in a tiny little box of their own construction which they are trying to push out against, and when they do they experience the pain and flinch like some wee animal in its shell cowering away from the pain. And you want to tell them that they have to push out against that pain which is something they have to get through and mustn't be avoided.

Anyway at this moment I have no choice. Andy the rescue guy is definitely in charge. As he fusses around with splints and gas cylinders and climbing harnesses, he sparks something up in me. It's definitely not courage. When he says 'I'm going to pull on your leg really hard to straighten it,' I say 'No', and when he insists, I start to argue about how, and so he just tells me. It's not courage—it's more that he has taken away my permission to die. He needs my help—he needs me to move, needs me to coordinate, and there is no question of my disagreeing. But he needs my help as he doesn't really know how the splint or the gas work, so now I have become involved in a *process*. I'm no longer passive. I'm engaged in purposeful, focussed activity.

On the other hand, crucially, there's no negotiation, no explanation, and definitely no question of faffing around with consent. I'm not exactly an *agent* either. And this is profoundly comforting. It goes against everything I think about medical ethics

It reminds me slightly of the Lamaze theory of natural child-birth: that by engaging in purposeful, controlled, focussed activity, a labouring mother's pain so changes its significance as to be manageable. Andy was no midwife, but he did exude confidence, authority, purpose. He gives me a canister of gas and air, and when I tell him it's empty and he says it's not, and it's true that when I suck really hard, it *does* make me light headed, and when he does pull on the broken bone I'm going along with it—I have no choice—and then I pass out again, seeing as I do that red flash, that crack, somewhere in the world. The gas cylinder is, as it happens, empty. I know that, because when we are winched into the dark, wet tin belly of the helicopter he throws it to the winchman and says 'it's fucking empty!' Oddly though, the emptiness of the cylinder didn't stop it from doing its job. There was something of the leader in Andy. You find something of the same in Ambulance Crew, Fire officers and soldiers. When he said 'breathe on this empty cylinder while I pull on the grating ends of your fractured bones', I wasn't going to say no. I didn't want to let him down.

It's like I'm taking part in a different performance, now, in a different show. Although it's definitely me, and only me, that is lying here with a broken, now straightened and splinted leg, there's now something slightly less absolutely solipsistic about my experience. My pain, I find, is connected to a whole world of social activity, which in turn profoundly influences every aspect of it. Every aspect of my pain and its perception and how I perform it is influenced by my new sense of social connectedness and purpose. My faith in the essentially passive and subjective nature of my experience is being severely undermined, And actually I think that this is always the case with pain – I don't think it's just me. I think that pain often, perhaps always, has this performative or social aspect. It's not entirely subjective at all. We're human beings, after all, and our social nature, our language, our connectiveness informs every aspect of our being from how we perceive the world to how we perform in it – it's our identity.

## Myra

I knew this woman once, a patient called Myra. She was one of these undercover immortal patients who are old for ever and don't seem to get any older I seem to have been looking after her for twenty years and she is still 95! She is a bright, demented lady, hops in like a little bird, says 'I've got the memory of a hen ... I cannae mind why am I here... oh yes, it's my back pain, and the pain in my legs. It wakes me every hour of the night". And she smiles up at me bright as you like. The thing is, although she complains of it constantly, nothing in her behaviour, or examining her, suggests that what she is describing as pain is what I understand by the word pain. But I would absolutely insist that she's not 'putting it on'. I don't think she is capable. And I don't think she's mistaken either. I'm not sure what that would mean. As I said in my introduction—pain is *incorrigible*—you can't be wrong about it. I'm not sure what *that* would mean. And it's not that her pain isn't *real* either. Words like real or not real don't apply in any meaningful way to what we describe as phenomenal experience. It's as real as eggs are eggs. I'm not sure what an *unreal* pain might be, assuming that she's not lying; why would she lie? What she calls pain is as real as any other aspect of her behaviour.

When other doctors have seen her, she has been started on analgesics, which have been escalated to 'enough tae stun a coo'. Remember the pain ladder? Pain as the fifth vital sign? How we have been encouraged to treat pain as a target as if it were diabetes or hypertension. The effect of rigorous pain management on Myra was to age her. She became, tired, confused, as well as demented, and depressed. Her *reported* pain never changes; it doesn't matter how much analgesics she is on. When I reduce, and stop all of her analgesics, she returns to baseline — the little

hopping bird-like lady, with the memory of a hen, driving her family nuts by complaining about pain. It's as if, in her cognitively attenuated state, complaining of pain, is what the social Myra *does*. For some elderly people an 'organ recital' ("my back, my bowels, my liver, my head") is an activity, and complaining of pain is what the social Myra *does*.

In this case, pain is not so much a thing that you *feel*, so much as a thing that you *do*: a performance. It's not put on – we've been through that. And the more that I think about it, the more that I recollect a zillion patients for whom I have thought this.

As an aside: stopping peoples' painkillers is one of the most satisfying and therapeutically things that I do. There is nothing better than stopping people's drugs and seeing them come back to life. I even love treating drug addicts which in Edinburgh means heroin. There was one particular guy who has a quite severe personality disorder and has spent a lot of time in prison. He is on methadone but still uses heroin. He has chronic pain, big swollen legs from injecting and comes to see me walking with two sticks. He is really angry because I never give him what he needs to manage his pain. He shouts his demands for "mair vallies and drunken sailors" (pregabalin in Edinburgh) I've been looking after him for a couple of years and he's not been my favourite patient. Then a few weeks ago something changed. He had a new girlfriend. His demeanour had completely changed for the better and he was cheerful and friendly. He had 'forgotten' his sticks. So I said "You're not using heroin any more, are you?". "How did you know that, doctor?". "It's stunningly obvious, because your pain is better! We've had a ten minute conversation and you've been nice to me – you're a really nice person when you're not off your face!" It is striking from my perspective that if you stop these agents people will get better.

Back to me in A&E – or was it really me?

At some point in her life, pain became part of Myra's social identity. During the months and years of recovery from the fracture, *not* being in pain became mine. But that's all in the future.

Andy's cylinder may have been empty, but the one in the emergency room certainly wasn't, and the fentanyl they gave me was real enough too. The pain persisted—I know that, I was there, but it was no longer perceived in quite the same way. The pain was definitely *somewhere around, in the room* but I was now indifferent to it, and quite detached. I remember in my detached, let's be frank, *off my face* state, noticing this phenomenon: that the feeling that you experience can be quite clearly of the same quality, but if it doesn't matter any more. If you are indifferent to it, then it no longer seems to count as pain. But I'm no longer entirely sure that the person that all of this is happening to, is actually me. The effect of the gas and the fentanyl taken together have quite dramatic effects on other aspects of myself, apart from making me indifferent to the pain. I become quite ebullient – grandiose – perhaps a little lascivious. (Not like me!) There may even have been singing involved. They discovered during the secondary survey that I had gored myself in the groin with an ice axe. I don't remember much about the emergency room, but I remember trying to teach the (female) junior doctor how to tie surgical knots. That memory still punches through. But it was definitely me: I remember it: there is a connective chain of recollection, instances – little jewels of consciousness connected by this long chain of memory linking me with this person. But it doesn't *feel* like me. It wasn't me, in the sense that I don't recognise that subject to whom all these embarrassing things were happening, as that same, familiar presence that I think I carry around in my head. That person was an artefact of the drugs. So although I have this strong memory of this person with ostensibly severe pain which,

though persisting, wasn't truly felt, I have this strong sense that all this befell someone who, in some fundamental sense, wasn't really me.

It seems that Andy's wild side fracture reduction wasn't as great as we had hoped. The foot, blue and pulseless, is at risk. The fracture needs to be reduced *again*. The casualty doctor warns me, gravely that this will *really* hurt. Although backed by years of education and experience, he has none of Andy's authority. And I am terrified. He is clearly in something of a rush. 'Don't worry,' he says, approaching me with a syringe of Midazolam. 'We're going to give you something that will make you forget about it after.' I remember this, clearly, and I remember being troubled and puzzled by the ethical and metaphysical implications. But the rest of what happened in that ER is gone. The person that had the ankle reduced was excised, amputated and binned. It undoubtedly did hurt. A lot. I know this. It happened to me. But I do wonder: what is the status of an un-remembered pain? I wonder sometimes where in the universe that howling orphaned part of me might be?

What do we really know about pain?

So to go through my list of generally accepted characteristics of pain again:

*It is felt.* No, it doesn't have to be.

*It is instantly cognitively available:* not really; it is constructed by memory, story, meaning. It's something you do,

*It is a thing to be avoided.* It's not; if you are in that pain room you can shrink into yourself as much as you want until you are a tiny little thing like an oyster in its shell that pain will still come and get you.

*It is subjective* - experienced by a self; no, it is something that is experienced within a network of perception. It is universal

*It's a perception, not an action and passive in its nature.* No, it is fundamentally something that you do. There is no absolute difference between perception and action. One of the bits of syntax we have in our heads to make the world manageable is 'Doing is being is healing.'

*It has an evolved, hard-wired function to warn us of damage or hazard or harm:* but it doesn't have that function in the sense that .....

*It's the worst thing that you can have!:* it's not. Sometimes it is a friend that accompanies you

*You know when you're in pain. You can't be wrong about it:* I don't know if when Myra uses the word pain if she is using it in the same way that I do; it seems different and I often think that about my patients. They may know they are in pain but that is contingent on what we are talking about when we are talking about pain.

Nothing that I had thought so obviously and intuitively true about pain is as solid as I might have hoped. Indeed, when we are talking about pain, *we don't really know what we are talking about.*

We have this concept of epistemology within the philosophy of language ... you have necessary and sufficient conditions for a thing to be true. You need necessary and sufficient conditions to describe something as pain. I put up as many such conditions and have knocked them all down. So there is something as universal and important part of ourselves as pain for which we have no necessary and sufficient conditions to define it. So we have a big epistemological problem with what we think we know and can say about pain.

## Conclusion

When we talk about a token instance of pain, that is an individual pain, we're talking about something idiosyncratic and unique. It might be that there are elements upstream from the moment to moment instance of pain: the nerves, the brain, the culture, the performance, the emotions, the colours, the stories, the meaning and the memories – all the things in their coloured boxes connected by lines - all may be things that can be described objectively using scientific or empirical terminology as, what a philosopher might call natural or constructed kinds of things. But downstream to the pain itself, the perception of pain, the phenomenological occurrence in our heads: *that is unique*. The pain itself is its own thing, out on its own. And individual instance of pain is not something you can't generalise from, nor apply generalisations to. So our usual empirical, materialistic, scientific kind of way or thinking and talking about any individual instance of pain cannot work because it's not that kind of thing.

I think that this may have clinical implications. I'm hoping that some of you will disagree because the point of philosophical conversation is to shape an argument and see what falls off it and if you can find a better argument.

## Discussion

*In the Falklands war all the British soldiers were issued with Omnopon for their own use but in the battlefield they used it on each other. But those guys who had a leg blown off in a minefield, like they didn't feel any pain till they got back to the base hospital because the primitive brain knows that you are in a very fateful area and could be shot at any time, so it keeps you going to survive and there is an integration of the survival instinct and pain.*

*The tools that we have to represent pain change our perceptions of it rather than the other way round. So our representations of pain aren't necessarily what we believe pain to be. The more we represent pain as flow diagrams and computer circuit boards, the more we imagine it to be a property of the central nervous system. Historically, pictures of pain used to show people in agony, and then as time went on medical textbooks showed passive faces of people with no gender, and then the faces were removed altogether and became diagrams ...*

I wasn't being totally glib when I pointed out similarities between representations of pain structures and structures of pain services, because that is how our heads work. We human beings are linguistic creatures and we use metaphor. This is a wee challenge: next time you are in a difficult conversation with an uneducated person, listen for the metaphor and its richness with which people who haven't had a fancy education will still describe their worlds. It's a fundamental thing: when we report and talk about an event we use metaphor. We also experience events through the lens of metaphor and language. There is a wonderful book called *The History of Pain* by

Joanna Bourke and a chapter in this which describes the change in metaphoric structures of pain, how in the 19<sup>th</sup> century people described pain as *excruciating* - like Christ on the cross. The word *gout* comes from the French *gout* which means drop, and what it might feel like were you to drop some molten lead on your big toe. I would suggest that the ground of our metaphor constantly changes, so a drop of lead on our toe is no longer an effective ground for metaphor and *excruciating* has become culturally limited. Our ground for constructing metaphor which in turn affects how we act in and experience the world looks like circuit diagrams and algorithms because that is the nature of our interconnectiveness.

*What we are dealing with in the pain clinic or the GP surgery is not so much pain as suffering, and I was wondering how much of what you have been saying is relevant to suffering. Pain is obviously a huge component of suffering and you can't separate the two but ...*

There are themes that I have talked about ... one underlying theme is the problem of language, and one of the problems we have when dealing with pain is that we have this one little word *pain* which we are asking to do all this work. When we talk about pain we can't agree necessary and sufficient conditions for a thing to be described as pain. The more we think about it the more this concept comes apart in our hands. Philosophers talk about the intentional fallacy, which is when we use a word that has a meaning we think we all understand but actually fails to do the work we ask of it. A classic example of the intentional fallacy is: is it appropriate to describe Clark Kent as someone who flies through space and will be killed by Kryptonites, or are these the properties of Superman? We think that Clark Kent and Superman are co-extensive but they are not. We use this word *pain* to do all this work: to encompass suffering, horrible stories, bad memory, trauma, but that word can't do that work as well as ... the use of the word *pain* that we all agree is what I experienced when I broke my leg. That is a paradigm case of pain. But we need another word which might be suffering ...

*... which is even more difficult to define ..*

... but if we are going to use the word *suffering* we have to rethink what a pain clinic does. Because pain clinics have a paradigm case of pain as an epistemic privilege; they like the idea of pain as a thing that can be treated with drugs or something that is susceptible to being acted upon by a doctor or physiotherapist.

*In Welsh we have different words for pain: the pain after exercise is *Scrwb* (*Scroob*) and that can be a nice pain – just a bit of *Scrwb*. So a word can make a lot of difference.*

*In my talk I introduced some people who had recovered from chronic pain, some of whom had had it for twenty years or more. They had found that the meaning of pain had changed, the fear of pain had gone. They still had pain but their relationship with it had changed but they described it as 'normal' pain,*

A parallel interest of mine is that of medical humanities. A great deal of the work we do in general practice is like story editing. That is to say that we co-construct with our patients the narrative and the diagnosis. So if a patient comes to me and says "I feel tired all the time" and if I exercise I ache all over and I feel anxious etc. When I see them for the first time, I have the opportunity of co-constructing with that patient a narrative and diagnosis about what the symptoms mean. I could say to them on the telephone: "You have fibromyalgia and I will refer you to the fibro clinic"... Done. But in so doing I have imposed a narrative on that patient which is not only unhelpful

but will give how that patient experiences their life and their symptoms not just because of the label of FM which I think is unhelpful but will influence the way that patient experiences their life and their symptoms not just because of the label of FM which is I think an unhelpful one, but even the whole dynamic of me treating that person as a thing over the phone and passing them down the line like a rugby ball - disposed of them - I have made that person a passive subject of an abusive action and have not listened to them or dealt with them as a person. They will feel used, like a thing, with a part in a story which is profoundly pathogenic. We have this huge responsibility to help patients tell their stories.

*What I realised listening to you this morning was that all my patients who recovered had found their Andy! [the rescuer]*

*The same part of the brain lights up with mental pain as with physical pain – they are all linked together*

*Regarding narratives: I do phone consults and it is possible to co-construct narratives but the patient doesn't give you a clue so you say what's the story? - and help them to tell it. But we are trained in medical narrative and impose a particular medical narrative onto the story that the patient is trying to tell us. What we are not trained to do is to think of what kind of story they are trying to tell: is it a story of agency or loss of agency, a moral story about the kind of person that they are; is it a story to which the end is already written; is it a story that begins with something ... If we were so trained we would be more open to that.*

The way we are trained as doctors is the idea that a disease – in this case a pain – is an ontologically stable thing in an external world waiting to be discovered through our observations, questions and investigations. It would be true if it were lung cancer or plague which would be what it was irrespective of the person asking the questions and observing it. If I've got a broken bone it doesn't matter what the history is. But the problem is that a vast amount of the stuff we deal with in medicine is not that kind of thing. It's just as real; it's even more important but it has this phenomenological aspect. It is subjective and subject to change when it interacts with the world, particularly this horrible doctor asking questions ...

*...That's why we have to be open and listen to the patient without judgement ...*

... but we have to co-construct: if we simply listen passively, the story – the thing that is being described is not yet formed. Often when the patient gives us their story it is the beginning of a narrative which we must pick up and form with them.

*We hear what they say but we also hear what they say but we also have the ability to expand and explore and probe. When I started in a pain clinic in Northern Ireland we gave them a pain questionnaire at the initial consultation and people only put in 23 words; and after half a dozen appointments they were still putting in 23 words! I found that Stephen Morley's construct of pain that initially interrupts, then interferes, and then changes identity very useful because it is the identity that is the bothersome bit.*

*I walked by the river this morning and it occurred to me to wonder how many molecules are making up this water and are hitting the stones and becoming turbulent. Turbulence could be thought of as a bad thing but the sound was delicious ... and it made all the difference ... it was gone by the time you looked at it ... and that is about as solid as that diagram.*

So you are making something transient - of a moment – to form something much better ...

*... and the music will remain although that will never happen again.*

*You gave us a list of factors that comprise the experience of pain and challenged each one. It's rather cross-cultural; you must see in general practice people from all walks of life and different cultural backgrounds. Have you any comments as to how pain might be experienced in an Asian versus how it might be felt here? Are we talking about the same thing? If pain is something we act and has a social construct as well, if we are talking about an Asian who has back pain can you ever, or is it just not meaningful, try to equate that to someone with all the same descriptors from Western society. And then there is language - even in Wales they have different words for pain and in different cultures there will be all sorts of different descriptions like burning and in pain questionnaires the words have different meanings in different cultures.*

First of all I'm really hung up on this idea of the perception of pain being invisible as slightly hard to get your head around but using that model makes sense of the world. I have noticed that Asian women, for example, perform pain differently. I spent three months in Pakistan where I saw a lot of a rural ... not of the typical ethnicity of southern Pakistan, but mountain people in the north who are very stoical and perform pain extraordinarily differently. I was sitting with some medical students in a clinic and this guy comes in with a black plastic bag and this doctor from the south sitting next to me says "you will never have heard of the black plastic bag sign" and the man puts down the bag and his insides come out! He explains that in communities where there are lots of long horned buffaloes the black 'plastic bag sign' is a sign that he has been gored. They say "We'll take this chap to theatre and clean him up and he will probably die" but the fact that this guy has walked to the hospital with his insides in a bag was as stoical as you can possibly imagine. I worked for a couple of years in the rural Andes in Bolivia with mountain people and observed a similar kind of thing: people with bits of them chewed off by wild dogs ...

In this country it's different: I often see people who seem to me to be elaborating pain behaviour as a means of exerting power. Quite powerless people have been deracinated and don't necessarily have great English who perform pain in a particular kind of way which is about power in a particular situation, and I see their daughters and their granddaughters who are just like Edinburgh natives. So it's not about being Asian it's your context. And the language is important.

*It's the same in Cambodia: they are very active and don't lie in bed all day if they are ill or injured*

*You talked about traumatic amputations from explosions and probably when you lose a limb the trauma to the remaining tissues is enough to induce temporary neuropraxia so there is no reason to have pain - you have lost the limb so there is nothing to hurt. When I was in China we did a lot of surgery with acupuncture and a bit of local anaesthetic. The surgeons were very gentle, and if you take a very sharp scalpel and slice open someone's abdomen there is actually very little trauma. In the midline there are very few nerves. In China in the sixties when they were doing a lot of surgery without anaesthesia the surgeons had small hands like fish and the patients didn't need much analgesia and the purpose of hypnosis or acupuncture was to reassure the patient that it's OK. It's the thought of having the surgeon's hands inside your abdomen that provokes the emotional response, and most of what we are dealing with is the response, not the stimulus – there may not even be a stimulus.*

Response is a downstream thing which is affected by ...

*... What you are describing – if you were distracted from it - If you cut yourself with a sharp knife while washing up you may not even be aware of it until you see the blood and you think it really hurts*

*Why do people get chronic neuropathic pain in their scars?*

*... That's way down the line....*

*... but you must have activation of the nerve ...*

*... well, a form of reorganisation presumably – but I'm talking about the distinction between stimulus and response; even with neuropathic pain such as trigeminal neuralgia what we see is whatever is going on in the nerve plus their response to it.*

*When I am talking to people who have recovered I ask them what happened and what did you learn; why and how did the meaning of pain change for them. They needed to learn what happened to their biology and that is how the fear was taken away and they learnt that movement wasn't harmful but actually beneficial. I don't run a 'pain management' programme because I hate the term – if someone told me I would have to manage my pain for the rest of my life I would be lost before the course had even started – and I run a wellbeing programme for people with long term pain. But I do run a session – and you are making me question this – on pain and what we know about it at this moment. I do put a diagram up which it is one that I constructed myself and I hope that it shows some of the complexity. I do have lines representing nerves going up to the brain but I say that's only a small part of the conversation which involves everything social, everything that is going on in their world in that much wider context, I think it's important that they understand the complexity because they then understand why taking a pill can't possibly rectify that. So I am wondering how we actually get that information across which is really difficult in words.*

I wouldn't want to overstate this but ... first of all, nothing I have said about having a deeper understanding of the nature of pain is an argument for recommending that we know less about the physiology and mechanisms of pain. I think it is laudable to try as hard as you can to explain to a person what is going on with them. But have your eyes open to the fact that every time you explain you are substituting one metaphor for another. Your representation of pain is not pain itself; it is a different kind of metaphor which in this instance is a great metaphor for what we think is going on in their body. That metaphor may work for people that share the same ground - for someone who has a basic understanding and is apt to understand such explanations for pain. But you need to know who you are talking to achieve that. If you try that metaphor on someone who is hostile to empirical world views and likes spiritual or magical explanations or stories – or someone who comes from a different culture and doesn't share this metaphorical ground, then you are simply substituting one metaphor for another and you don't know where it's going to go. And our track record with metaphors as doctors is probably not doing much good.

## Inflammation

## New ideas about an ancient process

Maureen Tilford

This talk is based on the book *The inflamed mind* by Edward Bullmore

We are all familiar with the fact that any injury which breaks the skin triggers an inflammatory response. Thousands of blood cells, the macrophages are swift in their response as they rush to the site and get to work ingesting any invading bacteria they come across. They spew out digestive enzymes and also produce pro-inflammatory substances, cytokines, to alert the rest of the immune system to the invasion. This process causes a lot of damage to innocent tissue around and about so it's just part and parcel of the inflammatory process – it's not perfect. What happens in tissues like skin and muscle and bone is that you get scarring; the brain is somewhat protected from that, but you do get damage to neurones and other healthy tissue. Macrophages going up your arm in the lymphatic system into the lymph nodes There are lymphocytes in these and they are reading the markers of the macrophages. So the macrophage is bringing bits of bacteria to the lymph node and they make antibodies to that particular organism. This can take a few days, which is why the glands don't swell up straight away. They pump antibodies into the bloodstream where they fight the bacteria which are being both eaten and attacked by antibodies. Unfortunately, sometimes a normal bit of tissue is going about in the blood and the lymphocytes think it is alien and make autoantibodies and start attacking healthy tissue. Rheumatoid is the most obvious example: you get redness and swelling and damage to the joint etc.

What is also interesting about inflammation is why do we see it in obesity? One theory is that as the fat cells and the tissue get bigger and bigger, bits of dead fat cells start occurring at the centre because the blood supply can't sustain this great big fat lump, so you end up with inflammatory cytokines coming in with the macrophages to get rid of the dead bits of fat, and people with obesity have high inflammatory markers. You would expect to see this in inflammatory disorders such as SLE and inflammatory bowel disease, but it also seems to be a consequence of things like poverty and debt, conflict, social isolation, child abuse as in neglect, violence, sexual abuse, social stress: public speaking! - and bereavement. People in war zones will all have high levels of cytokines and CRP – the things people you can measure to assess whether inflammation is going on in the body. and if you have been abused as a child early and severely enough you will have raised inflammatory markers for ever.

So what about the mind and inflammation? When Bullmore was a junior doctor he noticed that 50% of his rheumatoid patients were depressed; his consultant said "well, you would be, wouldn't you?" and the perception then was that it was a natural reaction to being ill, but he now thinks that it is very much entwined with the inflammatory process in the brain: a physical change in the brain bringing about the mood change. They did a study of obese children in the States and of the 95<sup>th</sup> percentile -very big girls - 30% were depressed.

This is what measurable things ... but there are lots of different cytokines and they do different things and you have to be quite specific about what you are looking for.

So people started looking at the connection between inflammatory diseases and depression, and we now have immunopsychiatrists and there have been a whole load of studies of patients with a major depressive disorder and the DSM 5 which

defines psychiatric disorders. (if you have rheumatoid or inflammatory bowel disease and you are depressed it won't be classified as a major depressive disorder because it is excluded from the definition.)

There was a study done in Copenhagen looking at low grade depression, with people just thinking they weren't accomplishing much and wanting to give up, found higher levels of inflammatory markers than happy controls, and the more negative they were feeling the higher the CRP.

We now know that cytokines and other inflammatory substances can cross the blood-brain barrier, and activate the microglial cells which are the macrophages in the brain to make more cytokines which damage nerve cells, degrading synapses which lose their plasticity leading to cognitive impairment, memory loss and reduction of adaptive behaviour. So when you think of someone who has been abused as a child they are not very adaptive, they fly off the handle and they aren't very good at remembering things. The same things happen after a very bad experience or depression. Serotonin production is disrupted with depression of mood.

So – what about anti-cytokine drugs for depression? Anti-cytokine drugs such as Remicade (Infliximab) given to RA patients have dramatic results on mood as well as on joints. A meta-analysis of 20 studies shows that anti-cytokine drugs such as etanercept and infliximab prescribed for inflammatory conditions such as rheumatoid arthritis can improve depressive symptoms, regardless of improvement in physical symptoms. Ward patients loved the nurses that gave them the infusions!

The other interesting thing in the mental health universe is psychosis which is notoriously hard to treat, and some people never completely recover. A small number of psychotic patients with an auto-antibody to the neurotransmitter NMDA were given immune treatment with rapid and lasting recovery (A new trial with larger numbers is ongoing). [NMDA receptor antibody encephalitis is a rare but well documented syndrome of acute psychosis, and may be involved in more psychotic patients than currently recognised ]

The vagus nerve has a massive network of nerve endings in the spleen where many macrophages reside. When these macros are activated as in inflammation the afferent and efferent messages are conveyed to and from the brain via the vagus calming the inflammation down. Stimulation of the vagus nerve via an electrical implant in the neck damps down inflammation and pain in RA. It is thought the mechanism is via efferent vagal fibres to the spleen reducing inflammatory cytokines in the body. These devices have also worked and are licensed for depression since 2005 but placebo controlled trials have not yet been done.

Can we reduce inflammation without drugs or electronics? - yes! Meditation and Tai-chi have been shown to reduce the expression of genes controlling the activation of macrophages in response to infection. Hypnosis reduced the level of cytokine IL-6 in Ulcerative Colitis; the inflammatory markers went down and the symptoms got better. Mindfulness reduces expression of genes in white blood cells influencing inflammation

Forest Bathing? Definitely!! The research hasn't been done yet but perhaps it's something for us! [The group had been enjoying this the previous afternoon]

*... grey matter changes in people who do it regularly ...*

... in people who have had early bad trauma the hippocampus shrinks ...

## Discussion

*The record of the first few minutes of this is fragmented, with brief interchanges of comments and people talking over one another, and difficult to transcribe*

*The pro-inflammatory Western diet, and sugary fizzy drinks (and artificial sweeteners) also enable cytokines ... the cardiac stuff. ... People who don't exercise have higher cytokines. Good sleep will lower them. ...*

*... exercise and sleep improve the biome*

*CRP is an acute phase protein ... chronically raised ...*

*High sensitivity CRP - there is a different way of measuring them – it's more nuanced*

*One of the interesting people on my Tai Chi course was a man who called himself a psycho-neuro-immunologist. He was about to set up an inpatient clinic for people with functional neurological disorders. He regards fibromyalgia as being in that range of conditions. He looks on them as derangements of your body's protective mechanisms which are not responding appropriately. So the three month programme is aimed at recalibrating these mechanisms from the bottom up. I'm not sure how he does this but it does seem to me that if you regard the immune system as one of them it is not surprising that in someone who has had childhood abuse these things have a lower threshold for activation.*

*There was a study of medical students measuring markers when they were taking exams They split them into two groups and taught one of them relaxation or mindfulness techniques and the levels were reduced in that group. That was triggered by the correlation of increased respiratory infections during the exam season.*

*And it struck me that when HME [??human monocytotropic ehrlichiosis?? or should this have been ME?] first hit the scene in a big way we were exceedingly thick about it because we didn't have any answers. And I think people were really trying to explore nutrition and wellbeing because conventional medicine didn't offer anything except you are going to die – it was almost like a curse – and some of them derived a huge amount of benefit...*

*... and when you think of the back and forth between the body and the mind ... if someone's lifelong partner dies quite often they die in a few weeks. It seems to me that the inflammatory markers must go up and if they've got any plaque in their coronary arteries the macrophages go in and eat the cholesterol foam cells which are just full of fat and the surface of the thing gets sticky and so a clot forms. So there might be an explanation – and this may be going on in the brain circulation and cause a stroke. So people probably do 'die of a broken heart'.*

*There was a study done in Harvard of a chap called Thomas Keating who is a monk who taught these high-flying students who were doing an MBA how to meditate twice a day for twenty minutes and all their marks went up by at least 10%.*

*Polymyalgia rheumatica seems to be triggered by stressful life events; when I was in general practice a typical patient was a 70 year old woman who had had a bereavement*

I went to a talk once by a French gastroenterologist who had done a study comparing Crohn's disease with Ulcerative Colitis and asked them what had happened in their lives over the last two years. He had found a marked difference between the two: most of the people with UC had had a major loss. When I was a GP in Norwich there was a child of nine who developed UC about six months after his best friend had been murdered. So his cytokines were probably way up and the bowel being attacked ...

But what is interesting about meditation and Tai Chi and all these things that we are aware of that make us feel better and all the rest of it ... it makes you wonder: what about the connection with the patients, the love and compassion and caring and giving a damn. We are all clinically experienced in that and connecting in this way perhaps changes the inflammatory markers and as the patient calms down this will have a 'physical' effect as well.

*We were discussing in the coffee break: how do we help people to become 'Andy's' [vide Peter Dorward's account of his climbing accident and the rescuer Andy] – to the point where they trust you enough to actually want to do what you are suggesting.*

*... we have heard stories of people who had changed them and been a catalyst for behaviour change and if we can be that person ... there is no reason why clinicians working around people in pain in all sorts of capacities cannot be that agent.*

You must use the right language and you can ruin the connection by fiddling around with the keyboard ...

*It's very much about being present in that place with that person - and people sense that. In my Tai Chi teachers' course, when I had to teach other people, my first pupil was a single mum who was a counsellor for young people who were terminally ill with cancer. She works fulltime and has a severely autistic son who needs 24-hour care and a severely spastic son, and has to work some evenings to pay her way. She found Tai Chi really helpful but between clients – who could be a fifteen-year old with only weeks to live or a twenty-year old who has just been diagnosed – between sessions she does that return to the centre, taking ten minutes to bring her mind into that space, emptying her mind of the last person. She finds this helpful not only for her own health but also her clients'.*

*There is research showing that if you meditate before a clinic it goes much more smoothly.*

## Changing the culture of Pain Medicine: has there been any progress?

Peter Wemyss-Gorman

This is going to be the reverse of the definition of a lecture as a means by which Information is conveyed from the notes of the lecturer to the notes of the student without passing through the minds of either. I have very little information to give you and I am relying on you lot to inform me and fill in my second hand impressions from your recent first-hand experience.

Changing the culture of Pain Medicine was the theme of our 2013 meeting at Rydal Hall . Over the years we have spent a lot time bemoaning the shortcomings of contemporary pain medicine and medicine in general and society and so-on – we are very good at identifying the problems but not terribly good thinking of anything optimistic to say about it or identifying the things that need to be done. So at that meeting we attempted to acknowledge the reality that identification of these was of little use if they continue to be regarded as inevitable, and we decided that our task that year would be not only to define a new culture of pain medicine but also to determine the best means of 'evangelising' the message of the need for change, not only to our colleagues in the speciality but to the medical and health professions as a whole.

We realised that we had set ourselves a formidable if not insurmountable task and if anything this was reinforced by our keynote speaker, John Loeser. His name was among those my generation of pain clinicians would have pronounced with hushed awe and he still stands among the giants of the pioneers of our profession. As one of the founders of the IASP and its president from 1993 to 1996, he was uniquely placed to command an overview of pain management throughout the world, and to have observed the trends and changes that have emerged during his long professional lifetime. I remember thinking that a possibly better theme for the meeting would have been *restoring* the culture; he had worked with Bonica and others in the early days when the concept of multidisciplinary management of pain and treating the whole person was paramount, but now found himself painting a dismaying picture of pain management in the USA now totally dominated by the business model and the power of insurance companies to dictate treatment,. Patients get what the insurance companies would pay for rather than what they actually need, and what they get is 'blocks' (ie injections) and most pain clinics in the USA are 'blocking clinics'. They don't want to pay for multidisciplinary pain management, resulting in its virtual disappearance. When I first got into pain medicine in the 70's we were decades behind the Americans in the concept of multidisciplinary pain management and PMP's and so forth and it is tragic that they have now fallen so far behind.

He did admit that - I am quoting him here -

" My remarks are based predominantly on what I know, which is the United States, and the USA and the UK have very different health care systems. So many of the issues that I will address may be more prominent and problematic in my country than in yours. But my travels have told me that the same issues come up in every country I have been in; it's just the relative proportion of which issue is the big one that changes".

His suggestions for changing the culture of pain management were, first of all, that we will need to select different health care providers. His main recommendation was that:

“ You don’t want surgeons or anesthesiologists to be the front line. We should mandate that most pain management is done at the primary care level. Pain specialists should be generalists, not proceduralists, and referral from a pain generalist should be required to see a procedural specialist. Nobody should walk into a pain clinic and get a block a half hour later. Chronic pain management should not be under the aegis of anesthesiology; it is a primary care function and procedural specialists should not be the entry point for care”.

This is a pretty radical solution to the pretty critical situation in the US; it would make a lot of sense here as the great majority of pain is dealt with by GP’s and although I doubt if many would welcome any addition to their already near intolerable burden it is certainly something that could be debated. We have done our part by trying to recruit GP’s to this group but have not been very successful so far. There are already nurse-led clinics within pain departments with nurses seeing new patients; perhaps we will see nurses as lead clinicians one day.

I asked him, in preparation for this talk, if there was any improvement in the situation in the USA since his visit and this was his reply:

“The only change that I have noticed is that more and more authors refer to multidisciplinary pain management as the preferred form of therapy for chronic pain. I am not sure that that translates into more treatments of that type. We are still swamped by injections into every part of the body and excessive procedures for low back pain. We still pay proceduralists far more than pain managers, and we have very poor distribution of pain specialists in the more rural part of the country”.

So ... so far so depressing.

But I don’t think anybody could argue with Loeser’s final point: “perhaps above all we need to change pain education. Pain must be introduced into the basic professional curriculum for all health sciences”. Ed Peile, Professor Emeritus of Medical Education at the University of Warwick who spoke at the same meeting talked about teaching *values* to medical students.

The best clinical decisions are based both on the best available scientific evidence and on the *values* relevant to the individual patient situation.

Looking again at the transcript I am aware that we never actually got round to defining the culture of pain medicine - possibly because we all thought we knew what we meant when we used the word - and perhaps we could substitute values – or ethos – for culture in the present context.

Are things much better here? In looking for evidence to support my suspicion that not much has changed for the better I came across an article in the British Journal of Pain: ‘ *A national survey of pain clinics within the United Kingdom and Ireland focusing on the multidisciplinary team and the incorporation of the extended nursing role*’ (Pungavi Kailainathan et al August 18, 2017)

<https://journals.sagepub.com/doi/full/10.1177/2049463717725015>

- which some of you may remember. This painted, as you might expect, a very variable picture. You may not be surprised to hear that “ Relatively minimal qualitative data (arguably the only important ones in our present context) were collected ... due to the fact that many responders were not forthcoming with opinions ... [perhaps] because they were worried that they might be quoted directly”. They found that 84% of the clinics which responded used a multidisciplinary approach and 16% did not. Only 59% had at least one WTE doctor, nurse and physio. 3% had daily Team meetings, 43% weekly ones and 29% never. 20% of clinics had no physiotherapists and 32% no psychologists, so did not meet the BPS criteria for minimum staffing. The fact that the remaining majority of clinics were indeed fully staffed is reassuring but hardly compensates for the depressing evidence that too many could not be said to be providing an adequate service for chronic pain patients. Of the clinics that included nurse-led clinics seeing new patients, opinions as to their safety were variable, although there were no worries regarding nurses seeing follow-up patients.

Incidentally they found that the percentage of patients referred for ‘injection- based therapies’ varied between less than 25 to 75% or more. I don’t know what the figures would have been 20 or 30 years ago but my suspicion is that they would be substantially higher. (There was no mention in the article about more sophisticated interventions such as neuromodulation.)

By the way, I haven’t been able to find if there are any pain clinics employing a hypnotherapist although of course many psychologists have trained in hypnosis and do use it in their practice.

Although this survey does present some relatively encouraging numbers among the depressing ones, one thing that doesn’t come out is the way in which the Pain Management Programme is regarded and presented to patients in different clinics - I mean, is it a last resort when all else has failed,(or when the patient has ‘failed to respond’ to treatment, as if it’s their fault) or as an essential integral part of what the service has to offer, and if it seems appropriate - or more appropriate than a probably ineffective intervention – something to be discussed at the first consultation, along with the wider problems of living with pain. My impression is based on admittedly little evidence including working as a locum in a department where the former certainly appeared to be the case and talking to members of this group, including Ian Stevens who was so fed up with his role apparently being regarded as simply to provide a dumping ground for the doctors’ therapeutic failures that he resigned his job as a physio in a pain clinic.

So I have a number of questions for you which I ask from the perspective of someone who has had no first-hand clinical experience for nearly twenty years

- Was the situation Ian described widespread? – is it still?
- Do patients still arrive in PMP’s resentful of the implication that psychological interventions were necessary because the pain is ‘all in their mind’, or have attitudes generally changed in the recent past?
- If it hasn’t changed, what hope is there for the future?
- What are the factors inimical to change? Are these common to the NHS in general? Managerial? Are they partly economical?

In this context, I am reminded of the argument that the cost of implementing the first lot of guidelines back in the 90's for the management of back pain was dwarfed by the huge cost to the taxpayer of treating this and the consequent loss of work.

- Are there any glimmerings of hope on the horizon that we will get much better at treating pain - especially neuropathic pain? Is the long-expected spin-off from research any nearer to becoming a reality than it was twenty years ago?

I have a suspicion that lack of recruitment to consultant posts in pain may be in some part due to the perception that medical graduates could be doing something more useful with their time and training than working in a speciality where failure appears to be, if not the norm, at least a daily experience. Is there any truth in this?

- Are we in danger of going or have we already gone down the same road that John Loeser described in the UK? – perhaps propelled by managerial pressures
- I think we would agree that pain clinics should be *both* about treating pain *and* healing suffering, rather than either or. Is this an impractical ideal?

## Discussion

*Pain Clinics don't seem to be progressing very well. There seem to be issues with the CCG's regarding referral for pain treatment. Where should pain lie? In neuroscience or part of anaesthetics? I don't think it should be part of anaesthetics at all. In America the first pain clinic in Seattle under John Bonica was multidisciplinary.*

*Isn't it going to change with the NICE guidelines on chronic pain which are just about to come out [as in June 2019. Publication date still 'TBC' in March 2020.]*

*One thing I was going to bring up after David [Laird]'s talk yesterday was what are we doing and what have we done as the Pain Society? We did put in a response to the NICE drugs ... I just want to talk for a moment or two about the way the NICE process works. It is very transparent and very thorough; the first thing they do is to set up a committee. The committee they have at the moment seems to be very 'non-interventionary'. There is a GP on it and an acupuncturist, physio's, no psychologists but Amanda Williams has been co-opted in that role, there are MSK physicians as well as lay people. So it's not obvious to me that on the whole the group would be in favour of sticking needles into people. It could be that their recommendations might result in a lack of this. Spinal cord stimulation is interesting: one of the problems with NICE guidelines is that they have already published them on low back pain, sciatica and neuropathic pain in which things like SCS are permitted, so it's difficult for them to come up with new guidelines for chronic pain in general.*

*Is it a mistake not having interventionists, given that there is a large number of people out there doing those things?*

*There is no doubt that injections can help in a multidisciplinary scenario, so it's very difficult to say "you definitely can't do that".*

*Our response from the BPS to the draft guidelines was they should be looking separately at assessment, management and treatments for chronic pain overall, Initially pharmacological and non-pharmacological treatments were part of*

management but in the revised guidelines they took them out of management in general. What they are now saying is that the management of any form of chronic pain will be the same unless it is something like neuropathic pain or low back pain and sciatica the pharmacological and non-pharmacological treatments will be separately considered but the general principles of management even of those conditions will still come under the chronic pain guidelines. The response from the BPS was to emphasise the complexity of the lives of patients who have persistent pain including high levels of psychological distress, a history of difficult interactions with health care providers, and that persistent pain problems frequently co-exist with anxiety, distress and depression. The response from NICE to that was "thank you for your comments; the scope of the guidelines has been amended to clarify that biological, psychological and social factors will be considered as key areas in the assessment of chronic pain.

Another comment from the BPS was: "it should be recognised that there are pain conditions that are not already covered by separate NICE guidelines on individual pain conditions that cannot be included in the general guidelines because they require more condition-specific guidance, for example Ehlers-Danlos syndrome and post-stroke pain. Treating persistent pain as a single clinical condition will be inappropriate in many cases".

The third point was that "the BPS agreed that the treatment of persistent pain generally has low measured efficacy in controlled studies, but are widely used with apparently greater benefit in the clinical setting. It welcomes the suggestion of better evaluations of these treatments together with their mechanisms of effect." NICE agreed with that.

The most important point we made was to "advise particular caution in designating pain treatments to be of no clinical value on the basis of lack of published evidence of efficacy in trials that may have little relevance to the complex clinical situations that are often seen in pain clinics. The benefits of patients attending pain clinics usually go far beyond the effects of any specific treatments they receive and include the recognition of their pain as a genuine phenomenon, insights into the mechanisms and effects of the pain, and an understanding of how best to approach the problem of living with pain" The NICE comment on this was "thank you for your comments. NICE guidelines are based on the best available clinical and cost-effective evidence... [Groan from the audience] ... evidence to inform the review questions will be carefully considered by the technical teams and committee when setting the protocols for the review. So it's a bit like ... saying no. The exact point we were making is that the evidence is likely not to be there, but it looks like NICE may not consider that. But some of the points we made have been taken up.

*Is the technical committee the same as the one you mentioned earlier?*

NICE is a huge, amazing organisation, including some amazing statisticians who do all the cost-effectiveness stuff as well as high calibre clinical scientists who go through all the papers and analyse them. They have advisory committees; I was on an advisory committee for the ..?... stimulator So when they don't understand something they come to experts for explanation. But the simple problem is that if the evidence isn't there.

But I am heartened by the fact that Jonathon's GP colleague is going to be on the committee. I think that what we will see is probably a move towards recommending what we have been talking about this morning: moving pain services generally into primary care.

But one of the main things we will have to consider- a vast elephant in the room – is that, at least in the Bath area Primary Care services are now run by Virgin Care. They are £2.5 million in debt. they have just cut 40 district nurse posts and have

*made the head of mental health services redundant. So the clinicians are having to try do what Virgin Care wants them to do but they can't. my course is funded by Virgin Care and it may not run again this year. They are constantly trying to get me to take more patients than possible.*

*There's some politics stuff: we're in Cumbria now – I think someone mentioned the Cumbrian Primary Care Partnership so basically Cumbria looks at the best thing to do and they closed their pain clinic in Carlyle and introduced largely primary care, largely psychologically based service to which there was a lot of reaction by the medic side of things, but seemed very sensible – provided it is well funded, and my concern is that all of this could be used as an opportunity to cut services and save...*

*... Even if they can save money more expensive pain clinic they probably won't put that money into the primary care service ...*

*... they do a calculation which shows they are improving care and saving money ...*

*It was a political decision not to give ... say Virgin Care got the tender ... some politicians up at the DOH decided not to give them enough money to do the job; they had tendered low to get it so the contract was underfunded and it won't work. And I think the CCG's across the board have got a body of money and it's all that instant money, for this year only, so the cost effectiveness of something that is going to take years to evolve is never ... Is the Carlyle scheme cost effective?*

*...I have heard some good things about it...*

*... a company called ?NHS?care? .... did a cost effectiveness analysis before and after ... they saved money and outcomes are better. One of the issues... an all singing all dancing medical side they found they got 30% more people than they thought they would ...*

*One of the criticisms made by a psychologist on the BPS council was not employing trained pain psychologists ; they were general psychologists. They were dealing with chronic pain patients in amongst any forms of distress such as morbid obesity, bereavement etc. and there was deep concern about that.*

*[unclear] There are different patterns. We are complex systems and we make an apparently simple change and the ramifications further downstream are magnified. In Durham they contracted PMS [ Pain Management Solutions] to run the services. The psychologists were keen to cross over into that service but PMS said 'here's how we want you to work; half hour appointments, maximum one year . ... and we had no integration with doctors or other staff ... but because they had the contract all the patients were coming through and having pain management programmes that were essentially just read to them.*

*I have certainly seen with Pain Management Solutions in our territory some fairly good results but I have also seen people who have been through it as an exercise and it has made no difference and probably made them more frustrated and more invalid to their narrative.*

*I get concerned about the triaging process. I have less experience of pain clinics but regarding mental health issues 40% of which are dealt with in primary care: depression, anxiety, OCD etc. , we had two psychotherapists embedded within our practise; we had a small budget for them and this service was extremely cheap to run; we knew each other, if there were problems they could come and discuss them*

*with us and it all worked extremely well. We had brilliant outcomes: 60% recovery within a year. Anyway, they binned it and everybody had to be seen through the wellbeing service which was triaging people through a system where the people who were frontline decision makers didn't really know what they were doing; they were the least trained, had no experience.... And it's all gone very bad, and everybody says the wellbeing service doesn't work.*

*In our area they have to save money made the clinical ? redundant and have replaced them with younger people who have a degree in health management and no clinical experience and taken away the one-to one psychology sessions; you now have to see the psychologist in a group even if you have real problems ... That programme is held in a locked psychiatric unit ...*

*I would like to try to be positive! In Scotland, Pain Association Scotland (<https://painassociation.co.uk/ourcharity>) which is funded by the Government and is very successful mainly because [... inaudible due low-flying aeroplane...] it is not run by a doctor nor a physio, but a philosophy trained former banker, Phil Sizer, who has written an excellent book on pain management. He is an amazing, intuitive communicator who continually evolves the way he delivers. He is an archetypal example of someone who delivers with good intent and well organised. He travels everywhere from the east end of Glasgow up to the outer Hebrides and delivers things at low cost as compared with huge bureaucratic ways of doing them, largely single handedly from a little office in Perth.*

*Do they see patients?*

*No – it's a purely educational wellness programme. He's not dictatorial. That kind of very low cost model with the right approach could be a solution for many places.*

*Another positive note about the opioid crisis: there is obviously a lot of concern about that but the fact that it has been recognised that opioids are not the answer to chronic pain has opened opportunities for alternative management and thinking about why these people are so distressed and what is going on in their lives. It's certainly made me think about some of my patients who have been on opioids and how they could have been managed more appropriately.*

*I think with the right intent programmes like that in a primary care setting could be a really effective model and I can't see any reason why that couldn't happen. In practice is requires GP's in that scenario to be enthusiastic about it ...*

*... That's the crucial thing. The reason it may not work is that there is a huge push towards everyone having exactly the same treatment. Removing any difference and putting a formulaic process in place so that everyone gets equally bad treatment... that's one reason why it makes this slow to take off.*

*What happened in our trust was that I had a two to three week waiting list and a little local admin budget of a few hundred quid which was replaced by a huge spider web of bureaucratic where everyone screens the patients and the waiting list has gone up from two to three weeks to four months. That is supposed to produce equality of care. This instead of saying "this chap is doing all right and seeing people quite quickly with no complaints – why don't we replicate that?"*

*... it needs to be solved in a way ... generic ... not too specific ... and keep it fairly open ...*

*There are huge vested interests... thinking perhaps of the neurostimulation group: I try to be positive about neurostimulation but I am convinced that for some of the people we have been talking about here it is probably the last thing they need and they probably don't get the care that they really need. On the other hand some do extremely well with neurostimulation and that perhaps reflects the complexity of the situation we are dealing with. It is very difficult to get people who are doing stimulation to listen to other arguments, and perhaps we don't listen to their arguments. PMP's, again: I think there are people who are over-zealous with their approach and that's what they get paid for so everyone has to come to them. There are a lot of inter-professional barriers.*

*People living with pain are receiving letters from pain clinics to say they don't fit the criteria....*

*So, Peter, when you opened this question, what were you hoping to hear?*

The word hope doesn't imply any certainty about the outcome of a question but I did harbour a smidgeon of hope that there might be some signs of improvement or sources of cautious optimism. So although I am encouraged to believe that more and more people recognise what needs to be done or changed, my optimism is rather dampened by what I have been hearing about the frustrations and administrative and financial restrictions people have experienced when trying to put these changes into operation, or even stop things changing for the worse. It sounds as if a lot of the financial measures are wasteful and counterproductive and one can only hope that the powers that be will start to recognise this before the system breaks down altogether.

*Can I just add: I am very concerned that healthcare professionals are being over-ruled by managerialists because it really does mean that no-one respects the former and it makes you wonder who is going to bother to train to be a doctor or nurse if that is the way they are going to be treated. It does make me worry for the future. If Circle can just come in and take over part of the NHS, that is very wrong. We need to fight back somehow.*