

Pain

‘To equip people affected by CFS / ME with the skills for self-management towards a better quality of life’.



Pride in our older people's and adult community services

What is Pain?

Pain is a function of the nervous system and can be experienced in any part of the body. Pain signals travel from the area of pain along 1000's of specialised nerve fibres, through the spinal cord to the brain. Pain signals are processed in the spinal cord and then in the brain where it connects with centres associated with anxiety, emotions, sleep, appetite and memory. Pain is never 'just in the mind' or 'just in the body' it is a complex interaction of the two.

Doctors often describe pain as being '**acute**' or '**chronic**'.

Acute pain is the body's alarm system alerting your brain to actual or potential danger by sending warning signals. It is a 'helpful' message that serves to protect us. The pain only lasts whilst the problem is there and the body will heal itself given the right circumstances e.g. a plaster cast over a broken bone. Pain medication is also generally effective in relieving acute pain.

Chronic pain is a persistent pain that has continued for more than six months (the time it normally takes the body to heal even after the most serious injury is 3-6 months). It is occurring over and above the pain of the underlying injury or illness that started it and can impact on every-day life. Sometimes scans or x-rays will show up changes such as arthritis or disc degeneration in the spine and these changes can be regarded as normal as changes occur in our bodies as we get older.

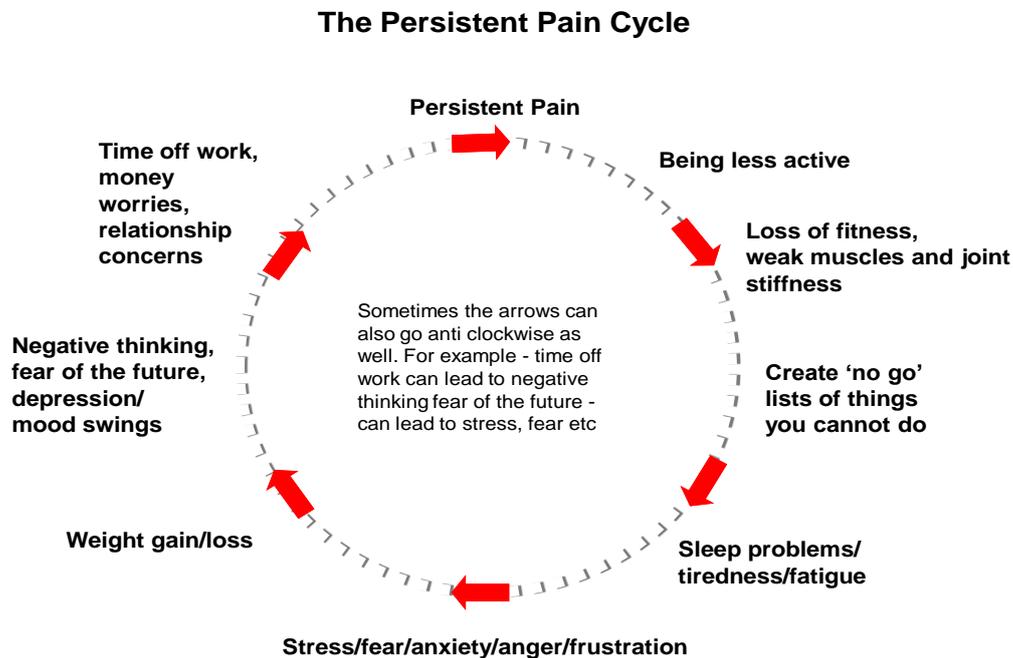
Why is the pain persisting?

Although the pain is a 'real' sensation, chronic pain does not indicate damage or injury. It is an '**unhelpful**' message as it continues even after the body has healed as best it can.

Although the pain **hurts** it does not mean **harm** i.e. the pain is due to how much your brain thinks you are in danger rather than how much pain you are actually in.

The medical profession does not yet fully understand why these 'false' messages continue to occur in the brain and often no physical cause can be found to explain it. This can be very frustrating when you know the pain is real.

If there is no obvious reason for the pain it is not surprising that many people who experience chronic pain feel trapped in a persistent pain cycle, like the one below.



www.paintoolkit.org

So why do some people with CFS and Fibromyalgia experience pain?

It is potentially due to central sensitisation. According to the Institute for Chronic Pain (www.instituteforchronicpain.org) central sensitisation is a condition of the nervous system that is associated with the development and maintenance of chronic pain. When central sensitisation occurs, the nervous system goes through a process called 'wind up' and gets regulated in a persistent state of heightened reactivity. This state of reactivity lowers the threshold for what causes pain and subsequently comes to maintain pain even after the initial injury has healed.

Central sensitisation can occur with all pain conditions. It can occur with spine-related acute injuries, whiplash injuries, fibromyalgia, chronic tension headaches, migraine headaches, rheumatoid arthritis, osteoarthritis, complex regional pain syndromes and endometriosis, to name a few.

There are two main characteristics of central sensitisation - heightened sensitivity to pain and the sensation of touch. However it can lead to heightened sensitivities across all senses e.g. light, sounds and odours. It is also associated with cognitive deficits such as poor concentration and poor short term memory. The nervous system is also responsible for emotions. You may experience increased levels of emotional stress, particularly anxiety due to the nervous system being stuck in a persistent state of reactivity. Please refer to www.instituteforchronicpain.org website for more information about chronic pain and central sensitisation.

Is there any hope to break the persistent pain cycle?

Yes. Pain may be complex, but the main way forward is to try and retrain the brain and nervous system. Taking a broad perspective and looking at all the things that can affect the nervous system can help you to identify what may be contributing to your pain experience.

Medication

Medication can help to manage pain but only to a limited extent. It is the more 'active' approaches that are necessary to retrain the brain.

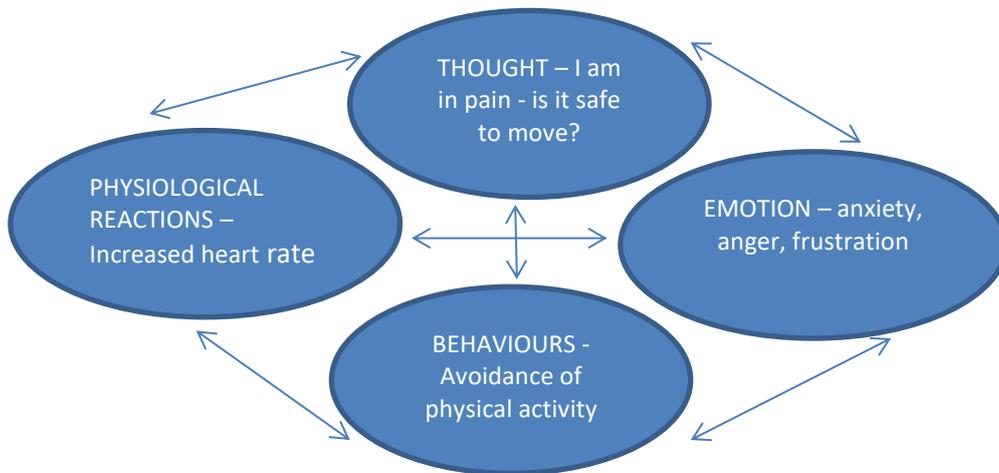
Diet

The role of diet and lifestyle may significantly contribute to a sensitised nervous system. What we eat and how much we weigh may have an impact on chronic pain. Looking at your lifestyle e.g. smoking, nutrition, alcohol and activity levels is helpful as what we eat and how we live may be significantly contributing to a sensitised nervous system. Please also refer to our diet booklet for further information.

Thoughts and Emotions

It can be helpful to consider how your thoughts and emotions are affecting your nervous system as thoughts and beliefs are brain impulses too. Many people with pain can make useful links between a worrying period in their life and a worsening in their pain experience. Recognising what was happening during the time the pain developed and recognising and exploring deeper emotions can be part of the healing process. Common emotions include anxiety, depression, frustration, anger and guilt. These thoughts and emotions can also impact on how we act or behave.

An example is below:



If we recognise that our thoughts, emotions, behaviours and bodily sensations are linked, then it can mean that if we make a slight change in one area the other areas will also be affected. For example if you have a thought “I am useless” this could trigger a low mood response. If you question or challenge that thought you may be able to acknowledge that perhaps other people do not view you that way and that there are things you can still do despite difficulty, resulting in you feeling more useful and hence less depressed. Please refer to our managing thoughts and feelings booklet for further information.

Please consider what thoughts you could question and challenge and write your examples below.

Stress

People with chronic pain often highlight the feeling of lack of control over their pain as one of the most stressful aspects of their condition. As stress has an impact on our activities, our thoughts and our feelings, learning ways to reduce stress and 'wind down' the nervous system can be helpful. This can be achieved by:

- Addressing the cause of your stress
- Changing the way you look at the problem
- Asking for help from family and friends
- Be kinder to yourself (especially if you are someone who tends to be tough on yourself)
- Doing some relaxation by 'doing' e.g. reading, crosswords, watching TV and relaxation by 'being' e.g. listening to relaxation music, engaging in simple breathing exercises.

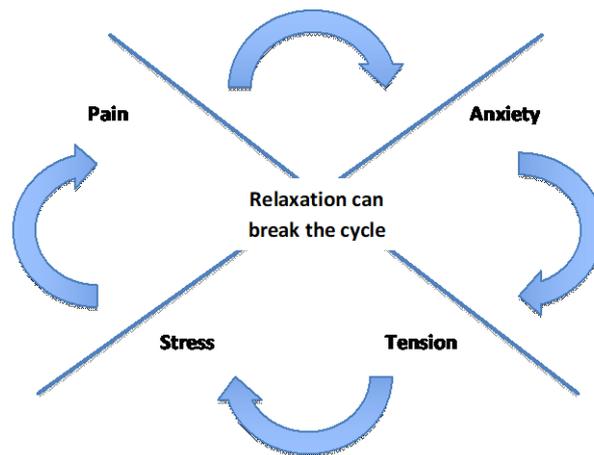
Please refer to our stress management booklet for further information.

Relaxation

Relaxation is a feeling of being calm and has shown to have a positive effect on the immune function, improvement in mood (decrease anxiety and depression) a reduction of tension and pain and improving quality of sleep.

Learning to relax involves recognising tension in the body and mind and letting go of that tension. It becomes more effective the more you use it so stick with it! Examples include:

Breathing Exercises - Take a moment to connect with your breath or to notice if there is any tension in your body and intentionally 'letting go' for a moment or two before carrying on with the rest of your day.



Distraction – Focusing on pain can make it worse. Being able to distract yourself with an interesting activity, enjoyable company or an absorbing television/radio programme can help to move the pain more into the background. Planning your day can be helpful so that you have less time to focus on the pain.

Visualisation – visualise the pain as being like a number of hot bars on an electric fire and then imagining switching off each bar one by one and visualising the glowing orange colour fading to a dull grey.

Mindfulness – This is a simple concept where we pay attention in a particular way i.e. on purpose, in the present moment and non-judgementally. The aim of mindfulness or being ‘mindful’ is to bring our attention back to the activity continually, noticing those sensations from outside and within us. Try being ‘mindful’ when you are engaged in washing up or when going for a walk.

Please refer to our relaxation booklet for further information.

Exercise

Physical activity and function is important. Many people with chronic pain have reduced fitness but chronic pain is not a warning that you should not move. It is okay to move and it is okay to exercise if you have pain. Getting moving at comfortable levels, without fear and where the brain does not have to ‘protect’ by sending pain signals is best.

- It is important to start with a few gentle exercises
- It is also important to increase the amount of exercise gradually, as you feel able.

- If anyone does more activity than they are used to doing, they may get some activity related aches and pains. This does not mean the body has been damaged.

Please refer to 'How to exercise with CFS' and 'Graded Exercise Therapy' booklets for further information.

Other tips to help close the pain gate:

- A good balance between rest and exercise.
- Pacing your activities.
- Hot and/or cold packs
- Warm bath or shower
- Massage / gently rubbing the painful area
- Positive mental attitude / laughing
- TENS machine
- Taking pleasure in things / socialising
- Increased awareness of good posture and movement
- Some evidence suggests complementary therapies such as T'ai Chi, Health Qi Gong and Pilates can be helpful, but remember to start at a level you can manage and work within your own abilities.

Managing Flare-ups

A flare up is when you have an increase in your usual pain (i.e. it is NOT a new pain). Sometimes it can occur for no apparent reason. Some common triggers are:

- Inactivity and immobility
- Imbalance between rest and activity
- Sudden increases in activity levels
- Anxiety and worry
- Stress and tension
- Cold weather (for some people)

To manage a flare up it can be helpful to do the following:

- Try and identify the reason for it e.g. have you been overdoing something?
- Recognise that feeling fed up and frustrated during a flare up is normal, but remember that negative thoughts can lead to more anxiety and low mood which can make the pain feel worse.

What to do next?

- Don't panic. This is a temporary setback - try not to catastrophise/overreact. Remind yourself that it will settle and you can cope.
- Stop what you have been doing and take a short break.
- Do something different for a short time – go for a walk, do some stretch exercises.
- Use helpful strategies that soothe the pain - practice your relaxation, mindfulness or distraction techniques.
- Challenge any unhelpful thoughts – “I have coped with this before, I can do so again”.
- Prioritise your plans for the duration of the flare-up.
- When the pain eases – think about how you coped: what can you learn? What could you do differently/better next time? What really worked?
- Refer to the Health and Wellness Plan Booklet that you may have completed as part of the therapy process.

Content in Pain Booklet from:

- Institute of Chronic Pain - www.instituteforchronicpain.org
- Lincolnshire CFS/ME Service – Lincolnshire Partnership NHS Foundation Trust.
- Department of Pain Management –North West Anglia NHS Foundation Trust.

Pain management resources:

Understanding and managing pain: information for patients -

http://www.britishpainsociety.org/book_understanding_pain.pdf

The pain toolkit - <http://www.paintoolkit.org/assets/downloads/Pain-Toolkit-Bookley-Oct-2010.pdf>

Fibromyalgia - Information and support regarding fibromyalgia. Links to helplines and local support groups.:

www.fmauk.org

www.arthritisresearchuk.org

Healing resources for managing CRPS, Fibromyalgia and Chronic Pain -

<http://princessinthetower.org/>

Breathworks - Information, courses and resources - to bring mindfulness as a tool for reducing suffering to people <http://www.breathworks-mindfulness.org.uk/>

Airing Pain Podcast - Pain Concern produces Airing Pain, an online radio show also available on CD. Airing Pain brings together people with chronic pain and top specialists to talk about the resources which can help.

<http://painconcern.org.uk/airing-pain/>

Explain Pain/Tame the Beast - It is a freely available, non-commercial education space that hopes to inspire research-based action in the treatment of pain.

<https://www.tamethebeast.org/>

Other Websites:

Therapy worksheets and relaxation music - www.getselfhelp.co.uk

Living with chronic pain - www.ableradio.com

Pain management plan - www.npowered.co.uk/the-pain-management-plan.htm?p=2

About chronic pain http://www.healthtalkonline.org/chronichealthissues/Chronic_Pain

Living with persistent pain - <http://www.sheffieldpersistentpain.com/>

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Patient Advice and Liaison Service

For information about CPFT services or to raise an issue, contact the Patient Advice and Liaison Service (PALS) on Freephone 0800 376 0775, or e-mail pals@cpft.nhs.uk

Out-of-hours service for CPFT mental health service users

Please call **NHS 111** for health advice and support.

If you require this information in another format such as braille, large print or another language, please let us know.

CPFT supports the **HeadtoToe Charity** – visit www.HeadToToeCharity.org for details on how you can help



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