# Take back CONTROL



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## Persistent pain is **COMMON** and can affect anyone

**KEY MESSAGES** 

RUTH

PPI

If you live with persistent pain, you are not alone. 30 to 50% of people in the UK have ongoing pain that affects their lives. You might think this applies mostly to older people or those with certain medical conditions, but pain can affect anyone.

If you have pain, it might feel as though you are the only one because pain is invisible so you don't know if the person next to you is going through the same thing. This can lead to feelings of loneliness and isolation that can make things worse.

## Talking about your pain and sharing your story with others can help – don't bottle it up.

I was 28 years old when a very minor injury whilst dancing led to the strange sensation of hot burning barbed wire wrapped around my thigh and pelvis that never went away. It was hard to understand that I could have this constant debilitating pain - I was young, active, went to the gym, taught fitness and dance classes. I was working for an NHS health promotion team and living in London with friends I socialised with often and enjoyed dancing a lot.

### Hurt does not always mean HARM

Imagine accidentally putting your hand on a hot stove. You'd likely feel a searing pain in your fingers and quickly withdraw your hand to safety. Or imagine you fall, twist your ankle and experience pain. This pain encourages you to take it easy for a few days while it heals. This is how most of us understand pain: as a protector. Pain stops us from burning our hand on the stove and it stops us stretching our joints too far and injuring the tissues. In the short-term, when protection is needed, pain is really useful and crucial for our very survival.

But many people continue to feel pain long after the body has healed, the injury has gone, and the tissue is completely safe.

## In these cases, the pain alarm system has become overprotective.

#### So why does this happen?

Persistent pain can be compared to a very sensitive car alarm. Ideally, the alarm should only go off if someone is breaking into your car. But an oversensitive car alarm can be set off by small, everyday things that pose no danger to the car – such as a pigeon landing on it. An overly sensitive alarm could be considered a false alarm and it does not serve a useful purpose. Sometimes pain starts after an injury (useful, protective pain) but continues long after the tissues have healed (persistent pain).







Nerves more **EASILY** carry messages of danger from your body to your brain



This is known as SENSITISATION

#### Persistent pain serves no useful purpose. It can hurt like hell but the tissues are fine.

This is what we mean when we say "hurt does not always mean harm". We are continually learning more and more about why this happens. We don't fully understand it yet, but we do know that pain persists due to a mixture of biological, psychological and social factors. Crucially, "hurt does not always mean harm" does not mean that your pain is not real: your pain is very real. However, better knowledge of the science of pain, and the sensitive alarm system, is helping us to understand the nervous system signals that lead to the output of pain.

> Acute (new, short-lived) pain protects us from harm, that's what it's for - to tell you to take your hand out of the fire. But long-term pain isn't always a sign that something's wrong or that we should stop what we're doing. Pain is something our bodies learn to feel, and the feelings can continue long after the initial cause has passed. Phantom limb pain is the obvious example. But we all, to a lesser extent, learn and become accustomed to our pain. The good news is we can unlearn it, too. JJ

## **EVERYTHING** matters when it comes to pain

Scientists gave a group of volunteers a really cold rod to hold in their hand. As they held the rod, some participants were shown a blue light and others were shown a red light. Even though the temperature of the rod was the same in both cases, those who saw the red light reported more pain than those shown the blue light.

What this experiment seems to show is that when it comes to pain, our expectations matter. If we think we are in danger, our pain will likely feel worse. As Billy Ocean once put it "red light spells danger".

Scientists have done similar experiments with problems in the real world and found the same thing. For example, footballers with hamstring strains feel more pain if they are told their strain is moderate compared to being told it is mild (even though in reality all their strains were of the same severity!).



# Pain isn't always an accurate sign that something is wrong within the body or that we should stop doing all the things that hurt.

Pain is complicated and affected by more than just our body parts. So why can pain feel worse or better even when the tissues in our body stay the same? It all comes back to the overly sensitive car alarm analogy (see Key Message: Hurt does not always mean harm). When our nervous system is primed for danger, like when we are told a rod is burning hot even when it's cold, or told a muscle tear is worse than it is, our bodies can become overprotective and activities that are not dangerous feel more painful.

Think about times in the past when your pain might have been particularly bad. Were you going through a difficult patch in your life at the time? Perhaps it was work or family stress, a poor night's sleep, a bereavement, worrying news or a shock. Many of these events may have seemed completely unrelated to the painful area of your body at the time. However, all of these things can make your alarm system more sensitive. All of these things can ramp up the protective pain response and increase our pain.

The good news is that our protective pain response can be reduced by things that signal we are safe and healthy, such as regular physical activity and holding positive beliefs about ourselves.

Being aware of these factors puts us in more control of our pain, helps us to make better choices on how to manage the pain, and often results in us feeling safer to move. Taking deep breaths, asking yourself whether your current thoughts about pain are 'true', repeating more positive mantras such as 'I am strong and safe to move' and building up activity gradually can all help. This is true, whether there are physical changes on a scan or not. Perhaps the greatest revelation in my learning to understand and manage my persistent pain has been that who I am, how I feel, and what I do, can also be factors in my pain experience.

For example I started to notice that stress, sleep difficulties, money worries, anxiety and working long hours made my pain worse, and that relaxation, a good work-life balance and enjoying the company of others made my pain better. This was a breakthrough for me - the door opened to being better able to improve and manage my pain.



### Medicines and surgeries are often NOT the answer

#### Some surgical procedures, injections and medications do work but it might come as a surprise to learn that many of these treatments actually have limited long-term benefit for many people with persistent pain.

Let's take opioid medications as an example. Opioids can be a useful tool when treating acute (short-term) pain – for example to reduce pain in the days following surgery or during dental treatment. However, they have little or no effect on persistent long-term pain that occurs over many months and years. On average opioids improve persistent pain levels by only 7%, which is less than most people would say is actually a worthwhile reduction in pain. When this is balanced against the side-effects that many people experience, such as drowsiness and constipation, you can see why opioids may not be the best solution for persistent pain.

## This begs the question, how do opioids help short-term pain, like after surgery, but not persistent pain?

The answer is that while the sensation of both types of pain might feel the same, the underlying causes are very different and you need to match the treatment to the cause. Think of it a bit like fire. All fire looks and feels the same but the underlying causes can be different, for example some might be electrical fires whilst others might be wood fires. Water will be the perfect solution for the wood fire but won't help the electrical fire, and in fact, as a nasty side effect it can make the electrical fire worse. So just as you need to choose the right fire extinguisher to tackle the right fire, you need to choose the right pain management tool to tackle your type of pain. For pain after surgery or during childbirth, certain medications can give great relief but for persistent pain, these treatments have little or no effect. Similarly, treatments that can be effective for persistent pain, such as physical activity and psychological therapies, are not likely to be the best choice for acute pain like during childbirth.

We have seen that there are many factors that can affect pain and that some of these factors aren't related to injury or damage in the body, for example stress. Armed with this knowledge, it is possible to flip your understanding of pain and see why not all surgeries, injections and medications work in terms of 'fixing' pain for everyone. In the past healthcare has focused too much on medical 'fixes' which we know hugely underestimate the complexity of persistent pain.

Looking at the bigger picture, including our lifestyle, beliefs and mental health often holds the greatest potential for reducing persistent pain. The best scientific evidence supports this view. I started getting pain-relieving injections into my back. The first couple were really effective but what I didn't fully appreciate was that the relief wouldn't last. I thought if I just had another injection, or more frequent injections, or another scan it would tell me what was wrong. When it seemed like further injections weren't working, I went for surgery (a spinal fusion and then later a spinal decompression). Despite initial good progress I was still in pain.



Looking back, my way of thinking about pain was that it was the consequence of something else rather than pain itself being the problem that needed treating. **JJ** 

### Understanding your pain can be KEY

#### Understanding pain involves much more than learning about the structures of the body: as we know, pain is often not a good measure of what is happening to our anatomy.

Once you learn to flip your understanding of pain then decisions that were once difficult to make become easier. For example;

> 'Should I move more or take a rest?' 'Is it safe to do this movement?' 'Does this pain mean something is damaged?' 'Does this pain mean I am doing more damage?'

Flipping our understanding of pain can take time. Turning around beliefs and behaviours held for a long time is hard. Health professionals can help, but you are in the driving seat and the potential to change rests in your hands.

Pain scientists have shown that people who learn about their pain and develop a better understanding of it have lower levels of distress and worry and feel better able to cope\*. They are more able to do things that are important to them and often feel more in control of their health and their future.

## Understanding your pain, for many, can be a key to recovery.

Get I found a website that explained the science of pain in a way I could understand. Suddenly science was telling me that my pain was real, and that some of the weird things I was experiencing actually made perfect sense! Seeing science explain my experience completely flipped my world upside down. Pain is way more complex than I realized, but that's a good thing!

It means there are lots of things I can do to feel better, and most of them are completely within my control. **33** 



\* Watson, J.A., et al. (2019). The Journal of Pain, 20(10), pp.1140-e1. https://www.jpain.org/article/S1526-5900(18)30747-8/fulltext

#### **Recovery is <b>POSSIBLE**

# Don't let anyone tell you any differently: recovery from persistent pain is possible. However, there are some important things to remember.

First, recovery can mean different things to different people. For some it can mean a reduction in their pain, for others it can mean being able to return to work despite their pain, whilst for others it might just be about feeling better in themselves. We have many people with pain who are part of the Flippin Pain team and share their stories of how a better understanding of their pain helped them on their journey.

Many describe themselves as recovered or in recovery, but some still have pain. Tim is a person with persistent pain and a member of the Flippin Pain team. As he puts it:

Knowledge is power and there's nothing worse than feeling helpless in the face of pain. Understanding your pain and what it means can help you deal with it.

Our brains 'learn' to feel pain and importantly, can unlearn it too. **JJ** 



The pain alarm system is always learning, changing and adapting but this doesn't happen overnight. It takes time, patience and persistence. The first step to improving your pain is understanding.

# Start small. And little by little, you will see that recovery is possible. Understanding your pain, for many, can be a key to recovery.



## Interested to know more about pain and how flippin' your understanding could be the first step towards recovery?

Our Flippin' Pain Formula includes a series of videos, podcasts, infographics and quizzes designed by pain experts and people living with persistent pain to help you balance your own pain equation.



# www.flippinpain.co.uk/formula