

GOING BEYOND
the
BIO PSYCHO SOCIAL

**The complex human in
a complex environment
and uncertain world**

Betsan Corkhill



Betsan Corkhill - I am a Lifestyle-health and Wellbeing Coach specialising in working with people who live with long-term conditions, particularly ongoing pain. I have a clinical background in physiotherapy spending many years helping those with long-term medical issues.

I left physiotherapy in 2002 having become frustrated at the 'system' I found myself in. I was working in the community and was expected to treat people with multiple comorbidities of all ages in a few visits. Many had the capacity to improve significantly given time and ongoing guidance. I felt they should be offered the opportunity.

I am a passionate advocate for a whole-person approach to health, from managing day-to-day stress and life's inevitable challenges through to managing ill-health. My many years as a physiotherapist have enabled me to combine my clinical knowledge with coaching to help individuals navigate our fragmented health and social care services, as well as to improve their health and wellbeing.

My work as a Lifestyle-health and Wellbeing coach involves working with individuals, globally; running 'Wellbeing for People with Pain' programmes; wellbeing modules on subjects such as stress, sleep, movement, pain, social connectedness; speaking and writing commitments and being a Tai Chi Movements for Wellbeing trainer. I have also been researching the meditative, creative and social benefits of knitting and developing the concept of Therapeutic Knitting to improve wellbeing. I work with local charities to enable those attending my courses to come at significantly reduced cost or free.

Going Beyond the Bio Psycho Social

The complex human in a complex environment and uncertain world

Betsan Corkhill

As I've learned more about pain, health and wellbeing, I've realised how complex they are and how little I know.

Getting to grips with complex systems is a bit like trying to get your head around questions like "Where does the universe end?" It can make your head hurt if you think about it too much. Dealing with dynamic, organic, complex systems involves things we don't fully understand, so it becomes easier to simplify, safer to compartmentalise, and we can go so far down this route we lose sight of the complexity. People and life are messy, and the longer you live with conditions such as long-term pain the messier and more complex it gets.

We've thankfully moved into an era where anyone taking a purely biomechanical approach is considered outdated. However, even the bio-psycho-social model doesn't grasp it all. As Cabaniss says, "It chops the patient

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

Robert Sapolsky 2017¹

into three neat packages."²

These artificial boundaries can result in silos of fragmented care that distract attention away from the person as a dynamic whole embedded in their environment. As a result those living with long-term medical conditions often acquire multiple labels and go down individual pathways of care for each of these with little consideration for the whole or communication between the siloed specialties.

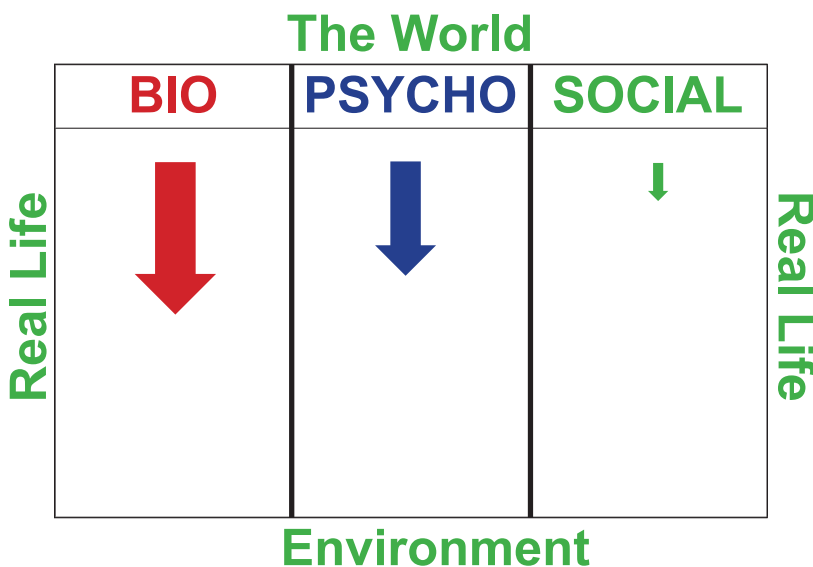
"There is no distinction between the liquidity of milk, the whiteness of milk and the nutritious qualities of milk. The consistency, colour and quality of milk are an integrated whole."

Satish Kumar³

Even the way we approach rehab and exercise is linear. We've all met people who avoid any unnecessary movement yet 'do their physio every day'. The message of being more active in general isn't being translated across into life as a whole.

As far back as 1946 Aldous Huxley said, "Medical science has made tremendous progress, there is hardly a healthy human left." His comment holds true today. It's clear that we need to change our thinking to create new approaches that encompass the complex nature of life, health, and ill health. Health and Social Care systems that aim at nurturing health and promoting recovery.

Humans are complex beings. The human body consists of a range of complex systems from cell to whole, plus trillions of microbes that all interact in complex ways, embedded in complex environments in an uncertain, complex world. Consider, for a moment, the fact that the genetic material of our microbes is greater than, and engaged in a dynamic complex interplay with, our own. We can't separate these out. Our health, wellbeing, what we feel and experience emerges from this wider complex interplay of



interwoven, intertwined systems. We experience the world through our lived, whole body embedded in information-rich environments.

Complex Systems

I've become increasingly interested in the Theory of Complex Systems and how this can be applied to the human being and experiences such as long-term pain. Here are some facts about complex systems -

- The whole is greater than the sum of the parts
- Separate out the parts, the whole will be lost - eg life
- 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 - eg X-Rays, scans
- They are dynamic and adaptive - constantly changing in response to experience and context
- To understand a complex adaptive system, you need to know its history - eg the person's story
- They are nonlinear and behaviour can be irregular
- Minor, simple change can trigger a BIG response - eg sleep improvement, stress reduction, movement
- Major stimulus or change can have little effect - eg surgery
- They are characterised by

"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 Wales⁴

feedback loops - eg the impact of pain feeds back

- They operate on the verge of chaos and it doesn't take much to tip the balance - eg flare ups
- Emergent properties are defining qualities - eg pain

In complex systems when you affect a part you affect the whole, often in ways that are unpredictable. We would do well to heed this.

Ecosystem Balance

When wolves (lupus) were re-introduced into Yellowstone Park in 1995, there was an unforeseen outcome - it changed the course of rivers and decreased flooding. Wolves predated on, and changed the feeding habits of, elk that fed on young willow growing on the riverbanks. This grew more, increasing the population of beavers, changing the flow of rivers and decreasing flooding. It has triggered a **"still unfolding cascade effect"** across the whole ecosystem.⁵

Changing part of an ecosystem, changes the whole, often in ways that are unpredictable. Prescribing opioids for long-term pain is a classic example of attempting to

address a part without considering the whole. Humans are ecosystems too. We are organic, dynamic systems constantly changing in an ever-changing environment. Medicine needs to remove the blinkers, to raise its head to see this wider picture and always consider the dynamic, complex, whole person embedded within this. To move away from reductionist, linear viewpoints to a new medicine that embraces and addresses the complexity of life because everything is intricately connected and changing all the time.

"In Britain in 2018, the NHS is still planned on Cartesian lines. Patients literally go through different doors, attend different hospitals, to consult differently trained doctors, about their dualistically divided bodies and minds."
Edward Bullmore⁶

Our environment, everything we do, everyone we meet, world events, even the things we listen to on the radio or watch on TV will impact us. Not taking this wider complex picture of humans embedded in their environments into account has already led us to

"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."

Jonathon Tomlinson⁷

“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.”

Peter Stilwell, Katherine Harman⁸

prescribing pills for problems that are rooted in social issues. We have seen this with opioids and anti-depressants. Opioids are more frequently prescribed to those living in poverty, with poor lifestyles. They may temporarily take the edge off some of the distress of a life where everything seems hopeless but they do nothing for the root problems, and over the longer-term, do significant harm, increasing the chaos of desperate lives.

Emergent Properties

From a complex system viewpoint, pain can be seen as an emergent property, emerging in the complex conscious person (a dynamic whole) who is embedded and inseparable from their complex environment and wider, complex, uncertain world, when credible evidence of threat is perceived. It is a subjective, personal experience.

1-10 scales can never capture the lived body experience of pain. Linear pathways of care can't address this. We like them because they're measurable, have boundaries and we know where we are going when we have linear procedures and pathways to follow. In contrast, the enormity of complex systems all interacting dynamically can be overwhelming so **it's helpful to keep reminding ourselves that approaches to problems in complex systems don't need to be complex.** Simple or small approaches often work

better with big overall effect. I believe complexity gives hope.

- Complexity gives hope because it gives us many avenues in to trigger change
- Small changes to one aspect can trigger a big overall effect
- Simple things can have a big impact and often do.

In Context

Health, wellbeing, pain never happen in isolation. There is always a context – past, present and predicted future – involving a range of factors associated with the person as a whole and their interaction with their environment and world. We are constantly interacting with, and adapting to, our environment. Life events, expectations, spiritual beliefs, past, present and predicted future play a significant part in our health, wellbeing and the pain we experience. Those systems within us that strive to remain in balance with the external world in order to preserve our integrity, change the way they respond as a result of this context. Trauma – past or ongoing – or adverse life events can cause them to get stuck and become unable to differentiate between what's actually dangerous and what's not, so they respond inappropriately.

Trauma comes in many forms. When Ben was eight, his teacher told him he was 'a thickie' and as a result he thought he was unable to learn or achieve anything in

life. He has avoided socialising and interacting with the world, and consequently lives with widespread pain and numerous other health issues. All of which are treated separately with an array of medication. That early experience changed his expectations of what the future would hold and this, in turn, has shaped his entire life.

Those who work long hours in challenging, stressful jobs or experience bullying often become ill as a result. Austerity, inequality, poverty, low income are traumatic. They can make you sick. And it goes deeper. The effects of trauma are passed down through generations via epigenetic inheritance. The baby's systems are programmed to enter a hostile world, so we need to be aware of this too.

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

Bessel van der Kolk⁹

Getting To The Core

As part of my research into the meditative, creative and social benefits of knitting, I've been collecting stories from knitters around the world since 2005 and have become intrigued as to how some people live happy, fulfilled lives despite a huge number of problems whereas others find seemingly minor issues difficult to deal with.

There are a number of core themes that crop up time and time again in these stories. These core issues need to be dealt with alongside medical treatments in order to address the bigger

picture and enable people to stay afloat when life's challenges hit.

These core issues are -

- Worry / stress / fear / trauma
- Social isolation / loneliness
- Lack of rewarding occupation, meaning or purpose
- Enforced change of identity / loss of identity

- Low self-esteem, confidence / sense of worthlessness.

I'm making a distinction between rewarding and dutiful purposeful occupation. Many people who are stressed, busy or unwell prioritise dutiful activities over those beneficial for their wellbeing. This needs to be

turned around. We need to be prioritising activities that promote wellbeing because it's the most valuable thing we have. Focussing on, and supporting, the creation of health - salutogenesis.

Understanding Recovery

Taking long-term pain as an example, one of the biggest

Evidence-Based Medicine in a Complex World

Where does this leave evidence-based medicine?

"Literature on complex systems highlights a more organic model of causality with multiple interacting influences. Ask not 'what is the effect size; is it statistically significant controlling for other variables?' but does this intervention contribute to a better outcome? Using the logic of complex systems, multiple interventions might each contribute to an overall beneficial effect even though none of these interventions individually would have a statistically significant impact on any predefined variable."

Professor Trisha Greenhalgh¹⁰

"As the population ages and the prevalence of chronic degenerative diseases increases, the patient with a single condition that maps unproblematically to a single evidence-based guideline is becoming a rarity. Even when primary studies were designed to include participants with multiple conditions, applying their findings to patients with particular comorbidities remains problematic. Multimorbidity (a single condition only in name) affects every person differently and seems to defy efforts to produce or apply objective scores, metrics, interventions, or guidelines. Increasingly, the evidence-based management of one disease or risk state may cause or exacerbate another – most commonly through the perils of polypharmacy in the older patient."

Trisha Greenhalgh¹¹

"Being evidence-based gives medicine **consistency** in practice, but not necessarily **efficacy**. In reality, clinical research can only offer an approximation to the likely effect of a treatment in routine practice. Evidence-based medicine offers a starting point for treatment, but medical practice requires careful attention to people's individual responses and the relationship with which this takes place."

Margaret Hannah¹²

barriers we face is the ingrained belief that nothing can be done for it. All that is left is managing or coping with it. That's a pretty depressing thought to live with. This belief in itself can drive ongoing pain. However, some people do recover, even after many years and we need to be asking them what recovery feels like. When I asked, their comments were remarkably consistent. They still have pain but their relationship with it changes. It no longer dominates their lives. The meaning of pain changes and they lose their fear of it. They re-discover who they are, often describing this as 'finding ME again'. They regain a sense of agency to live more fulfilled, meaningful, purposeful, active lives.

These comments tie in with Dr. Margaret Hannah's observation that **"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".¹³**

Learning about what recovery feels like can help us rethink our aims. If we talk about fighting disease we won't get anywhere. As soon as you talk about fighting or beating you trigger a stress response. With regards to pain, if we could beat it or suddenly discovered a way of fixing or curing it we would all die. We need pain to survive. The human race would have died off long ago if we didn't feel pain. So we need

to really think about our language and what we're aiming for.

Perhaps we should be focussing on ways of resetting, recalibrating our systems and learning to live well instead? Enabling those systems that may have become stuck to work appropriately again, changing our primary focus from one of pain reduction to one of improving wellbeing and promoting recovery as defined by those who have recovered - those with experience. All the time bearing in mind that we are dealing with dynamic systems in an ever-changing context. In addition, we should be working on ways of supporting those who are unable to recover, finding ways of easing their load, and nurturing those more vulnerable.

It's important to create the right context for recovery to happen. The clinician / patient relationship is key. It makes THE difference and is as important as what we 'do'. Even before we've opened our mouths we've made an impact and set the scene, the context, affected a person's anxiety levels, expectations, responses and outcomes.

"Every interaction is an intervention."

Karen Treisman¹⁴

From a complex system perspective think of it as two complex beings interacting and making sense together to enable emergent change and meaning that would not be possible if acting alone. This relationship in

itself can be a powerful tool to enable change. Focus on building relationships of mutual trust, respect, belief and kindness. A relationship of equals.

"Only once trust is established do the stories behind the stories come out."

Jonathon Tomlinson¹⁵

This involves looking after our own wellbeing because when we're stressed it's communicated in our approach, body language, the way we speak, little things people pick up on. It's important to be fully present, aware and receptive in every encounter. In medical consultations, it makes the difference between reaching a shared understanding of issues and being an automated source of repeated medication.

Humanity, Humility

Recognising and respecting the humanity of the person seeking our help is absolutely vital. These are people who have complex problems, not difficult patients. They want to be seen as a person not a list of symptoms or labels. We could all end up in the pit given the right / wrong circumstances. Don't kid yourself that you could never end up there. It's not about 'us and them'.

I highly recommend watching a YouTube interview by Dr Kieran Sweeney¹⁶, a GP academic who died from mesothelioma in 2009. The interview took place shortly before he died. I'll warn you, you will need some tissues. The interview brought tears to my

"If we come here as Indians, we meet Pakistanis. If we come as Hindus we meet Muslims - but if we come as human beings, then we meet human beings."

Satish Kumar¹⁷

“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 et al ¹⁸

eyes because much of what he said resonated with my husband's / our experience when he needed urgent surgery to repair a severely damaged mitral valve. Dr Sweeney discovered he had terminal mesothelioma at his kitchen table. We discovered, at our kitchen table, my husband was in heart failure after surgery.

Kieran Sweeney describes medicine as **“Being with people at the edge of their human predicament”**. He talks about

how the inadvertent small humiliations can add up – being instructed to **“Take your top off”**, to **“Get on the bed”** with no smile, introduction or basic humanity. My husband describes being wheeled backwards along a hospital corridor with an open backed gown on but feeling too weak to do anything about it. All these things add up to traumatise and humiliate a person when they are already low. Kieran Sweeney also warns that what's

routine for you are big life issues for your patients. Recognising and validating the fear a person holds is so important.

Building healing relationships is vital because the most valuable information comes from the person seeking your help. Taking the time to REALLY listen to and hear their story, to gain an understanding, to validate their pain and suffering. We need to know what their world looks like from their perspective, to focus

The Stories Behind Symptoms

I recall...

...the mother whose daughter attempts to take her own life at least once a month. Poor mental health services were failing to support her or the family. Is it any wonder that this mother has gut-wrenching abdominal pain of 'unknown origin'? I think the source of her suffering shouts out.

...the grandmother whose grandson has a distressing terminal illness who is constantly on call and ready to run to the aid of her daughter on their frequent trips to A&E. Is it a surprise she has muscle tension and pain everywhere?

...the lady who is being stalked and trolled by her abusive ex partner. Is it surprising she has fibromyalgia and high anxiety? Like the grandmother, she is constantly on alert and ready to run from the threats in her life.

...the young man who was repeatedly abused as a schoolboy, whose childhood trauma leaves a legacy of poor health.

...the young woman with leg pain who lies awake every night with her phone under her pillow with notifications on just in case her sister attempts to take her own life again. She saved her last time, so is ready and poised to run to the rescue again.

All these people are on high doses of pain medication including opioids that have little effect. When you know the person's story – the wider picture – it is no surprise.

more on what's happened to them rather than solely on what's medically wrong.

"The biggest communication problem is we do not listen to understand. We listen to reply."
Stephen Covey¹⁹

The Lived In Experience

Umwelt is a German word for environment or surroundings that represents an organism's / person's particular model of the world. Their lived environment as it is perceived through their senses and immediate experience. It includes all the meaningful aspects of the world for that individual. An individual creates and reshapes its umwelt as it interacts with the world. People have different umwelten even if they share the same environment.

I like to make the analogy of using a filter on a camera lens. What does the world look like through their filter on life? What are the things that have shaped their world? What really matters to them? Focusing on the person in the / their world whilst bearing in mind that it's complex and dynamic. Their reality will be different from yours because of their history, life circumstances and environment.

When we know their story, we begin to get an understanding of why they are in the place they're in and a realisation that, in many cases, they and their biological systems, were behaving logically in response to life events. People are given labels when often they are experiencing normal reactions to adverse life events and this encourages the medicalisation of social issues. Knowing a person's story helps us to better

understand the decisions they make and how to fit mutually agreed aims into their real lives. It can also help discover what lights their spark.

Knowing their story also stops us making assumptions about their lives based on our own experiences. I was talking to two ladies 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 sleeping bags on the sofa. These are young women in their 40s. Both take a lot of medication every day, but no amount of pills will address this. It's complex, all connected and always happens in context.

Cultivate Growth

Friedrich Hayek states that **"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."**²⁰ And in order to do this we need to know the story - the history.

Knowing a person's story and being aware of how preferences may change from day to day, and illness to illness is important. It will help you to work together within a shared understanding, to make decisions together. Having an understanding that there will be times when a person really wants you to take a lead because the struggle of life is already too much to bear, and other times when they are happy with gentle guidance and reassurance, is an important aspect of your ongoing relationship with them.

The turbulent sea turned out to be enough to bear without the burden of navigation too.
David Haslam and Nishma Manek²¹

Some people carry heavy life loads and we need to know what these are. Often people are telling us 'my life hurts'. Sometimes all we can do is help them find as much sanctuary as possible within this context. Helping to ease the load. When life events make it difficult to lessen the load, all we can do is to help them to put it down for a while. Relieving suffering may not always be the same as relieving pain. Those who are unable to recover need ongoing support. Caring for the vulnerable in society not only helps them, it enriches our lives too. It's a mark of a mature, civilised society.

What Can We Do?

So let's take a look at some simple issues that can influence change. This change may not be in intensity of symptoms but in other areas of life so their relationship with pain, for example, changes over time. I've grouped them under five main headings, although as you would expect there is some overlap.

- Security / Safety
- Belonging / Social
- Space
- Creativity / Curiosity
- General Wellbeing

Security / Safety

It makes sense for many reasons to consider how we improve feelings of safety as a way of resetting and recalibrating those systems that have become stuck on perceiving threat.

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

Bessel van der Kolk²²

Fear, and the feeling of being unsafe, loop back to change our expectations, making these systems more vigilant in seeking out threat.

When working appropriately, fear prepares us to fight, run or freeze when potential threat is perceived. However, our systems can get stuck so we feel fear even when there is nothing to be concerned about. For some reason, the systems don't get updated accurately. This ongoing fear interferes with, and prevents, healing and recovery.

I think fibromyalgia could be considered as a condition where these systems get stuck on perceiving threat and fail to become updated accurately. These include your alarm (nociceptive) system, stress, sensory and immune systems to produce experiences such as pain, fatigue, generalised aching and a range of other, sometimes strange, feelings that can be quite scary. Note I'm not using the term pain system. I don't think that's correct. Pain emerges from this process. It's the alarm or nociceptive system, within a complex interplay of the 'whole person in their lived in world', that gets stuck.

The indigenous Mapuche people of Chile and Argentina learn, in childhood, to transform feelings of fear into respect. Adults help children to feel secure and comfortable in potentially scary situations as well as teaching them to interpret those

situations morally within a belief that we are all part of the same whole. Approaching the scenario with respect and curiosity.²³

“Transforming fear into respect could encourage us to respond more thoughtfully, rather than engaging in automatic (and fearful) reactions. Instead, if we approached every interaction with respect, we would see more clearly the emotions of people that we view as different, decreasing our unhelpful implicit beliefs about them.”

Dejah Oertwig, Amy Halberstadt²³

We need to think of creating a sense of security across the board, from the environment of the clinic / surgery and waiting area to answer phone messages and the way we greet and speak to people. I was sent a follow-up appointment after a routine mammogram suggested I needed further tests. I had to attend the breast clinic at a McMillan centre. Everything was **purple** and **green** – the colours we associate with McMillan... with cancer. The walls were covered with posters and every one contained the word **CANCER**. I was just there for a more detailed scan but being in that environment moved my mind from thinking **“It's more likely not to be anything, just a blip on the scan, to S**T I've got cancer.”** I entered the consultation room in state of anxiety. All these things form part of the picture and can change the way people behave and react.

Simple things like approaching people with a smile in an open,

friendly way promotes feelings of safety. I attended my husband's consultations and I've been shocked by how many clinicians across the range don't introduce themselves, don't smile, don't seem to grasp how big a deal this could be for the person.

Using plain English when we speak to, and correspond with, people is important too. Examine the language you routinely use and ask yourself does it promote fear or safety? Nocebic language from health professionals can increase perceived threat and prolong pain. It's all part of respecting and caring for the human being seeking our help.

The image on the next page illustrates some of the issues those living with long-term health problems fear. The list is long. They are also afraid of getting better.

“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'll lose my home. I haven't worked for 15 years, who's realistically going to give me a job?”

Wellbeing course participant

Improving perception of safety is crucial for triggering change. However, there are some fundamental issues that we, as individuals, can do little about, apart from raising awareness, and this can be a source of great frustration. The foundation of feeling safe comes from having the basics in life – housing; a living income; good, affordable nutrition. Our current Benefits and Social Care systems here in the UK deter recovery and make

Pain **FEAR** **Harm**
Degeneration **Movement** **Getting worse**
Change *Being in a wheelchair* **Future**
Getting older **Hospitals**
Not being able to pay the bills **Loneliness**
HOUSING **SOCIAL SITUATIONS** **Travel** **Finance**
Intimacy **Isolation** **Coping?**
Coming off medication **Medication side effects**
Not being able to see the same doctor

people sick by creating an uncertain, unsafe environment that the most vulnerable people in our society are dependent on. It makes life more difficult and promotes dependence. Everything becomes a struggle.

“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 Kolk²⁴

Being unable to see the same GP who knows your story creates a sense of fear and uncertainty... or the same psychotherapist, psychologist so you don't have to retell your traumatic story over and over, reinforcing it. It prevents you building stable relationships of trust and respect. Continuity of care is vital.

The combination of austerity / poverty and cuts to services is making people sicker. It increases life's load for the most vulnerable

“Poverty has a psychology and identity all of its own.”
 Kerry Hudson²⁵

in society. I'm sure we all have powerful stories to illustrate this. Everything is a struggle for people living with health problems. Life is made difficult for those who need our help the most. In the COVID-19 pandemic, poorer people were significantly more likely to die from the virus for a number of intertwined reasons -

- They were less healthy to begin with
- Poor, crowded housing
- Poorer levels of education
- Poor nutrition
- Having to continue in low paid work to survive
- More likely to hold key worker roles such as carers, cleaners, bus drivers
- Lack of money to buy enough food, requiring frequent trips to higher risk environments
- Discrimination and inequality.

It's impossible to separate these issues out and this is where we need national / international organisations to raise awareness of the complex interplay of issues

in this bigger picture at a governmental / global level. Even if you are taking a purely financial viewpoint it makes sense. It makes sense not to create dependency, surely?

There are, however many issues that we as individuals and communities **can** address to promote an increased sense of security. Giving people knowledge is key to this. I've found people are really receptive and eager to learn. Those who have recovered from ongoing pain say that understanding the biology and complexity of pain is important. It helps them to understand at a deeper level. Learning about the wider, complex picture, and how we interact and adapt biologically to it, is important. The way we change in response to our environment and experiences through plastic change is an accepted biological fact.

Learning that change is possible is empowering because you need to believe that change is possible for change to happen.

Participants on my wellbeing course have often said **“I wish I'd known this information earlier.”** **“You have taken the fear away. I'm ME again.”**

Safety and Stress

Learning about, and managing stress, is important. It's a big part of improving health, wellbeing and pain. Comparing the short versus long-term effects of stress can be really effective in helping people to understand some of their symptoms. And not just focusing on what stress switches on but also the issues, such as digestion and sleep, that it tunes down in order to prepare you to run, fight or freeze.

The impact that pain and other health issues has on people's lives can loop back to become an ongoing threat they can't escape. Gaining an understanding of this is important because when you can't run or fight to escape trauma or threat you go into freeze or flop mode. Their biology is telling them 'if you move, you will be in great danger'. The freeze or flop aspect of the stress response is often omitted as we talk about 'fight or flight' but it's hugely important when we are trying to understand why people often find it so difficult to engage or be proactive even when they know the benefits of doing so and the dangers of not. Knowing the biology not only makes it easier to understand why it's so difficult to get going but that it's safe to nudge forward despite pain. Most are motivated to change but without knowledge, they believe, and do, what their biology tells them (to not move) or they go down the wrong paths looking for a 'fix', often at great expense.

Safety and Rhythm

Calming the primitive brain is communication at the deepest level. We can try it from the top down or bottom up or both simultaneously. In a crisis, trying to do it top down through meditation or instruction, for example, is difficult. You can't instruct the mind to **"RELAX!"** or **"CALM DOWN!"** but you can show it how good it feels through experience. It may be possible to recalibrate protective systems through the **experience** of feeling safe so from the bottom up. I think using rhythm to change the input (bottom up) is a way of achieving this.

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Stories I've collected from knitters tell of those who are unable to meditate or practice mindfulness (top down) because they are too stressed, busy or distressed, are still able to knit (bottom up and top down) and achieve a meditative-like state. Rhythmic movement seems to be important in this. I think rhythmic bodily movement has the power to calm the primitive brain and the mind.

The practice of tai chi taps into this. Two of the 'Core Understandings' of tai chi are -

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

Rhythmic bodily movement can change the atmosphere of the mind. I've observed several similarities between the practice of tai chi and knitting.

Many people with ongoing pain live 'outside' their bodies in an attempt to distance themselves from painful bodily parts. As a result, I've observed a 'fracturing' of the mind-body relationship. Indeed, many of us who are anxious, over stretched or busy, spend a lot of our time in either the future or the past, rarely being fully present in the 'now'. The body is always in the 'now', whereas our mind is often elsewhere. Rhythmic activities such as knitting and tai chi invite you back into your body in a safe, gentle, kind way, and this is

"Physical activity is a key constraint that organises the body, keeping it attracted to states of order that are healthy and functional. Without this constraint in place, the system tends towards entropy and chaos. Everything goes haywire without movement to provide order."

Todd Hargrove²⁶

somehow unifying. Examples of rhythm are -

- Rhythmic movement - dancing, tai chi, yoga, knitting, rocking, walking, running, drumming
- Laughter
- Singing, poetry, music
- Breath
- Heartbeat
- Stroking a pet, purring of a cat
- Waves lapping on the shore.

The brain likes rhythm because it is predictable. It makes your nervous system feel safe. It doesn't like surprises. I've recommended using a rocking chair to those with complex pain states where any movement is difficult. It introduces the concept of relaxed movement which they find calming. Perhaps our grannies who knitted in a rocking chair with a cat purring on their lap were on to something?

Safety and Movement

Movement is closely tied to a sense of safety. Immobilisation increases our primitive sense of fear because, in evolutionary terms, a sedentary being is more likely to be attacked. At the same time, movement can feel unsafe to those living with ongoing pain because of a belief that it's harmful. Knowledge is key here. It can teach that pain isn't a reliable measure of what's going on in their knee for example, that it's not only safe to move but that

movement nourishes the body. It's beneficial in so many ways, including lubricating and strengthening joints and muscles.

Rhythmic movement can feel like a caress, a means of self-nurturing, so we can begin to change a person's perspective from one of movement being harmful to one of it being beneficial and nourishing. Through experience, the person, as a whole being, learns that it's OK. It's safe to go against what their biology is telling them.

Another Core Understanding of tai chi is 'soft limit'. Moving and operating in life at the limit of your softness, so not over stretching or over extending, or restricting yourself either. When you are moving at the limit of your softness you are moving in a relaxed way rather than against tension, so repetition over time gently improves movement in a sustainable way. Taking this understanding into your life helps you to identify the areas in life where you are over extending or restricting yourself with the consequent stress that ensues. If we are constantly over extending or limiting ourselves we will eventually become ill.

This approach promotes feelings of self-nurture and kindness to oneself. 'Soft limit' is a much kinder phrase than 'pacing'. Pacing is not a nurturing word. When we combine moving within 'soft limit' with a state of embodied presence, it enables natural relaxation, so movement becomes more fluid and graceful. This promotes a deeper relaxation and sense of kindness and respect towards yourself as well as a sense of movement being nourishing and caressing.

We can make movement safer or more challenging by changing the context within which people move. Someone who can walk in the safe environment of a physio department may not be able to walk outside or in a crowded street. When people are ready, we should be giving them experience of moving outside in nature or in social groups and think about moving for general fitness not simply to exercise the painful body part in a linear, biomechanical way.

Todd Hargrove advocates moving through play as a way of influencing our complex systems.²⁶ Play involves, exploration, risk taking, uncertainty, variability, creativity and enjoyment. Play, fun and laughter promote feelings of safety.

Safety and Laughter

On my 'Wellbeing for People with Pain' course we have a session playing with Lego™. They get to the end of the session and realise they've had fun, laughed and haven't thought about their problems or pain. We learn a lot in this session. Fun, play, laughter all promote feelings of safety.

"I've realised I don't have to feel miserable. I can still have fun and laugh."

Wellbeing course participant

Laughter is rhythmic. I show contagious laughter videos and it doesn't take long for a room full of people with complex, pain conditions to all be laughing out loud. It's emotional, heart-warming, and often comes as a shock to them. You can source these videos on YouTube²⁷. I suggest people explore the ones

that make them laugh out loud and enjoy them on a regular basis. Experiencing enjoyment of life, and learning that this is still possible, is powerful.

"Laughter – a sudden realisation that there is nothing to fear in the moment ...It is rhythmic, contagious and emotionally bonding."

Chris Knight²⁸

Safety and Gratitude

Keeping a gratitude diary can, over time, rekindle and nurture a sense of safety and help to recalibrate systems by helping to refocus on the good things in life. To re-attune them to picking up this information. You can get stuck on focusing on threat.

Safety and Sleep

I've included sleep in 'Safety' because good sleep is closely related to a sense of safety. Your brain will only allow you to sink into deep, restorative sleep if you feel safe. You can't run from, or fight an imminent threat 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. We have evolved away from this as our environments have become safer. However, we have retained the ability to keep one area (the left cortical default-mode network) vigilant and alert in a dangerous or new environment. In these circumstances part of the left hemisphere is not sleeping as deeply as the right. It remains more vigilant in an unfamiliar environment or one we perceive to be unsafe. Many of us will have experienced that first night

in a hotel or strange place where we were unable to sleep.

Circadian rhythms and body clocks are not just about sleep. They affect the sequence of physiological processes, the timely interaction between systems, so when they are out of sync it can throw our complex systems into chaos.

Learning how to improve sleep is hugely beneficial. Within this you can look at establishing routines for sleep, eating and activity. Routines are a form of life rhythm. They make you feel safe because they are predictable.

A simple action such as switching off phone notifications and removing your phone from your bedroom can improve sleep. When you have notifications switched on your brain is constantly on alert, waiting, even if you don't think you are. Switching off notifications is a simple change that can trigger a big response in a complex world.

Belonging / Social Contact

Social contact and feeling you belong are closely tied to feeling safe. Referring back to evolution, lone individuals are singled out by predators, so we feel safer in a tribe or herd. It is often useful to refer back to evolution. We have always needed to work together, to cooperate to survive.

Moai describes a practice started in Okinawa, Japan. When a baby is born the parents link to four others. This group of five commit to look out for each other for life. More recently it has been used to describe an informal group of people with the same interests who look out for each other. Everyone needs a tribe, some moai in their lives.

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John Cacioppo's work on social connectedness and the neuroscience of loneliness found that the feeling of loneliness puts our brains into survival mode, **"increasing implicit vigilance for social threats along with increased anxiety, hostility, and social withdrawal to avoid predation".²⁹**

Loneliness puts a different filter on your lens of life. You see the world as more threatening. As a result, your interaction with others, communication - verbal and body language - changes. This impairs your ability to communicate, make friends, read a situation. People who are lonely can often come across as rude, so we need to bear this in mind. This can take a real toll on you and the relationships you're trying to create.

"It's a continual effort - to try to remember the humanity of the people that you're interacting with and imagine what it is that makes their lives what they are, and makes them do what they do, particularly if they're being horrible to you. You're lifting against gravity all the time."
Peter Dorward³⁰

We know too that loneliness increases inflammation through a stress and immune response to the perceived threat and is highly detrimental to health and wellbeing in many ways. The quality of the social interaction is key - it's not about the numbers,

"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 Hannah³³

it's about the emotional quality and reciprocity.

There is a growing realisation of the importance of human connectedness for health and wellbeing. In recognition of this there is a move to create compassionate communities. The Frome Model of Enhanced Primary Care³¹ was set up in 2013 by GP Helen Kingston and Jenny Hartnoll (Service Lead for Health Connections Mendip) in Frome - a small town just outside Bath, UK. It has reduced emergency admissions to hospital by 30% over three years.

It aims to connect people to -

- Their own local support networks
- Networks that support the basic activities of life, such as help with shopping, gardening, looking after pets or providing transport
- Extensive community activities.

They have a food bank (with a therapeutic knitting group), a clothes bank, community fridge, walking groups, couch to 5K running group, singing groups, men's shed and other creative activity groups. William House, a retired GP in Keynsham near Bath, has set up Keynsham Action Network (KAN)³² where the community comes together to support each other.

Social prescribing, when done properly, can significantly ease the pressure on clinicians who can then become guides, while

ongoing support is done in and by the community. But it's not just a case of prescribing anything that's available. Social prescribing needs to be done with the same diligence as prescribing drugs or any other treatment. We should always be asking, **"Will this change this person's story?" "How will it affect their biology?" "Will it have side effects?" "Is there anything in this person's story that will interact with this, beneficially or detrimentally?"**

Ongoing support groups are important. An eight-week course won't heal a lifetime of problems. Support groups leave pathways of communication open and provide an ongoing sense of safety and stability while supporting people on their ongoing journey of improvement. They also provide stability for those unable to recover and a safe haven for those who cannot escape the trauma of their real lives, enabling them to forget, laugh and enjoy the company of others, even if it's only for a short time. Helping to put the load down for a while. I would recommend popping into these support groups on a regular basis. We can learn a huge amount from the conversations that happen there and provide an added boost to motivation where needed. If you have a relationship of mutual trust and respect, I've found boundaries are respected and it doesn't increase the risk of dependency. On the contrary, the sense of stability created helps to promote independence.

Social activity groups move the focus onto the activity so can help people who are fearful of social contact, or on the margins

"I cannot say exactly how nature exerts its calming and organizing effects on our brains, but I have seen in my patients the restorative and healing powers of nature and gardens, even for those who are deeply disabled neurologically. In many cases, gardens and nature are more powerful than any medication."

Oliver Sachs³⁴

of society, to integrate into their communities. They also provide an opportunity to 'just be' in the company of others without feeling the need to participate.

Space

The concept of 'Space' can range from environments where people feel safe to share who they really are, to creating a safe sanctuary in the home or somewhere to escape to. Learning to find safety within yourself when the world is falling down around you is a powerful tool. You can, for example, find moments of safety in your breath, in meditation, visualisation or counting to 10.

Going beyond safety, there are other aspects of Space we need to consider. It's important to put space between the YOU that is YOU and your medical condition. Many people who have recovered from pain say, **'I've found ME again'**. A programme that focuses on improving wellbeing and reconnecting to what matters to them as a person, their passions, rather than focusing on managing symptoms, helps to create space. It nourishes them as a person without the burden of labels.

Space, Nature and Awe

Shinrin Yoku translates from the Japanese to 'forest bathing'. There is increasing evidence that being out in nature is beneficial in many ways. 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 re awaken AWE in the world. At the same time as feeling a deep sense of connection there is a feeling of having your place in the world. It helps to put things into perspective.

"The effects of nature's qualities on health are not only spiritual and emotional but physical and neurological. I have no doubt that they reflect deep changes in the brain's physiology, and perhaps even its structure."

Oliver Sachs³⁴

Enjoying space in nature re-awakens curiosity. Becoming curious about the world focuses the mind on more constructive thoughts. I sprinkle my wellbeing programme with facts that are designed to create an interest and awe in the world once again.

Creativity / Curiosity

Meraki is a Greek word describing doing something with soul, love, or creativity. Weaving a piece of yourself into what you are doing.

When we are focused on problems and life's challenges it raises levels of threat which in turn focuses our brains more on problems, so it becomes a vicious

circle we get stuck on. Developing interests outside ourselves, rediscovering our curiosity and creative ability is important because it steers us away from life's problems and relentless negative thinking patterns. It opens up the world. Creative activity whether alone or in groups can be hugely beneficial for wellbeing. If you're thinking creatively you have more options open to you.

Creative activities can enable people to experience 'enjoyment of solitude'. Where loneliness is detrimental to health and wellbeing, enjoyment of solitude, and learning to 'just be' in your own company, is highly beneficial.

Creative activities -

- Are constructive in what can seem like a destructive life and world
- Are colourful in what can seem a grey or dark world
- Open up an avenue for giving gifts, helping family, charities, or acts of volunteering
- Create feelings of anticipation, excitement - they awaken lost emotions
- Provide a means of enjoying 'Flow' - becoming absorbed
- Provide a way of learning new, diverse skills
- Provide a way of achieving, of feeling successful
- Encourage you to develop interests outside yourself
- Help you find purpose and meaning to each day
- Provide a means of enjoying moments of solitude.
- Expand your experience base
- Provide alternative topics of conversation with others.
- Provide a means of meeting different people, friends.

Creative activities reintroduce the feeling of 'being successful'. Many people who live with long-term medical problems have nothing in their lives they feel successful at. Experiencing success can have a powerful effect. It can change your personal story. It creates a desire 'to do', a springboard to other activities...hope. All these things help to lessen the load on a person to enable them to put their burdens down.

Creative activities can also help a person find their 'reason for being', the reason they get out of bed, something to live for. The Japanese call it your Ikigai³⁵ - the motivation for living life well. Many people have lost sight of this under a burden of health problems, poverty, stressful life circumstances or big workloads.

"Creativity has a biological basis and, as perhaps the ultimate whole-person output, can powerfully unleash beneficial bioplastic change."
David Butler³⁶

General Wellbeing

A linear approach to health and conditions such as long-term pain often omits to consider the importance of general wellbeing and fitness, focusing solely on the isolated, problematic or symptomatic part or condition rather than the whole person. Approaches that include a focus on improving the general wellbeing of the whole person in their lived world are beneficial for many reasons -

- They take the focus away from symptoms
- They focus on things people

can do, their values, passions and interests

- Enable individuals to discover a purpose and meaning
 - their reason for being, Ikigai
- They give hope for meaningful, sustainable change
- They can provide the trigger for the individual to move from surviving to thriving
- They encourage measurement of success in areas other than symptoms or pain reduction
- They are social.

Running wellbeing workshops and courses, focussing on enabling those living with long-term conditions, such as pain, to live more fulfilled lives in place of 'management' programmes sets a different tone. The name change alone changes a person's expectations, the way they interact and attendance. In addition to the issues such as stress, movement and creativity I have already mentioned, wellbeing courses can also share knowledge about condition specific issues such as pain as well as information about -

- Living a less inflammatory life
- Sleep, and the importance of light and circadian rhythms
- Nutrition / hydration - the importance of gut biome.

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. This becomes a vicious circle as fat cells, particularly around the abdomen, secrete inflammatory and stress chemicals. We now

“Ubuntu – 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.”

Barack Obama³⁷

know that altered gut biome affects pain, mood and many more aspects of health. Opioids change gut biome.

The Wider Picture

Looking at the wider complex picture, poverty and austerity make it difficult for a large section of society to eat a nutrient rich, diverse diet. This affects them in a multitude of ways from their microbiota to the ill health they experience as a result. Going even wider, we should consider the nutritional value of our food today. Intensive farming has depleted soil biodiversity and hence the nutritional value of the plants we eat. The inhumane treatment of animals kept in constrained environments and fed a cocktail of poor food and medication has done the same for the meat we eat. It’s complex and it’s all intricately connected.

The load on clinicians, particularly GPs, is unsustainable. We could ease the load by spreading the load to appropriately trained community resources, so that clinicians become guides. A good way of

doing this is to develop ‘Healthy Living Networks’ through development of widespread social prescribing, community-based groups and programmes – a network of mutual support with multiple entry points. Creating relationships of trust and respect within a wider network. Reaching out, educating people in this network so that everyone is singing from the same song sheet. Communities working together for the benefit of all.

“What’s missing is a recognition of the abundance and complexity of real life, which offers surprises, paradox and the potential for more radical change.

Margaret Hannah³⁸

The implications go far and wide. We are all connected and part of the complex system that is the world. As our environment / the world influences us, we interact and influence it in a complex dynamic interplay. Our behaviours affect our wider communities, and ultimately the world. Those who are struggling

to survive aren’t able to care about wider world issues because survival has to be their primary focus. They can’t expend energy on climate change or eating a sustainable diet, for example.

The future depends on us recognising this complexity. What’s bad for individuals is bad for communities and wider world and vice versa. If we nurture individuals, we nourish communities and the world. We are all interconnected. Recognising this connectedness is the basis of nurturing a healthy world because the impact of global travel means we are ultimately only as healthy as the weakest link. COVID-19 was a stark reminder of this.

As we’ve seen during the COVID-19 pandemic, rapid change in health and social care systems is possible if the will is there. And as Trisha Greenhalgh states, we should never forget that **“Using the logic of complex systems, multiple interventions might each contribute to an overall beneficial effect even though none of these interventions individually would have a statistically significant impact on any predefined variable.”**¹⁰

Simple or small actions can have a big impact.

It’s complex, always happens in context, is all connected and crucially, it’s all interdependent.

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