

Persistent Pain Management Service

It's not "What's the matter?" but "What matters to you?"

We aim to put you in control of your own healthcare and deliver care that is tailored to your



Who is this Leaflet for?

Pain can have a huge impact on our lives; from how we move, to our mood and sleep. Frustratingly pain can affect what matters most to us in life; from our relationships with family and friends, to our ability to work or take part in hobbies.

> "Being in pain is exhausting – it wears you down however much you try to stay cheerful."









If you are experiencing persisting pain ask yourself:

- Do you understand your pain?
- Would you like to be able to manage life with pain better?
- Would you like to be more confident in managing activities without increasing your pain?
- Would you like to feel more able to deal with the stress of living with pain?

If you relate to any of these questions than this leaflet may be of help to you.

What Can We Help You Do?

Our Pain Team is made up of Doctors, Physiotherapists, Nurses, Psychologists, Occupational Therapists and Pharmacists all specialising in pain. We understand that there is not a "one size that fits all" when it comes to pain. Together as a team our aim is to listen to you, help you understand pain and deliver care tailored to your needs to:



Focus on What Matters to you Most

Pain makes life tough. We often give up or struggle with the things that are important to us. Working together, through goal setting and utilising your local services, the Pain Team can support you to make meaningful and purposeful changes to your life.



Understand Pain

How can we cope with something that we do not understand? Pain demands an explanation. Our Pain Team can work with you to help understand your pain experience and how it impacts on your life. Occasionally this may include tests and scans, but for most they are not necessary.



Managing Pain Differently

In helping you to manage pain, we may offer you relaxation, physiotherapy, exercise, psychological therapy and Pain Management Programmes. Sometimes medications or injections may be useful.

Pain - I Just don't Understand it?

Sometimes pain is easy to understand, like falling over and scrapping our knee or touching something hot and burning ourselves. The pain makes sense. We can see the cut or burn, and the unpleasant sensations we feel act like a warning that something is wrong with our body. This is very helpful. You need to know about the cut or burn so that we can look after it until it heals.



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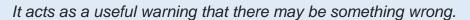


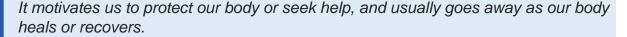
Other times we may not be able to see the cause of pain but this does not mean it is not real, for example abdominal pain with appendicitis. Again the pain is useful as it alerts us that something may not be right, and we may decide to see our doctor for help and advice.



Whilst unpleasant these type of pain are useful, and are known as acute pain.

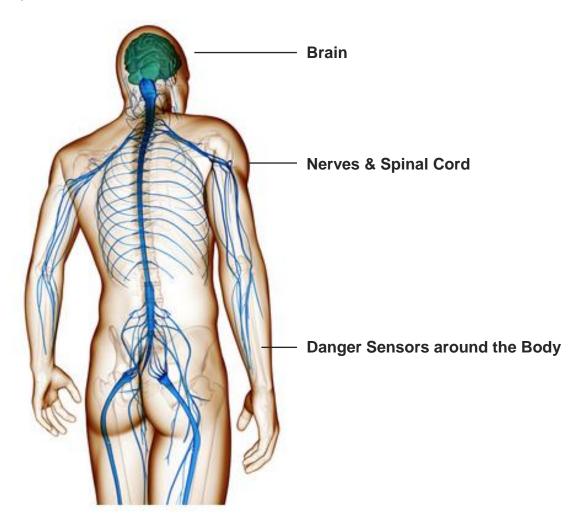
Acute pain is like an alarm going off.





So Why Does my Pain Continue

Most of us grow up understanding that as the body gets better the pain will go away. So how can we make sense of pain that doesn't go - a pain that becomes persistent? First we need to understand why things hurt. It can be useful to think about how we experience pain in 3 parts:















Part One: The Danger Sensors in our Body

We are made of lots of different parts; bones, muscles, joints, skin, organs to mention some. Most body parts have different types of danger sensors. A bit like a fire alarm detects smoke if there is fire, we have sensors that detect inflammation if we are injured. We also have other sensors that tell us if we touch something hot, something sharp or pressure.

Part Two: The Nerves and Spinal Cord - Our Wiring System

Our nerves carry the messages detected by the sensors from the body to the spinal cord. Like passing the baton in a relay team, the message is passed from the nerve to the spinal cord where it travels up to the brain.

Part Three: The Brain

As the messages arrive the brain has to try to figure out what to make of the situation and what should be done. If the brain thinks the message means danger it will pay more attention and sound the alarm making us hurt. Emotions like stress or low mood also play a part in how loud the alarm rings and why pain is such a personal experience.



The journey of the messages from the sensors in the body to the brain are automatic. The decisions made in the brain are subconscious. The body and its sensors, the nerves and spinal cord, and the processing of information in the brain all play a part in how we experience pain.

We are all familiar with acute pain and so naturally we might focus on the different parts that make up the body for an answer - **BUT** that's only part of the story. To understand why pain persists we need to consider the **WHOLE** of the warning system, including the nerves and the brain too.



Pain is never "just in the body" – it is a complicated mixture of signals from the body and how the brain interprets them.

The Body: "Is there an issue with our tissue?"

Most things in the body heal as well as they can after 3-6 months, so with persistent pain that may have been present for many months or years it is much more difficult to find a specific cause. Rarely there may be a specific treatment for you pain such as injections of medications. More commonly specialist tests often reassure us that there is nothing worryingly wrong with the body, but often do not tell us why we are in pain. This can feel frustrating but does not mean that the pain is not real, simply that there is more to the story.







The Nerves and the Brain: "What about the Rest of the Warning System?"

The nerves and brain play an important role in all pain experiences. Sometimes our warning system becomes overly sensitive, like steam from a boiling kettle setting off the fire alarm:

- When the alarm goes off we commonly rest and protect. However over time being less active causes our body to become less fit meaning we struggle to do the things that are important.
- Pain can be stressful. It can impact how we think and feel emotionally. What we now know is that how we think and feel and cope with stress will make our warning system more sensitive.
- Poor sleep can make us feel tired, less motivated and irritable. This can make us less able to cope with life stresses and impact our pain.
- Pain isn't always in one place. For some people it can feel like the pain is all over and can move from one place to another. Rather than the fire alarm going off in just the kitchen, we can now hear the alarm going off in other areas of the building too.
- All pain is **real**

All pain is real, even if scans and tests are normal.

Persisting pain is like a fire alarm continuing to sound after the fire has gone out.

Persisting pain is not always helpful and can affect all aspects of life.

How Does Pain Affect You?

When it comes to living with persisting pain patients tell us that it's not just the pain that's the problem, but also how the pain can affect every part of life.



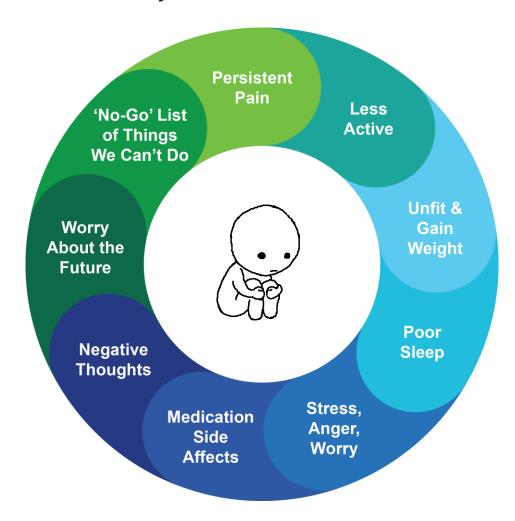
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Seeing lots of different people trying to find something that helps and getting nowhere can be frustrating and tiring. Often we can feel like we are stuck going round and around in a pain cycle.

What Does the Pain Cycle Look Like?



The challenge for both you and those treating you is to **understand** your pain, and work **together** to find the best way to **manage** it and **break** the pain cycle.

Management Strategies

Acceptance



Living with pain is a journey. We may explore different avenues and roads. Some may lead to dead ends and others may bring us back to where we started. Along our journey we may take detours, stopping off to see a different specialist or try a different treatment. Searching for an answer or quick fix can feel like getting stuck in a one-way system going round and around the same town not finding our way out. Changing our





focus from finding a cure to reducing the burden of pain may reveal a road less well travelled; a more rewarding journey that may help and improve our quality of life.

Approaches to Daily Life and Pacing



Living with pain often affects how active we are, and we may use different approaches at different times in our day to day lives. We may try to **avoid our pain**, leading to very low activity levels and an unfulfilling life. We may try to **ignore our pain** and push through, getting satisfaction

from achieving tasks but at the cost of being in pain or working to exhaustion. Often we sit somewhere in the middle; on good days pushing ourselves but often paying the price, then cutting back what we do or resting on bad days. This is known as the **over-under activity trap** where our pain tends to be in the driving seat.

Pacing is a different approach. This may involve planning our day, taking breaks or changing the way we do things, helping us take part in activities that we value.

Values and Goal Setting



Values are our desires for the way we want to interact to the world and people around us. Considering what is important to us and what gives our life meaning is like choosing a direction on a compass that we would like to travel in. This could be related to our family relations, social life, career etc. Goals are the destinations we would like to visit along this route which we can cross off our list. For example your value may be to always travel east, and your goal is to travel from London to Geneva. The key is that our goals are realistic.

Activity



Being active is important for our physical and mental wellbeing. We now know that people with persistent pain who are active tend to feel better and can do more. Activity that we enjoy, that raises our heart rate and gets our body moving release our body's own feel good chemicals and has a positive effect on our mood and fitness. Becoming more active isn't easy, but using a *graded approach* can help improve our confidence and fitness despite our pain.

Living With Your Busy Mind



We all get caught up in our busy minds, thinking about what this is causing our pain or worrying how we will cope in the future with work or family life. One worrying or upsetting thought can lead to the next. This can affect our mood and can keep us feeling low or anxious. Becoming aware of our thoughts can help us to do things differently and reduce the impact which pain has on our mood.





Medication



Often common medications that help with acute pain are not as useful with persisting pain. The longer we use these medications; the less helpful they become and the more side effects we may experience. Discussing your medication plans with a doctor or Pain Specialist can be helpful to find what's appropriate for you. There are different types of medications that may be more helpful. Medications may help in reducing symptoms and rarely take the pain away. Reducing medications for pain often doesn't make the pain worse, but can improve our wellbeing.

Injections



Injections can be useful for specific problems with the body. Injections of drugs called local anaesthetic and steroids can be helpful to reduce inflammation, and the benefits often last a few days to a few months. Many people with persistent pain hope these injections will cure their pain, but this is rarely true and for many they may not be appropriate.

Stress Management



Stress is a part of all our lives and in moderation can be a good thing. However prolonged stress can have a negative impact on our health and wellbeing and can increase the sensitivity or our warning system. Relaxation can be a useful tool to manage our stress; as little as 10 minutes a day can have a positive impact on our wellbeing, with longer lasting benefit if we make it a part of our daily routine. Mindfulness is another useful tool which can be used to manage daily stresses and the emotional impact of living with pain.

Sleep



Being in pain can make getting a good night sleep difficult causing daytime sleepiness and fatigue, irritable moods, poor memory and concentration, less motivation and less ability to cope with daily difficulties. Sleep Guides can provide useful information to improve our quality of sleep.

Psychological Therapies



All pain is linked with our emotions, whether it is fear, worry, anger or low mood. Psychological therapy allows you to understand the impact of your emotions on pain and learn ways of managing these emotions in different ways, to explore the relationship you have with your pain and identify ways of managing your pain differently, and to examine psychological barriers and obstacles that may get in the way of being able to do things differently.

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Planning for Set Backs

Living with pain is an ongoing journey and there will be bumps in the road. How we negotiate these bumps and learn from our experiences is an important part of developing our pain plan. Planning for setbacks helps improve how we cope with these situations. This may include medications, prioritising our day, relaxation, distraction, distancing ourselves from worrying and upsetting thoughts or other self-soothing techniques. It is important to recognise that setbacks don't last forever, and learning from our experiences so that we negotiate these bumps in road better in the future is often helpful.

Where Can I Find Out More?

Sussex MSK Partnership Central Website	www.sussexmskpartnership central.co.uk/pain	Links to our services as well as other educational videos and resources that you may find of benefit
Local Lifestyle Services	www.sussexmskpartnership central.co.uk/my-health/	Links to wellbeing and mood support, healthy weight management and activity opportunities local to you
British Pain Society	www.britishpainsociety.org	Largest professional organisation in the field of pain in the UK providing patient leaflets for medication and medical procedures.
Pain Toolkit	www.paintoolkit.org	Self help guide to managing pain. Free download available
HealthTalk	www.healthtalk.org/peoples- experiences/long-term- conditions/chronic- pain/topics	You are not alone. At healthtalk.org you can find information and support by hearing and seeing people's real life experiences
Sleep Council	www.sleepcouncil.org.uk	Free sleep guide

