

# Explain Pain – Patient Leaflet



## What is Persistent Pain?

Persistent pain (sometimes called chronic or long-term pain) is described as *'pain that continues for three months or more and may not respond to standard medical treatment'*.

It is quite common and affects around one in seven of us. Persistent pain can be caused by health problems like arthritis or nerve damage or as a result of a specific problem that has often healed. It can also develop slowly, sometimes for no obvious reason. It may even come on some time months or years after an activity or injury like a road accident or surgery.

Persistent pain can be felt in a specific part of the body like the back, shoulder or leg(s), or throughout the whole body. The pain may be continuous or vary in its level. Sometimes it can flare up or getting worse very quickly while at other times being easier to manage. It can have other symptoms like numbness, burning or electric shocks. Pain can be in tissues like muscles, ligaments, joints, or be coming from the nerves. It can be made up of both tissue pain and nerve pain.

## What is going on when people have persistent pain?

Persistent pain is different to short acting 'acute' pain that lasts some weeks and goes away. It often doesn't respond to usual treatments. We now know the problem is in the pain sensing system itself, rather than being a specific problem in the body itself.



*"I was constantly looking for a cure or ways to fix it. Now I have found ways to manage it far better. I get some support from my GP and nurses, its miles easier" TG*

One way to understand persistent pain is to think about a very sensitive car alarm. Car alarms are good when someone is trying to break into your car. The lights flash, the siren blares-out and it grabs your attention instantly to tell you the car is at threat of a break in. However car alarms are annoying when the same thing happens just when someone brushes past the car or a butterfly lands on the roof. The siren still sounds and the lights flash yet there is no break in threat. The body's nervous system is like this too. In persistent pain the pain sensing nerves send off the same signals as if there was an instant threat of injury or damage when none exists. It's not just annoying though, and it hurts too!

However the car alarm system it can be fixed or replaced. With persistent pain you are stuck with your faulty sensitive nervous system, which needs to be managed. Sadly there are no treatments to fix the sensitive pain sensing nerves and nervous system at the moment. Scientists are exploring ways to change the sensitivity settings and so new treatments will emerge in time. Pain relief medication can reduce some of the pain, so reduce some of the sound of the car alarm. They cannot stop it sounding or switch it off completely. It is too complex a system and we do not have enough knowledge yet to stop persistent pain. So at the moment we don't have a complete cure for persistent pain.

## Why do people develop persistent pain?

There is still an awful lot that is not understood about why pain can continue after injuries heal, or why it can be present without any ongoing physical problem or damage. We know for example if there is nerve damage that has healed the nerves can still be very sensitive and excitable. We also know that managing moods like stress, frustration, depression can change the sensitivity, so lessen pain. It is the same if a person is very distracted or focused on an absorbing activity, pain becomes less. However we do not know all the reasons why nerves are so sensitive or how to make them less excitable or sensitive. It remains a puzzle at present.

Studies suggest some people are born with genes that make them more vulnerable - in other words some are unlucky and more prone to developing problems in their pain systems.

## How does persistent pain make people feel?

Living with persistent pain can be stressful and can affect people in lots of different ways. Managing at home, work duties and dealing with friends and family can be difficult. People often feel they have no control over the pain and are unable to cope with it.

Experiencing pain can lead to feelings of anxiety or fear about what might be causing the pain and what the future might hold. This is usual for many people, especially where there is no obvious cause. Feeling pain can also make you feel tense, especially if you expect the pain to come back or get worse. You may feel easily angered and hostile towards people that don't understand your situation or how your pain affects you. Some people even feel anger towards the pain itself.

When things aren't going so well, it can lead to troubling thoughts. You may feel hopeless and very down about feeling this pain, which can result in depression.

The pain itself or worrying about it may cause difficulties with sleeping. Being tired and having a sleepless night can make you feel more upset and bad tempered.

*"They said to live with it and I found after a struggle that pacing my activities everyday, setting plans and doing more fun things helped. They call it self-management, it's just looking at doing things differently, adapting and looking at life differently. It helped me and the family a lot." GT*



[www.paintoolkit.org](http://www.paintoolkit.org)

## What can you do about persistent pain?

Many people with pain have to accept that this is a condition they have to live with long-term. In fact acceptance, and no longer searching for 'the fix or cure', is an important part of controlling your pain. Acceptance helps reduce pain's nasty effects on your life and health.

Everyone creates their own toolbox for managing their own pain. Like a gymnast, cyclist or athlete who hones their skills to get the most from them, you can learn how to make the most of the skills you already have for managing your pain. You may learn new ones to add into the ones you've got. Some people become so good at managing their pain that it fades completely into the background for much of the time.

Everyone is different so the right self-management plan will vary from person to person. This could involve understanding more about the way pain works – for example the fact that fear, uncertainty about causes, past experiences (including traumatic childhood events) tiredness, your genes and many other things **ALL** effect the way the pain system behaves. It could involve learning how to do things differently (acceptance, pacing, positive focusing skills). It is also about learning about the right sorts of treatments and medicines, as well as thinking and reacting differently to the pain and life events in general.

For more information to help yourself to self-manage your pain, please visit [www.paintoolkit.org](http://www.paintoolkit.org)

Special thanks  
Dr Frances Cole & Dr Ollie Hart  
For producing Explain Pain leaflet



New Pain Toolkit App's being launched in November 2014.  
Contact [pete.moore@paintoolkit.org](mailto:pete.moore@paintoolkit.org) for more information