

Pain Management Programme

Community Chronic Pain Service



This handbook complements the Pain Management Programme (PMP), run by the Community Chronic Pain Service. It covers all the topics on the programme and provides links to other resources and reading material that may help people living with chronic pain to improve their quality of life.

“ I have found this course extremely helpful. Firstly, seeing so many other people who suffer as much, and maybe more than I do, has made me feel not so alone. The talks were so interesting and my guilt is gradually evaporating. I realise now that I count and am important. ”

Introduction:

Why managing your pain is so important 2

Part one: Living with pain

Neuroplasticity and chronic pain 4
 Different types of pain 8
 The role of psychology 10
 Cognitive behavioural therapy (CBT) 13
 Acceptance and Commitment Therapy (ACT) 14
 The role of mindfulness 15
 Stress and chronic pain 16
 Family, relationships and sex 19
 Chronic pain and relationships 21
 Chronic pain and sex 22
 Acceptance 23

Part two: Self-help and daily living

Pacing and goal setting 25
 Tools for communication 29
 Medication 32
 Sleep 38
 Drugs and sleep 40
 Nutrition and hydration 41
 Exercise and chronic pain 44
 Relaxation 46
 Flare-ups 50
 Useful websites 54

Why managing your pain is so important

If you live with chronic pain; sharp, stabbing and aching pains are probably part of your daily life. Chronic pain can lead to depression and anxiety, loss of sleep and productivity, an inability to work, problems in your relationships, weakness and fatigue.

What were once simple tasks, such as making the bed, grocery shopping or dressing may be difficult because they now aggravate your pain. In fact, it can impact negatively on every aspect of your life.

Chronic pain is not visible to others and it remains poorly understood by patients, families, healthcare professionals and society. Many people with chronic pain find it difficult to acknowledge and accept their condition. This can lead to isolation, embarrassment about its ongoing and unpredictable nature, and feelings of failure for not getting better.

Advances in the way medicine deals with chronic pain are now a regular occurrence, so do not give up hope that a solution might one day be found. However, **it is important not to pin all your hopes on a single method of treatment as this will often lead to disappointment.** Instead, work with your healthcare professionals to find out what strategies and techniques work for you.

It is important to stay connected with others who may be able to help and support you. Think about joining a support group to meet other people in similar situations, who will understand what you are going through, and speak to your healthcare professional about what support is available in your local area.

When people with pain work together with their healthcare team and take an active role in their pain management, they get the best results possible – less stress, less pain and more involvement in life. Learn to understand the ups and downs of your pain experience and how it impacts your life.

Pain management aims to help you self-manage your pain and your lifestyle as independently as possible while keeping your pain at a minimum level.

Living with a long-term health condition like chronic pain can be a daily challenge however old you are, and however long you have lived with your condition. Everyone will have different experiences and ways of coping.

It is very important to take control of your own health. **Self-care is about individuals taking responsibility for their own health and well-being.** It includes self-management which is about you coping with difficulties and making the most of your life. It often means looking at ways to manage your pain and minimise the ways it affects your life.

Leading a healthy lifestyle is also very helpful when living with a long-term health condition. Watching what you eat and drink and getting some exercise will boost your general well-being, improve your mobility and help ease your symptoms.

It is important to get moving without fear of pain. For example, Tai Chi classes are particularly beneficial for gentle exercise and relaxation, but are also helpful for posture and balance.

A number of self-management strategies focus on confidence-building and providing individuals with the knowledge and skills to set and achieve personal goals.

Part one: Living with pain



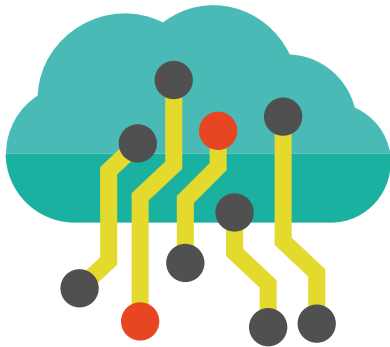
Neuroplasticity and chronic pain

The nervous system co-ordinates the mind and body – it adapts and responds to everyday experiences, which helps you to survive, grow, adapt and function.

The nervous system is sometimes thought of as 'hard-wired', but it is in fact 'plastic' and can readily adapt to changes in your body and the surrounding environment.

The term 'neuroplasticity' refers to the ability of your brain and nervous system to adapt and change.

Neuroplasticity can be helpful in life, freeing up brain capacity for other functions, for example driving home on 'auto-pilot' or remembering how to ride a bike.



Sometimes the nervous system can become extra sensitive and hyperactive if it experiences pain for a prolonged period of time. **Chronic pain is an example of neuroplasticity becoming unhelpful.**

Living with chronic pain often means that normal tasks become painful when they shouldn't be. Psychological and physical stress can also trigger unhelpful neuroplasticity, which can lead to a worsening of chronic pain.





Why do you have pain?

Pain exists to protect us and keep us safe. When we experience a painful event our thoughts, feelings and physical reactions will vary, depending on:

- the context in which the event occurs
- what you think and believe is happening
- what you know and understand.

Pain is often experienced when the believable evidence of risk is greater than the evidence of safety.



Imaging: Best evidence in chronic pain

Scans and x-rays can sometimes show exactly what is wrong, but most frequently these results are unable to account fully for a person's chronic pain.

The presence of degenerative changes, disc pathology, muscle wasting, spondylolisthesis and spondylosis are in fact common in those without pain.

Central sensitisation

The brain and nervous system can go into overdrive and become extra sensitive. Chemicals which 'turn up the volume' of information received and processed by the brain are released, increasing the number of connections and signals whizzing around in the brain and spinal cord.

Because of this, pain may be felt during activities and movements that should not normally provoke pain. Pain may even be felt without moving but just by thoughts alone. Sometimes pain may also spread to other parts of the body.

What else can increase pain?

Multiple body systems are involved in central sensitisation. Many of these systems working over-time can be exhausting.

This can lead to:

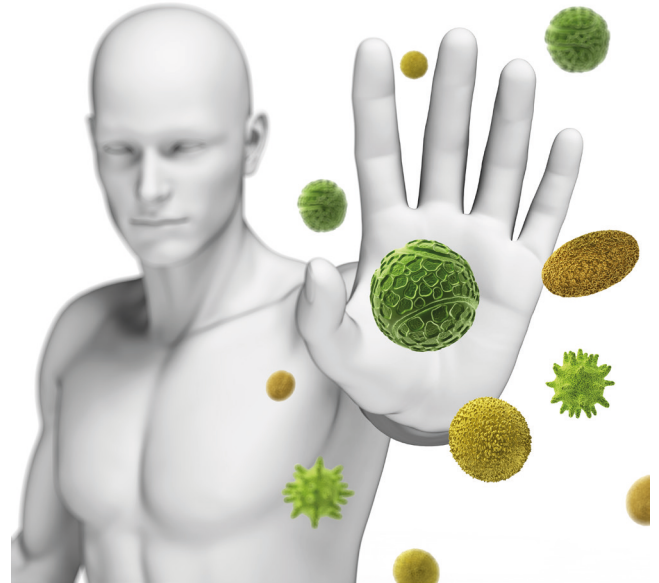
- changes in body perception
- increased anxiety and fear
- changes to breathing rate
- firing of the immune system
- increased low mood and social withdrawal
- increased muscle tension
- 'brain fog'
- changes to the way we think, talk and feel
- firing of the sympathetic and endocrine systems.

The role of the immune system

The immune system produces lots of chemicals that can make a pain experience better or worse.

Our immune system is kept healthy and in balance by our own:

- ability to develop coping skills (resilience)
- perception of stressors
- social interactions
- belief systems
- exercise
- intimacy
- diet
- keeping our brains active



Summary

Pain is a critical protective device.

Pain depends on how much danger your brain perceives you are in and not how much you are really in.

As pain persists, unhelpful neuroplasticity can mean that our brains get 'better' at producing chronic pain.

Helpful neuroplasticity however means that our brains can start to change in a positive way in order to manage chronic pain.

Helpful ways to retrain the brain include relaxation, gentle paced exercise and recognising and changing unhelpful thought patterns.

Different types of pain

Pain is one of the body's most important communication tools. It is one way that the body tells you something is wrong and needs attention. But pain, whether it comes from a bee sting, a broken bone, or a long-term illness, is also **an unpleasant sensory and emotional experience**. It has multiple causes and people respond to it in multiple and individual ways. The exact cause of a person's pain is often difficult to determine. Understanding the different kinds of pain that you may be experiencing and the terms used to describe them will help you to understand why we need different approaches for each type of pain.

Acute pain comes on suddenly, usually from an injury or surgery. It can usually be treated and lasts a short period of time. It is a useful response and helps to protect us from further injury.

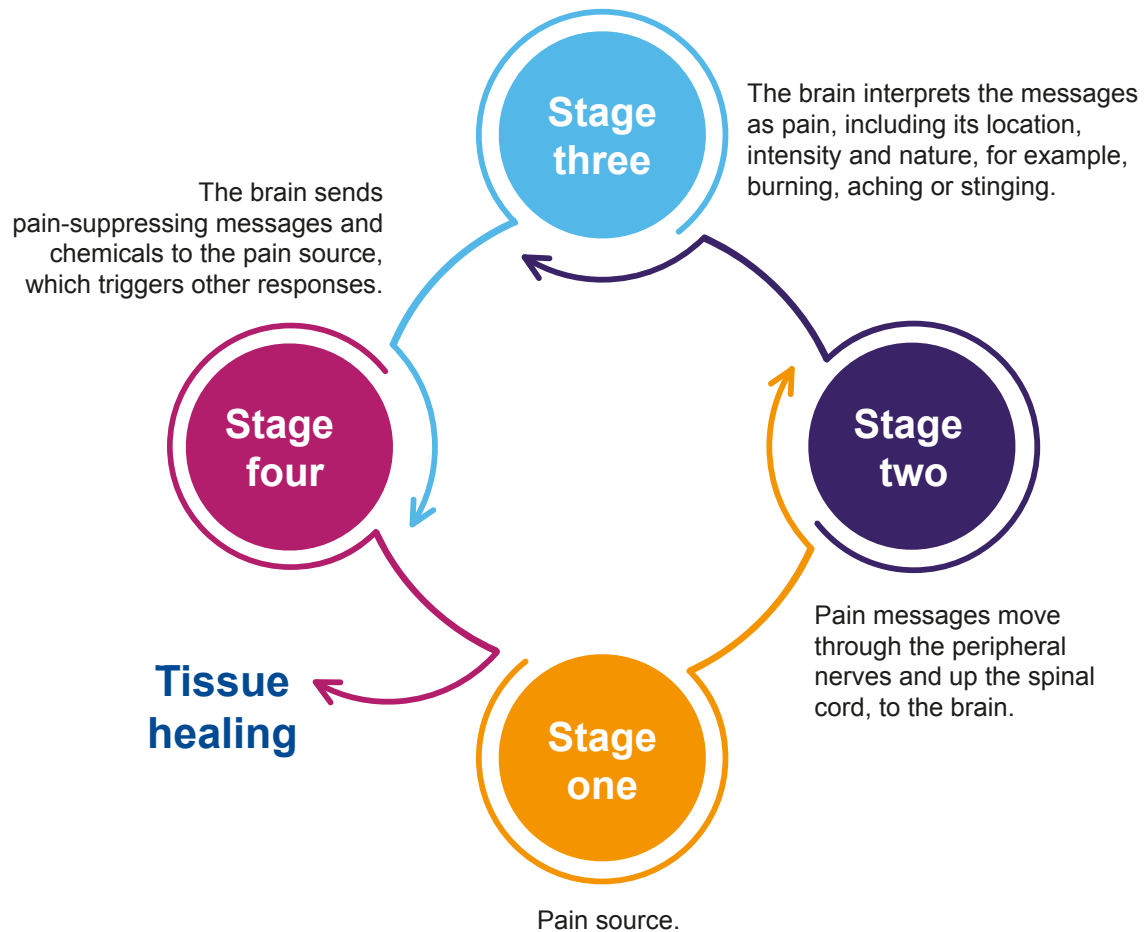
Chronic pain is pain that lasts beyond the usual, expected healing time. This type of pain does not always need an injury to start and could either start spontaneously or develop over time. Chronic pain is not a useful response and can often exacerbate the pain we feel. Chronic pain is therefore very different from acute pain. In fact, **many of the techniques we use to treat acute pain tend to be unhelpful when managing chronic pain**.

How is pain transmitted?

Pain is the way our brain interprets information about a particular sensation that the body is experiencing. Information about this painful sensation is sent to and from the brain via nerve pathways.

Often the cause of pain is obvious, for example a broken leg or a surgical scar. There are times however, when pain starts for no reason at all or when its source is unseen.

The following diagram shows the different stages that take place when someone experiences acute pain:



How does pain become chronic?

The exact mechanisms of chronic pain are complex and remain largely unclear. It is therefore often very difficult to identify why pain persists.

Chronic pain is an indication that a person's nervous system has undergone certain changes, i.e. it has become sensitised.

These changes in the brain, spinal cord and other body tissues result in a disruption of how messages are transferred and interpreted between your body and brain. This means that your nerves are more easily 'triggered' to react to external stimulation, so that you can feel pain without there being any damage to your body. **Your nerves can trigger your body to think it is under threat, so you experience pain.**

The role of psychology

Psychological interventions and treatment are a very important part of pain management. **Understanding and managing the thoughts, emotions and behaviours that accompany the discomfort you feel can help you cope more effectively with your pain and can actually reduce the intensity of your pain and the impact on your life.**

Receiving psychological support for your pain does not mean that your pain is imaginary.

Diagnosis or no diagnosis?

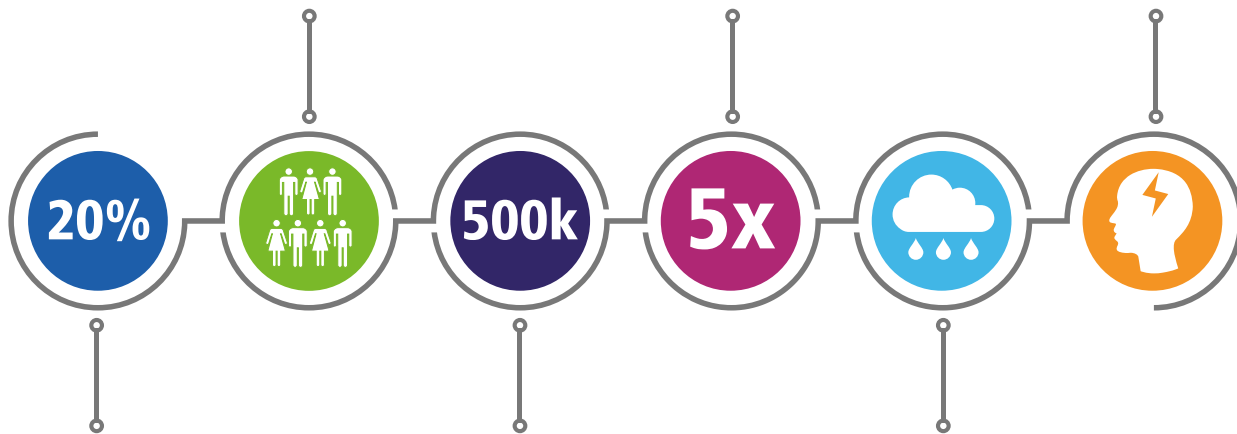
Some people have a clear diagnosis for their pain, while others do not. Although having a diagnosis can help some people get their head around their pain, the impact the pain has on day-to-day living still remains. We know that diagnosis often does not lead to successful treatment or a cure. **Pain is not 'all in your mind', but your mental outlook is very important in coping with your pain and future.**

Pain facts

Seven million adults in the UK have painful musculoskeletal conditions, with 20 per cent of these having suffered for more than 20 years.

People with chronic pain consult their doctor up to five times more frequently than others, resulting in nearly five million GP appointments a year.

Poorly managed chronic pain also has an effect on society as it accounts for 208 million days off work, equating to £18 billion a year.



Statistics show that nearly one in five people in the UK have chronic pain.

Over half a million people in the UK have neuropathic pain.

Untreated pain can affect quality of life for individuals, carers and families, resulting in helplessness, isolation, depression and family breakdown.

Pain and depression

Chronic pain can often leave us feeling negative or depressed. It can make you feel a loss of life, leading to a feeling of pessimism about the future. **It is important to address any underlying depression or anxiety early in order for effective pain management strategies to work.**

Pain and anxiety

Chronic pain can make us feel anxious. Worrying excessively about the future leads to mental and physical tension, which can make pain worse. Some people take a lot of medication or drink alcohol to try and reduce their anxiety but in the long run this is unhelpful. Others avoid activity because of their pain and worry they might hurt themselves. This pain avoidance is also unhelpful, sets up further vicious cycles and the pain can start to take control.

Chronic pain cycle



Pain and anger

Chronic pain can also make us feel angry. People in pain often feel the need to look for someone to blame for their pain – someone who caused it, a healthcare professional who did not treat it properly, themselves for not coping better, or life not being fair.

Anger tends to keep your focus in the past, in a negative and unhelpful way. This leads to another vicious cycle characterised by frustration, tension and increased pain.

Pain and guilt

Feeling guilty is a common emotion brought about by chronic pain. Many pain sufferers feel guilty because they see themselves as no longer being the husband, wife, breadwinner, parent or friend they once were.

Many tend to focus on the negative and overlook what they are doing or can learn to do, for example, housework and cooking rather than home improvements, playing card games instead of football with the kids or learning something new. **Guilt is only helpful if it promotes change.**



Pain and your family

Chronic pain affects the whole family and it can be difficult to strike the right balance. The person with pain may need some help but does not want to be a burden or spoil life for others. It is helpful for partners to be supportive but not to reduce the person's independence. Both can protect the other too much sometimes, leading to loss of communication, anger, guilt, frustration and further distress.

Pain and personality

Our personality affects how we behave and cope with pain. Two main types of personalities have been identified in people with chronic pain: 'perfectionists' and 'people pleasers'. It is therefore important to look at your overall lifestyle and coping style.

It is also important to recognise that some people may have been affected in other ways before their pain developed, for example, working long hours, having a physical job, doing lots of driving or having little relaxation. Pain triggers many problems but may not have been the only cause.

Pain management is a mixture of what you do and how you think.

It aims to help you find the best coping strategies, to help maximise your quality of life. It looks at adapting the way you do things and/or approach things, and helps you accept the changes.

Additionally, medications can sometimes cloud the brain further so any benefits from medication must outweigh the side effects to make sure the problem is not exacerbated.

Psychological approaches to pain management

There are several psychological techniques and approaches used by professional in pain management.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy (CBT) for pain management is based on the cognitive-behavioural model of pain.

This model acknowledges that pain is a complex experience that is not only influenced by its underlying pathology, but also by an individual's thoughts, feelings and behaviours.

Thoughts

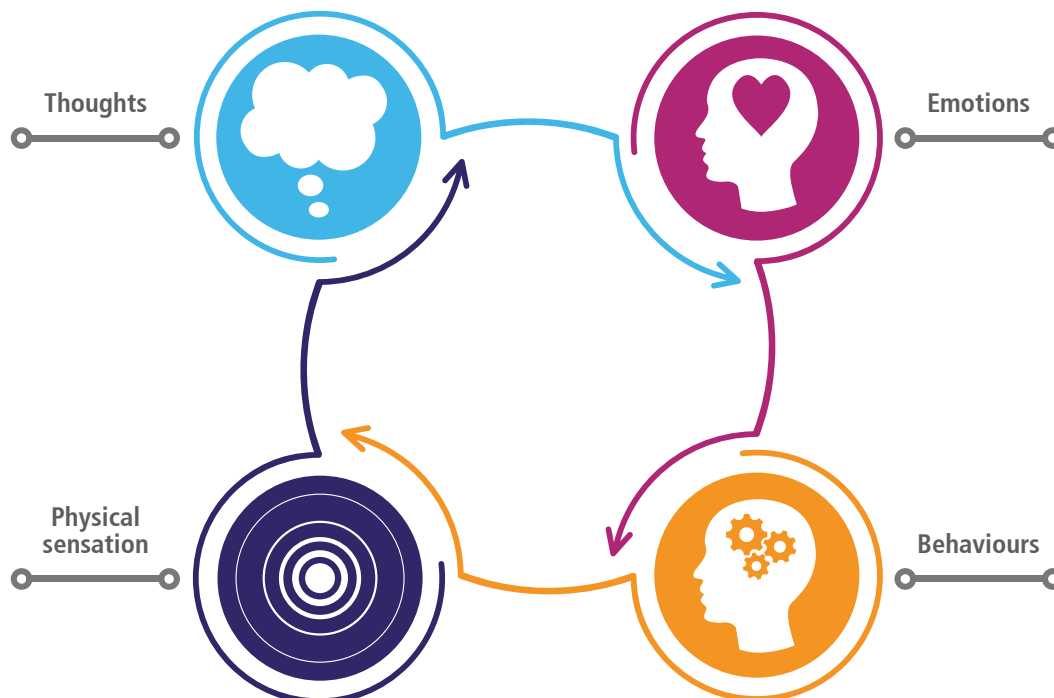
The way we think affects the way we feel and behave. This can be about ourselves, other people and the world.

Thoughts can be:

- true or false
- helpful or unhelpful
- realistic, optimistic or pessimistic
- biased
- distorted
- negative or positive
- automatic.

Emotions and behaviours

Emotions are how we feel about things. Behaviours are what we do about specific situations we find ourselves in.



Acceptance and Commitment Therapy (ACT)

ACT focuses on three areas:

- Accept your reactions and be present.
- Choose a valued direction.
- Take action.

Acceptance

Whether it be a situation you cannot control, a personality trait that is hard to change or an emotion that overwhelms, accepting it can allow you to move forward. ACT invites you to work with what you have.

Some acceptance strategies include:

- Letting feelings or thoughts happen without the impulse to act on them.
- Observe your weakness but take note of your strengths.
- Give yourself permission to not be good at everything.
- Acknowledge the difficulty in your life without escaping from it or avoiding it.
- Realise that you can be in control of how you react, think and feel.

Defusion

Defusion involves realising thoughts and feelings for what they really are, like passing sensations or irrational things that we tell ourselves – instead of what we think they are like feelings that will never end or factual truths. The goal of defusion is not to help you avoid the experience, but to make it more manageable for you.

Some defusion strategies include:

- Observe what you are feeling. What are the physical sensations?
- Notice the way you are talking to yourself as these feelings are experienced.
- What interpretations are you making about your experience? Are they based in reality?
- Grab onto the strands of your negative self-talk and counter them with realistic ones.
- Now re-evaluate your experience with your new-found look.



The role of mindfulness

Mindfulness is about being aware of the present moment without judgement. You are not trying to stop thinking or clear your mind, but rather just being aware of what is happening right now. Being present means that thoughts of past or future pose no threat.

Useful skills to practice:

- 1. Lying or sitting comfortably**, close your eyes and gently take your focus to your body, noticing the contact with the bed or chair. Now take your attention to your breathing, noticing the rise and fall of your chest as you breathe in and out. In particular, note how your body relaxes on your out-breath. This is a natural response and one that can be used to consciously reduce muscle tension. You are creating an awareness of how your body is feeling. When your mind wanders, or something grabs your attention (pain, a noise, a feeling in your body), gently bring your focus back to your breath. Continue for a few minutes and aim to gradually increase the length of your session.
- 2. Mindful tasks** – when you are doing a job at home, at work or walking, take note of what is happening right now. Become aware of the sensations, the surroundings, your thoughts, your body; but without judgment. Just be. Notice how the weight of worry eases.
- 3. Check-in** – this is when you create awareness of what is happening right now. How am I feeling? What am I thinking? What is my body doing? You can do this as often as you like. The more, the better, because it gives you the opportunity to make a change.

The practice of mindfulness can help to improve body awareness, thoughts and feelings. This can affect chronic pain by allowing you to focus on your breath while performing daily activities, for example, taking a walk, making a cup of tea or eating.

It can help to reduce anxiety and fear of movement, while preventing stiffness and de-conditioning, regardless of age or disability.

Helpful resources

Breathworks

www.breathworks-mindfulness.org.uk

Frantic World

<http://franticworld.com/free-meditations-from-mindfulness/>

Stress and chronic pain

Stress is your body's way of responding to challenges. A stress response is triggered by an event that provokes physical, mental and behavioural reactions. It can be caused by both good and bad experiences.

The stress response is also known as the 'fight or flight response' and is needed for survival when in danger. In an emergency situation when you are afraid that something or someone may physically hurt you, your body responds with a burst of energy so that you will be more likely to survive the dangerous situation (fight) or escape it altogether (flight). This response involves the activity of the adrenal, pituitary and thyroid glands, and was designed for short bursts of activity.

A stressful situation sends messages to the brain and this causes the autonomic nervous system to be stimulated. This part of the nervous system has two parts known as the sympathetic and parasympathetic nervous system. The sympathetic nervous system is responsible for the fight or flight reaction whilst the parasympathetic nervous system governs relaxation and recuperation.

The stress response floods the body with hormones designed to prepare us for fight or flight and inhibits the production of hormones such as serotonin and endorphins.

This results in:

- increased heart rate
- increased sugar and fat levels
- increased perspiration
- increased mental activity
- activation of the adrenal glands, pituitary gland and thyroid gland to produce hormones.



When a stressful event has passed, the parasympathetic nervous system initiates the relaxation response and after about an hour the body is no longer alert and ready for fight or flight.

The relaxation response is triggered when the danger has passed. This produces chemicals which switch off the stress response and allows the production of serotonin and endorphins.

The problem is that **in the modern world we are often faced with stressful situations that do not go away and therefore the relaxation response is rarely activated.** It is bad for our health when we are constantly stressed.

The following health problems can all be caused or exacerbated by stress:

- pain of any kind
- sleep problems
- digestive problems
- heart disease
- depression
- obesity
- autoimmune diseases
- skin conditions.

We respond to stress by displaying both emotions and behaviours. Emotions associated with stress may include:

- anxiety
- depression
- anger
- guilt
- hurt
- jealousy
- suicidal feelings.

Behaviours associated with stress may include:

- sleep disturbance
- increased nicotine and/or caffeine intake
- restlessness
- loss of appetite or overeating
- being more prone to accidents
- poor time management
- withdrawing from relationships
- teeth grinding
- frequent crying
- alcohol and/or drug misuse
- avoidance and/or phobias
- aggression or irritability
- tics or spasms
- poor eye contact.

It is worth remembering that **not all stress is bad**, as it gives us strength, courage, energy and stamina.

However, it is important to take time out for relaxation as this will activate a similar response to that of the parasympathetic nervous system, which is important for recuperation following a stressful event.

People in pain are generally dealing with a lot more stress than the average individual without pain.

As a result of this, it does not take a great deal to push these stress levels even higher and on an upward trajectory to distress.

Stress levels can be influenced by a variety of emotions, such as anger and guilt or sadness on realising how quickly moods can change.

We might feel even angrier with ourselves for taking out our frustrations on our loved ones, which places us under even more stress. It is very easy to get caught up in this vicious cycle.

It is therefore important to develop a wide range of methods to deal with both the physical and emotional impact of too much stress.

A key feature of effective pain management involves developing techniques to help us relax and unwind.

Stress management techniques

Change your reaction

Adapt

- Re-frame problems.
- Look at the bigger picture.
- Adjust your standards.
- Focus on the positive.

Accept

- Don't try to control the uncontrollable.
- Look for the up-side.
- Share your feelings.

Change the situation

Avoid

- Learn how to say no.
- Avoid people who stress you out.
- Take control of your environment.
- Pare down your to-do-list.

Alter

- Express your feelings instead of bottling them up.
- Be willing to compromise.
- Be more assertive.
- Manage your time better.

Family, relationships and sex

Chronic pain and the family

Chronic pain is a health problem that affects not only the individual but also family members. 'Family' means different things to different people. Family may be thought of as parents and children or it may include grandparents, aunts and uncles, cousins and in-laws. Family may also be extended to include close friends and members of a person's faith community.

Caught up in the problem

There is no doubt, from a practical and from a medical point of view that families get caught up in chronic pain problems. For family members, the obvious distress and suffering of a loved one in pain generates an initial emotional response of sympathy, uncertainty, worry and an eagerness to offer assistance. When the pain problem persists over months, years, or even decades, family members may develop frustration, anger, resentment and emotional exhaustion. These negative reactions are often heightened because people in pain become inwardly focused on themselves, their pain and misfortune. In effect, a person in pain withdraws emotionally from their spouse or partner and other family members. A family member's negative reaction to this withdrawal is a natural response.

A person in chronic pain usually has a reduced ability to function in activities of everyday living. Homemaking and child-rearing tasks get reassigned. Employment and income may be affected. Leisure activities are abandoned.

These changes place burdens on family members. At the beginning of a chronic pain problem, family members are usually eager to accept these burdens in a willingness to help. This is often no longer the case months or years later as family members' fatigue and frustration set in and savings dwindle.

The reactions of family members and friends in turn have an effect on the person in pain. In the beginning, the emotional support and practical assistance are welcome and helpful but later, as the pain problem persists and reactions change, the effect may not be favourable. The person in pain may come to feel like a burden on their family and the sense of being a valued family member is lost. Self-esteem may also be impacted.

Scientific research supports the idea that overly solicitous or helpful responses by a spouse can actually lead to higher levels of pain and disability. In effect, a person's experience of pain itself can be influenced by their spouse's behaviour.

What to do

There are many things that family members and friends can do to help. It begins with learning about the pain problem and behaviourally based rehabilitative principles.

There are many sources for reliable information from books and on the internet.

In addition, family members can:

- participate actively in the healthcare of their loved one
- attend appointments so they can hear first-hand about the pain problem and treatment
- prepare questions in advance, and ask about ways to improve things
- be patient and supportive, but shift the focus of attention away from pain and onto other topics.

Shifting this focus can be accomplished through:

- encouraging the person in pain to gradually increase their level of functioning despite the pain
- being involved in activities together again, such as child care, homemaking tasks and in social or leisure activities
- promoting a return to a more independent level of functioning
- helping the person in pain adopt a knowledgeable, thoughtful, consistent approach to the use of medical services and medications.

Together review and implement principles for healthy living, with attention to diet, exercise, stopping smoking, and moderation in the consumption of alcohol.

Strive to rekindle the rewards of your relationship and the joys of life together despite the chronic pain.

Although families often get caught up in problems related to the pain, a common sense approach to resuming a normal pattern of daily life can help all involved to improve a difficult situation.



Chronic pain and relationships

The importance of communication

Chronic pain often brings about a change in the nature of our relationships with the people we are closest with. Our loved ones are distressed by our suffering and may not know what to say or do to help us. We are no longer available to help as much as we used to be. We may isolate ourselves from others, especially during flare-ups. Chronic pain can make us grumpy and frustrated, causing us to lash out at those we love. Chronic pain can also cause difficulty with our sexual relationships. Frank, open and honest communication is the key to maintaining good relationships.



When talking to your loved ones, use “I” statements instead of “you” statements. This small change can help create a supportive atmosphere for the conversation. For example, instead of saying, “You never help with the housework,” you could say, “I need a little more help around the house.” Instead of saying, “You never talk to me anymore,” you could say, “Please let me know what’s going on, I miss our talks.”

Sometimes it is hard to know how open we should be about the pain. For some of us, the tendency is to carry on in silence but we can’t expect our friends and family to read our minds. On the opposite end of the spectrum, if we mention every ache and pain, we can inadvertently cause loved ones to feel helpless and overwhelmed. **It is important to find a balance between saying too much and not saying enough.** If friends or loved ones are in a position to help you or lend a shoulder to cry on, it is completely acceptable to let them know you are hurting.

It is critical that you learn when to ask for help and believe that it is okay to ask for it. Our friends and family members often want to help us but don’t always know how to take the first step. It is frustrating for them to watch us struggle with something they could easily help with. On the other hand, if it is meaningful for you to be able to do something yourself, let your friend or family member know that you would like to accomplish the task on your own.

Chronic pain and sex

Sexual intimacy fulfils the need for human connection and affection, and is an important part of a healthy relationship. Pain medication, antidepressants and stress can all impact on sexual function.

Chronic pain can cause problems, with almost 80 per cent of people living with chronic pain and/or a disability and their partners, reporting a significant reduction or loss of sexual functioning.

Sometimes the person in pain no longer feels attractive or desirable. Sometimes sex just hurts too much. Sometimes one or both partners fear increased pain with sex. **Many of these issues can be overcome with thoughtful planning and communication.**

The first step is to be open and honest with your partner. Having a frank conversation while fully clothed about your worries and concerns can help improve your sex life. Talk about your worries and ask your partner about his or her concerns. Don't assume you know everything that is happening in your partner's head before you have an honest discussion. You may think your partner no longer finds you attractive, but your partner may be afraid of causing you more pain. You may be surprised to discover what your partner is thinking.

When talking with your partner, try to use "I" statements instead of "you" statements. For example, instead of saying, "You never touch me anymore," say, "I miss your hugs." Using "I" statements often prevents a defensive reaction from your partner and allows both partners to express their feelings in a supportive manner.

A common assumption about sex is that it must be spontaneous, but living with chronic pain often inhibits spontaneous sexual intercourse.

Lots of couples experience arousal at different times of the day, but couples coping with chronic pain often have to manage other barriers to spontaneity, such as separate beds or demanding medication and therapy schedules. To compensate for a lack of spontaneity, couples should plan ahead for a date. Know which times of the day you feel your best and plan around them. If you are prescribed pain medication, schedule sex for when your medication is at its peak.

If your favourite position is now too painful, don't be shy about experimenting with new ones. Depending on your pain condition, 'spooning' or side-to-side sex, can be a less painful option. **Try to remain upbeat and turn these challenges into adventures!** Remember, sexuality is much more than the act of sexual intercourse. Other options include mutual masturbation, self-stimulation or oral sex. Touching and caressing can enhance your relationship and lead to increased feelings of intimacy and affection. The extra effort is worth it.

Sex can increase your quality of life, the quality of your relationship and can even decrease your feelings of pain. In fact, studies have shown that during orgasm the body releases endorphins that can act as natural pain suppressors, often lasting up to a few hours afterwards, leading to less pain during and after sex. In addition, all of us crave intimacy and achieving sexual closeness with your partner can help you feel stronger and more able to cope with your chronic pain.

Useful resources

<http://painconcern.org.uk/sex-and-chronic-pain/>

www.relate.org.uk

Acceptance

Acceptance of chronic pain requires the person in pain to focus on participation in valued activities and the pursuit of personally relevant goals, instead of chasing a cure.

Before we consider these themes, perhaps we

can consider how acceptance 'usually' comes about.

Think about a time in your life when you have experienced bad news. Does your experience match with the diagram below?

The cycle of acceptance



Quite often we can respond like this when we are going through significant change in our lives. Indeed living with a chronic condition challenges virtually every part of our identity, something we would naturally be reluctant to have 'taken' from us.

Is it any wonder that we struggle to maintain our 'former' selves? Quite often in our efforts to maintain our lives, we

can find ourselves pushing beyond what we or our bodies can now cope with. This may contribute to 'unnecessary suffering'. Gradually accepting pain means accepting yourself as you are now.

Acceptance therefore asks us to identify the things we cannot control while focusing on the things we can. It also encourages us to identify the difference between pain and suffering.

Part two: Self-help and daily living



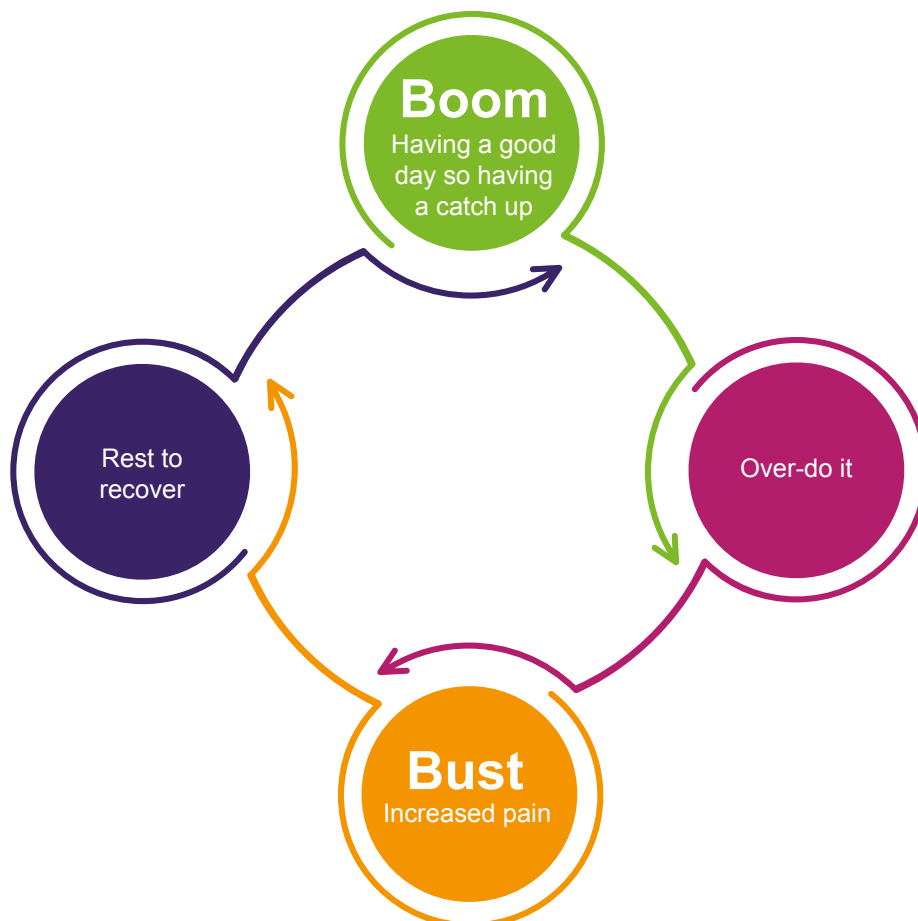
Pacing and goal setting

Chronic pain often leads to a dilemma. People with pain know that the more they do, the more likely they are to experience pain. However, there are certain tasks that are inevitable and it is very easy to get caught up in the boom and bust cycle of doing too much on certain days and doing very little on others.

Like most things in life, balance is key!

One of the skills that could help you to achieve balance is called **pacing or activity management**. Using this technique can help you to consistently carry out activities without causing extra pain.

It is a middle ground between doing nothing and over-exertion. Pacing could have several meanings. It could mean spending just enough time on an activity to get the most out of it, without pushing yourself so far that you end up in more pain. It could mean that you change your position or the way you use your body regularly while performing a task. It could also mean doing more instead of doing nothing at all, since doing too little can be as unhelpful as doing too much. Over time you may find that pacing helps you to do more.



Some people choose to be very active and to battle through the pain.

This approach can make sense but it can also be counter-productive. Some people find that they push themselves too hard and end up suffering. They can be laid low for several hours or days following over-exertion.

Others make the choice to do less, or to do nothing.

This is not entirely helpful either. Doing nothing can lead to boredom and depression, which can make the pain worse. Also, doing nothing makes you less fit. This means that it takes less and less activity to tip you into over-activity.

What is pacing?

Although pacing can mean different things to different people, effective pacing avoids the boom and bust trap and provides more stability, control and sustainable levels of activity. **Pacing is about balancing physical and mental activities with rest.**

In the long-term, pacing is one of the techniques that can help you to do more without necessarily experiencing higher levels of pain.

Why is pacing so difficult for some?

Many people find pacing one of the most challenging skills to develop in pain management. This is often because the initial steps that help us to learn how to pace bring us face-to face with our limitations. The person in pain is faced with the realisation of how much their body has changed, and this often leads to a feeling of guilt for not being the person they were or would like to be.

People in pain are often faced with several dilemmas when it comes to activity.

It is easy to get caught up in the flow of an activity and not really want to stop. It is quite common for the mind to want to push the body beyond its current capacity. A person in pain can often feel that they have no choice but to press on with activities, either because they have no one to help

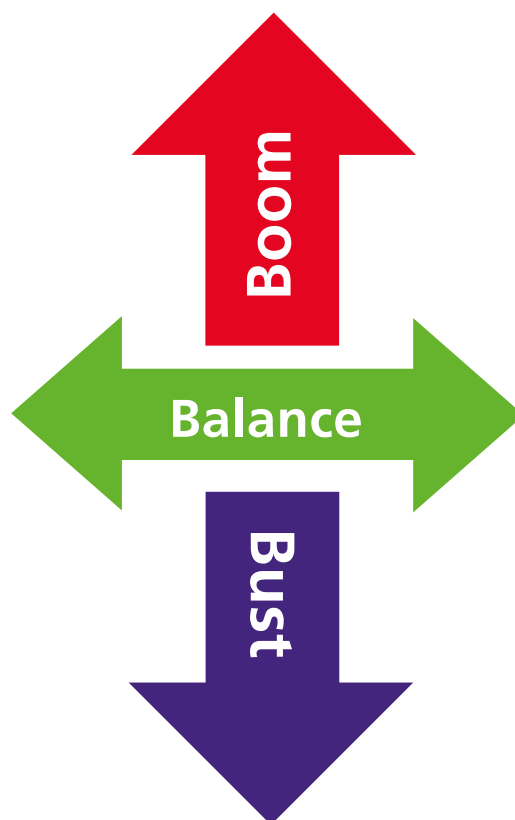
them or because others are dependent on them. All these factors can act as real barriers to learning how to pace effectively for pain management.

If activity impacts on your pain then perhaps you can look at doing those activities in a different way.

Where to start?

It is important to start by identifying which physical positions or tasks consistently tend to flare up symptoms, create tension or cause difficulties.

Common activities that people find they need to pace include walking, computer work, standing, ironing, cooking, driving, as well as fun things like painting, sewing, knitting and other hobbies.



Prioritising and planning

Living life with chronic pain often presents us with a dilemma – doing the things that need to be done at the expense of doing those things that give value to our life, and that we want to do.

Pacing asks you to pause for a moment and think before beginning a list of tasks:

- Does it all need to be done today?
- Does it need to be done at all, or is there any part of the task that could be done differently?
- Can I get someone to help me with all, or part of the task?
- Which jobs need to be done first?
- How can I still do the things I want to do to suit the way I feel today?

One of the most important factors that supports self-care is the ability to say 'no'. Many of us are 'people pleasers' – always be polite, pitch-in and keep going. We don't like letting others down. Also, many chronically ill people are known to be at home and people think they have the time and energy to do things for them.

Saying 'no' can often feel impossible and very awkward, however, the sense of relief will outweigh the moment of distraught at saying 'no' to someone's request.

Learning to say 'no' - some tips

- Be clear about what you want to say yes to. Everything else should be a no.
- Know the implications of saying yes. The more you say yes, the further you drift from your vision.

- Realise that saying no is ok.
- Use the medium you are most comfortable with to communicate – Facebook, instant messenger, email, face-to-face or phone.
- Keep it simple – you don't owe anyone any explanations.
- Be respectful – value the other person's stance.
- Provide an alternative if you want to.
- Make yourself less accessible – provide your contact details only to those important to you.
- Write everything down first – to process your thoughts.
- Delay your response – there is no need to reply right away.
- Sometimes no reply is a form of reply.



Tools for communication

The traffic light system

A traffic light system can help you identify which tasks are easier for you to do and those that require more energy. It can also be a valuable communication tool to give an indication about what kind of day you are having.

Red

This takes a lot of effort and energy.

Amber

This is a bit much, but still manageable.

Green

This is ok.



The spoon theory

Christine Meserandino

www.butyoudontlooksick.com

This is a useful metaphor, used to explain the reduced amount of energy available for activities and productive tasks that may result from disability or chronic illnesses.

'Spoons' are an intangible unit of measurement used to track how much energy a person has through the day. Each activity requires a number of spoons, which will only be replaced as the person rests. A person who runs out of spoons has no choice but to rest until their spoons are replenished.

One of the principles of the spoon theory is that many people with disabilities or chronic illnesses must carefully plan their daily activities to conserve their spoons, while most people without any disabilities or chronic illnesses don't need to worry about running out. Because healthy people do not feel the impact of 'spending spoons' for mundane tasks such as bathing and getting dressed. They may not realise the amount of energy expended by people in pain just to get through the day.



Activity

You have 20 spoons at your disposal for today. Each spoon represents the energy needed to complete a part of your daily routine. Once you run out of spoons, you are out of energy. So, how would you use your spoons today?

Work out how many 'spoons' each of the following activities could cost you and plan which ones you can do today without running out of 'spoons'.

- Get out of bed
- Get dressed
- Take the kids to the park
- Call your parents
- Shower
- Cook dinner
- Walk the dog
- Wait in line to pay a bill
- Visit the doctor
- Grocery shopping
- Take the kids to school
- Socialise

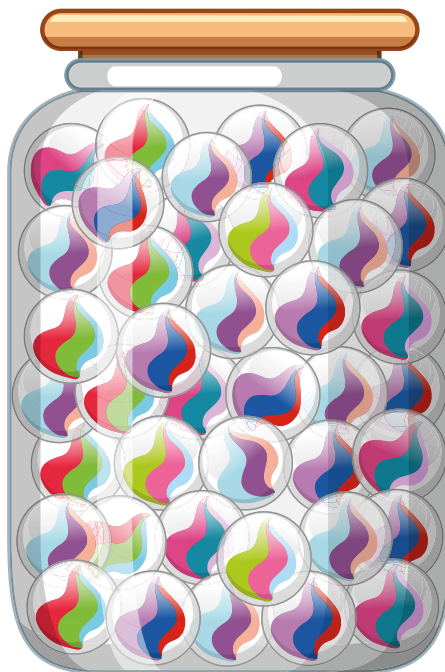
The jar of marbles

This can be another useful tool for improving your pacing skills. Place two jars next to each other and fill one with as many marbles as you feel you have energy that day.

During the course of the day, and as you go about various tasks, remove the number of marbles that you feel each task is 'costing

you' and place them in the second jar. As the day progresses, the number of marbles in the first jar will go down, while those in the second jar will go up.

This can be a good visual cue to help you gauge your levels of activity in comparison to your energy levels.



Step one: Non-opioid analgesics

Non-opioid analgesics include paracetamol and non-steroidal inflammatory drugs (NSAIDs).

Paracetamol blocks the production or action of chemicals involved in the inflammatory process centrally (in the brain). These chemicals, known as prostaglandins, are involved in the transmission of information about pain to the brain.

Paracetamol is a relatively safe drug; however it can cause liver damage when taken in overdose. It is therefore important to stay within the recommended daily dose and to be mindful of taking other medication that may also contain paracetamol, for example, co-codamol and cold and flu remedies. Paracetamol can also affect the anticoagulant effect of warfarin. Therefore it is important to let your healthcare professionals know if you have recently started these drugs.

Non-steroidal inflammatory drugs (NSAIDs) also block the production of prostaglandins, which play a part in the body's defence system and are involved in sending pain signals to the brain when there is inflammation and tissue damage. Some common examples include naproxen and ibuprofen.

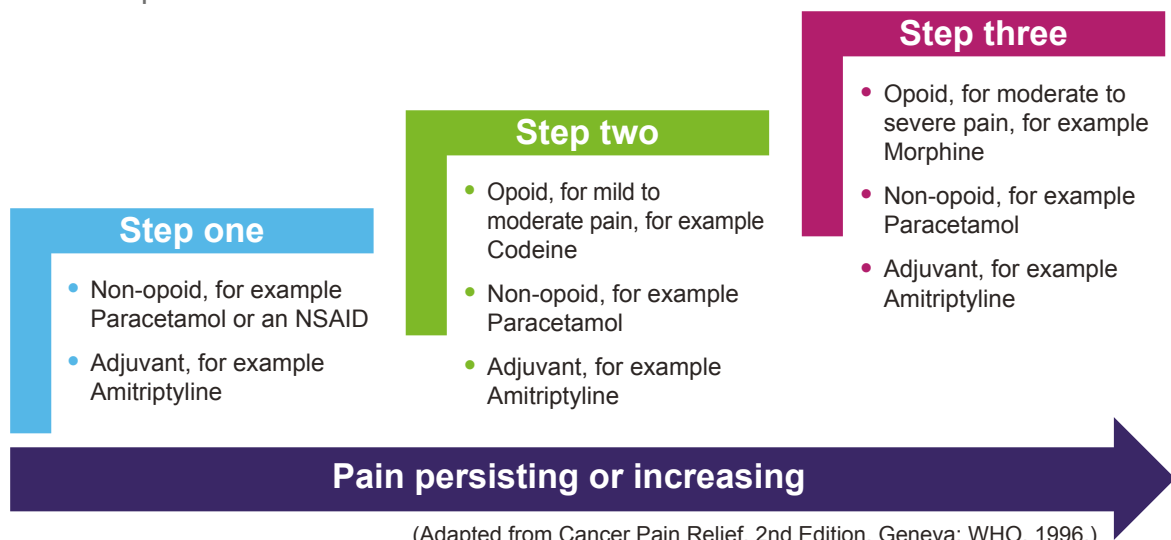
Although NSAIDs are commonly used, they are not suitable for everyone and can sometimes cause side effects.

They should be used with caution in the elderly and in those who suffer from diabetic vascular disease, asthma, renal failure or cardiac conditions. Long-term use of NSAIDs is not advisable as their use increases the risk of strokes and cardiac problems.

It is advisable to take some form of gastric protection (such as omeprazole or lansoprazole) if taking NSAIDs regularly.

NSAIDs should **not** be used if:

- there has been a previous adverse reaction or history of hypersensitivity
- there is a history of peptic ulcer
- you are currently using other NSAIDs
- you are taking oral anticoagulant therapy or have clotting problems.



(Adapted from Cancer Pain Relief, 2nd Edition, Geneva: WHO, 1996.)

Step two: Weak opioids

Codeine is an example of a weak opioid. The body converts codeine into morphine, however, a small proportion of the population is born with the inability to process codeine.

Sometimes weak opioids are combined with paracetamol to make them work better, for example, codeine and paracetamol combine to make co-codamol. It is important not to add any extra paracetamol when taking co-codamol.

Step three: Strong opioids

Opioid medicines (for example, morphine, oxycodone, buprenorphine and fentanyl) either come from the opium poppy or are chemically related to drugs made from opium. Opioids mimic the action of our own natural pain killers – our endorphins. Since opioids act both centrally (in the brain) and peripherally (in the rest of the body), their effects can be quite wide spread.

Opioid drugs can help manage some but not all types of chronic pain.

Some types of pain need non-opioids and some may need opioids together with other types of medication.

In chronic pain it is usual to use a slow-release version of medication as this will allow for a steady level of the drug over a 24-hour period. The dose will be adjusted to a level that provides you with adequate pain relief, without too many side effects. Fast-acting opioid drugs and opioids which are drunk or injected are not recommended for managing chronic pain.

Taking opioid drugs for many months or years can affect your body in other ways. These problems are more common if you take high doses of drugs for long periods of time, and can include:

- **reduced fertility**
- **low sex drive**
- **irregular periods**
- **erectile dysfunction (the inability to keep an erection)**
- **reduced ability to fight infection**
- **increased levels of pain.**

There is a lot of information available about the use, benefits and disadvantages of long-term use of opioids.

Useful resources

www.youtube.com/watch?v=MI1myFQPdCE

<https://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware>

Tramadol is an opioid medication used to treat moderate to severe pain. Depending on the dose, it can be classed as a weak or strong opioid. It is a dual acting drug that can be helpful for both nociceptive (ordinary) and neuropathic (nerve) pain, especially if the neuropathic element is milder.

Adjuvants

Adjuvant pain medications are not typically used for pain but may be helpful for its management. Adjuvant pain medications can include antidepressants, anti-epileptic medications, muscle relaxants, anti-anxiety medications and botulinum toxin (botox). Antidepressants and anti-epileptic drugs have been found to be helpful for a specific type of pain, known as neuropathic (nerve) pain. **Being prescribed an antidepressant or an anti-epileptic drug does not mean you are depressed or that you have epilepsy.**

The doses prescribed in pain management are normally very different to those prescribed in depression or epilepsy.

Examples of adjuvant medication:

Antidepressants	Amitriptyline, nortriptyline and duloxetine,
Anti-epileptics	Gabapentin and pregabalin
Topical creams	Capsaicin cream

Side effects

All medication has the potential to cause side effects, however, many side effects can be managed in a way that does not prevent a person taking a particular drug if it is helpful for their pain. Some side effects are transient – until your body gets used to the medication – but others can be quite permanent. It is important to review your medication regularly and to discuss any new or intrusive side effects with your health care professional.

Common side effects may include:

- **Constipation**

This is common with opioid medications and is unfortunately one of the permanent side effects. Constipation can affect quality of life and wellbeing quite drastically if not managed well or early enough.

- **Nausea**

This is often a temporary side effect of many medications. It is often helpful to be prescribed an anti-sickness medication in the first few weeks of starting a new medication that is known to cause nausea.

- **Dizziness**

- **Hot flushes**

- **Dry mouth**

- **Sleepiness**

- **Mood changes**

People who take opioid medicine for a long period of time may develop tolerance and even physical dependence. This does not mean however, that a person is addicted. In general, addiction occurs in only a small percentage of people living with chronic pain and not when used as prescribed by their healthcare professional.



Tolerance, dependence and addiction

Tolerance	Dependence	Addiction
<p>A state in which a person no longer responds to a drug.</p> <p>A higher dose is required to achieve the same effect.</p>	<p>A state in which a person only functions normally in the presence of a drug.</p> <p>Manifested as a physical disturbance when the drug is removed (withdrawal).</p>	<p>A state in which a person engages in compulsive behaviour.</p> <p>Behaviour is reinforcing (rewarding or pleasurable).</p> <p>There is loss of control over limiting intake.</p>

Drug driving law

It is illegal in England and Wales to drive with legal drugs in your body if it impairs your driving.

It is an offence to drive if you have over the specified limits of certain drugs in your blood and you haven't been prescribed them.

All morphine and opioid-based drugs have the potential to affect your ability to drive. Therefore it is important to make sure medication is taken in accordance with the advice of a healthcare professional and/or as printed in the accompanying leaflet.

If you are taking prescribed medication at high doses, we advise carrying evidence with you, such as repeat prescriptions slips.

For more information visit www.gov.uk/drug-driving-law

Summary

It is important to review your medication regularly in order to make sure that it is as helpful as it could be.

Often the pharmacy may be a suitable option in the first instance.

Remember not all medication taken falls under the drug driving laws, but if a medication makes you feel drowsy (such as antihistamines) then you should not be driving while experiencing side effects.

Sleep

Sleep disturbance is unfortunately one of the biggest problems caused by chronic pain. The average person spends almost a third of their life sleeping, and although the national average for sleep is eight hours a night, a person in pain is often left with barely three to four hours of sleep a night, which is often interrupted.

For years, researchers thought that pain was not perceived during sleep, however we now know that this is not the case.

Sleep is not a passive or an inactive state but a highly orchestrated series of states that occurs in a cycle each night.

During sleep a series of behavioral, neurochemical and physiological changes occur, which include decreased muscle/skeletal activity, decreased heart and breathing rate and a lowering of body temperature and blood pressure. A person's sleep program is based on interactions between the internal clock, melatonin levels and the action of the pineal gland.

Sleep jargon

NREM

Non-rapid eye movement.

REM

Rapid eye movement.

Sleep latency

The amount of time it takes you to get to sleep.

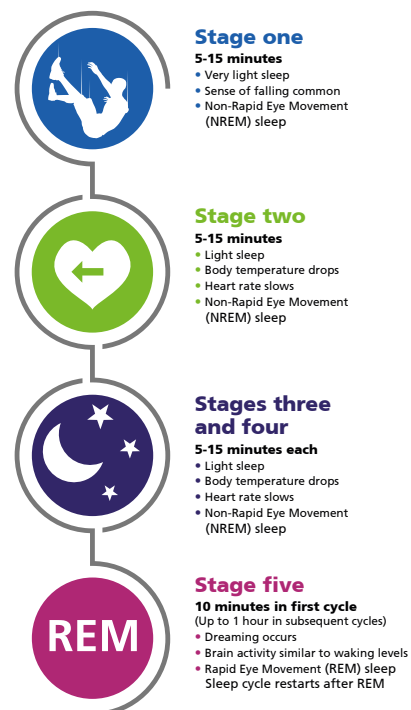
Circadian rhythm

A daily cycle of biological activity based on a 24-hour period and influenced by regular variations in the environment, such as the alternation of night and day.

Stages of sleep

The sleep cycle can be divided into five stages, consisting of both NREM and REM sleep. Each sleep cycle lasts about 90 minutes.

An individual without sleep problems normally has an average of four to five cycles per night. Adults spend 75 to 80 per cent of the time in NREM and 20 to 25 per cent in REM.



NREM sleep is important for the restorative and recuperative processes in the brain and body. REM sleep is important for emotional restoration and recuperation.

Sleep deprivation can lead to:

- chronic tiredness
- mood changes
- frustration
- difficulty controlling emotions
- inability to think, focus or make decisions
- absenteeism from work and social activities
- weight gain
- poor immunity
- poor pain control.

According to the National Sleep Foundation:

- Approximately 50 to 70 per cent of people suffering with chronic pain report that their sleep is disrupted.
- This percentage of people with disrupted sleep is much higher in those who have neuropathic pain and fibromyalgia.
- Sleep deprivation can trigger a decrease in pain tolerance and pain thresholds.
- Chronic pain patients have marked alterations in their sleep structure and continuity.
- This often leads to non-restorative sleep and sleep fragmentation.

Pain and sleep

Pain often leads to more nocturnal waking. In addition, the person in pain will frequently wake up tired and be fatigued in the daytime.

However, we do have a tendency to overestimate how little sleep we have had.

Some tips to aid sleep:

- Try to go to sleep at the same time each night and get up at the same time each morning regardless of sleep quality the night before.
- Establish a relaxing bedtime ritual.
- Try not to sleep during the day, unless naps are appropriate.

- If you can't fall asleep and do not feel drowsy, get up and read or do something that is not overly stimulating until you feel sleepy. Not housework, watching TV or anything on a computer.
- Eat regular meals but avoid large ones and spicy food for two hours before bedtime. A light snack before bedtime, however, may help you sleep.
- Exercise daily using your pacing strategies. Avoid vigorous exercise before bedtime.
- Keep the clock face turned away and do not focus on how much time you stay awake during the night.
- Avoid retiring to your bedroom during the day when in pain.
- Avoid using your bed for anything other than sleep or sex.
- Make your sleeping place comfortable. Be sure that it is dark, quiet, and not too warm or too cold.
- If light is a problem, try a sleeping mask.
- If noise is a problem, try earplugs, a fan or a white noise machine to cover up the sounds.
- Avoid caffeine, nicotine and alcohol late in the day. This includes tea, coffee and fizzy drinks.

Caffeine and nicotine are stimulants and can keep you from falling asleep. Alcohol can cause waking in the night and interferes with sleep quality.

The following list gives an indication of the caffeine content of some of the more common things we consume daily:

Cup of instant coffee	100mg caffeine
Cup of filter coffee	140mg caffeine
Cup of tea	75mg caffeine
Can of cola	40mg caffeine
Can energy drink	Up to 80mg caffeine
50g bar of plain chocolate	Up to 50mg caffeine
50g bar milk chocolate	Up to 25mg caffeine

Drugs and sleep

Medication-induced changes to sleep quality are not the same as sleep disturbance.

- In some cases the changes may be therapeutic, while in others they may be benign or not well understood.
- Although pain drugs may directly degrade sleep quality, they can result in better sleep if they reduce discomfort that would otherwise keep you awake.
- Studies are usually carried out on healthy individuals in sleep laboratories so the results should be interpreted with caution when applying them in practice.

Opioids

Opioids impact on the entire sleep cycle. They cause you to lose out on slow wave sleep: Stages three and four. They can cause initial drowsiness but may not be long lasting. Opioids can actually cause sleep apnoea as they can cause excessive relaxation of the throat muscles.

Paracetamol

Studies have shown that paracetamol has a beneficial effect on sleep quality even in patients free of pain.

NSAIDS

There is conflicting evidence regarding anti-inflammatories. Some studies have shown a negative effect, whereas others reported ibuprofen and aspirin have minimal to no effect.

Anti-depressants

Amitriptyline, nortriptyline, duloxetine and mirtazapine all suppress REM or dream sleep, improving the patient's mood.

Anticonvulsants and anti-neuropathic agents

Similarly to the antidepressants, gabapentin reduces dream sleep. Pregabalin increases NREM and has no effect on REM. Latest studies show an improvement in sleep hygiene of about 20 per cent in pain patients using pregabalin.

Benzodiazepines

It is still unclear whether the use of medication such as diazepam, temazepam, lorazepam and clonazepam has any effect on sleep. They could affect the sleep architecture and have an adverse effect on breathing during sleep. They also place patients at risk of developing tolerance and dependency.

Sedatives

Sedatives like zopiclone and zolpidem are not designed to be taken on a regular basis, as they can actually reduce sleep if taken long term. Such medication affects sleep architecture, creates tolerance and can lead to dependency.

Conclusion

- Remember you are not alone – all of us have sleep problems from time to time.
- Anxiety will make it worse.
- Focus more on the quality of sleep rather than the hours of sleep you get.
- If pain wakes you up, use your flare up strategies – pacing, re-positioning to enable you to get back to sleep.

Useful resources

www.sleepcouncil.org.uk

Nutrition and hydration

Nutrition

Most of us know the importance of good nutrition and the positive effects it has on our health. A well balanced diet helps us to look, feel and perform better.

Maintaining a healthy weight can lead to reduced fatigue, increased energy and reduced risk of developing certain health conditions, such as heart disease, high blood pressure, diabetes and some cancers.

Everyone knows how important healthy eating habits are and we also know that good nutrition advice is easy to find.

Good nutrition is also important for people dealing with chronic pain.

There is no such thing as a 'chronic pain diet'; however, nutrition is an important part of the self-management process. Eating healthy can help people with chronic pain in many ways.

And yet, the food on our plates is often far from what health experts recommend. This is particularly true for people who suffer from chronic pain, since they frequently lack the energy to prepare a healthy, balanced meal. Sometimes, they aren't even hungry. As a result, they get caught up in a hard-to-break cycle, as poor nutrition can make it harder for them to combat their pain.

Food gives us the energy we need to do things and carry out everyday tasks. It is the fuel that keeps our engines running. Not uncommonly, people who suffer from chronic pain are physically exhausted, and poor nutrition can be as much to blame as the pain itself. Also, eating badly or not enough, can have significant consequences, leading to a loss of energy, fatigue, stiffness, a reduction in activity, and feelings of discouragement. Any of these can increase the severity of pain. It can also be perceived by the body as a threat and therefore evoke the stress response.

Excess weight can cause pain in the back, hips, knees, ankles and feet. People who are overweight are also more vulnerable to more serious health problems, such as cardiovascular disease.

An unhealthy diet may also contribute to:

- sensitisation of the nervous system
- increased inflammation in the body
- disrupted sleep patterns
- an increase in anxiety and depression
- an increase in the intensity of the stress response.

A healthy diet should consist of foods from the following groups:

- fats
- carbohydrates
- fruits and vegetables
- proteins
- dairy.

Inflammation may be increased by eating saturated fats (solid at room temperature) and trans fats (vegetable oils processed to become solid). Examples of these include lard, butter, fat on meat, full fat dairy foods and most takeaways and processed foods, such as pre-packed cakes, pastries, and biscuits.

Inflammation may be reduced by eating poly-unsaturated fatty acids. There are two main types: Omega-3 and Omega-6 fatty acids. It is important to distinguish between Omega-3 and Omega-6 fatty acids as a high proportion of Omega-6 to Omega-3 ratio may increase inflammation.

Omega-3 fatty acids can be found in oily fish, rapeseed, soya, flax, linseed oils and walnuts. Omega-6 fatty acids are found in vegetable oil, nuts, lean meats and eggs, and should be eaten in moderation.

Carbohydrates are our main source of energy and play an important function in the regulation of our blood sugar levels. In fact, 50 per cent of our energy should come from carbohydrates. There are several types of carbohydrates: Starchy, non-starchy (sugary) and dietary fibre. Starchy carbohydrates come from bread, flour, rice, pasta, couscous and breakfast cereals. These are absorbed slowly and help maintain stable blood sugar levels and therefore energy levels.

Sugary carbohydrates cause peaks and troughs in blood sugar levels which can contribute to a lack of energy.

Proteins are the building blocks of our body and are vital for metabolism and organ function. Sources include all types of meat, eggs, dairy, beans, lentils, nuts and seeds. Proteins are better absorbed if eaten with starchy carbohydrates.

Diet and Sleep

Tryptophan is a protein found in food. It makes serotonin, the 'feel good' chemical. It is thought that people who experience anxiety and depression may have lower levels of serotonin. Tryptophan is also linked to the production of melatonin, the chemical which promotes sleep.

Diet and the stress response

The stress response is triggered by the autonomic nervous system and is our brain's response to a threat. The threat may be actual or potential and may be physical or emotional. It was intended for short bursts of activity such as the threat our ancestors faced from wild animals.

An unhealthy diet is a physical threat to the body and it may trigger or maintain the stress response as a protective mechanism. The stress response is also more likely to be triggered by an already sensitised nervous system.

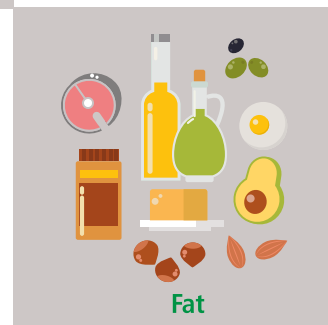
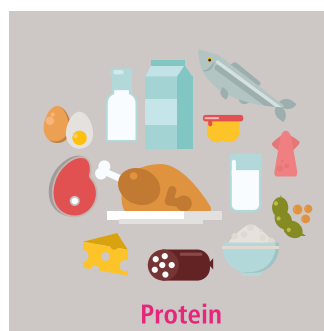
Supplements

Generally speaking, if you are eating a well-balanced diet, nutritional supplements are unnecessary. However, the following information may be relevant:

Omega 3 fatty (0.5-1g of EPA+ DHA) daily may be beneficial in those with inflammatory conditions such as rheumatoid arthritis.

Magnesium 600mg daily may be beneficial for fibromyalgia.

Vitamin D3 600iu daily may be beneficial for fibromyalgia.



Hydration

Good hydration is essential for the functioning of our bodies. Water makes up approximately 60 per cent of the total mass of an adult body, with the brain, muscles, blood and discs in our spines having much higher water contents.

As a result, dehydration can have a big impact on the way that our bodies work, and even slight dehydration can cause poor concentration, increased pain, cramps and affect the way we heal, amongst other things.

Unfortunately we are not very good at recognising when we need to drink, and therefore unless you make sure that you are regularly having soft drinks throughout the day, it is likely that you are not well hydrated.

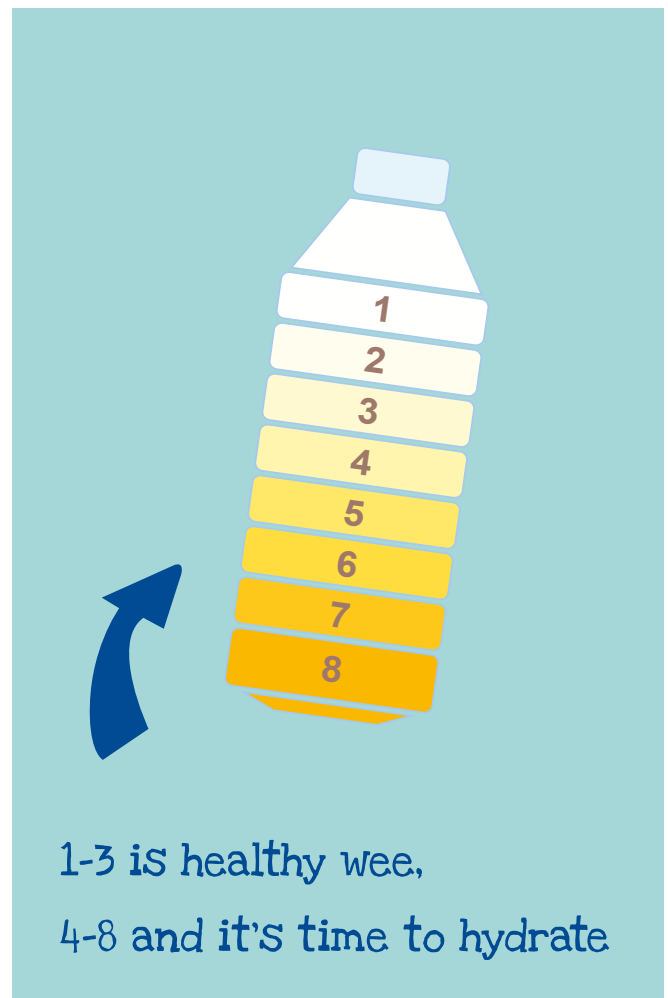
Drinking sufficient fluids (not alcohol) throughout the day can help improve many of the symptoms that people with chronic pain tend to suffer with, including decreasing the chance of cystitis, decreasing swelling, improving constipation, improving concentration and vigilance and helping to decrease pain and muscle cramps. It even helps with hormone production.

Everyone needs a different amount of fluid throughout the day depending on many different factors, and therefore the easiest way to tell if you are well hydrated is to look at the colour of your urine. If it is pale straw coloured or lighter you are probably well hydrated. The darker your urine, the more likely it is that you are dehydrated, and should therefore try to increase your daily fluids with small, regular soft drinks.

Helpful resources

The British Dietetics Association (BDA) website can provide helpful fact sheets about different conditions and healthy eating.

Visit www.bda.uk.com



Exercise and chronic pain

People with chronic pain often avoid activity or exercise for fear of making their pain worse. Usually it would make sense to take it easy when we feel pain and that is normally the sensible thing to do if the pain is caused by a traumatic injury such as an ankle sprain or hamstring tear.

For anyone suffering with chronic pain though, it looks as if the opposite may be true. Recent research indicates that **regular, gentle exercise can help manage chronic pain.**

Many people living with chronic pain tend to get caught up in a cycle of increasing immobility. **Immobility leads to weight gain, muscle wasting, loss of mobility, muscle tightness and a sense of helplessness.** Getting caught in this downward spiral often leads to increased pain.

Research has shown that exercise can be an effective way to reverse this downward cycle of deconditioning and worsening pain, and gradually over time help those with chronic pain engage more in activities of enjoyment and essential activities of daily living with greater ease.

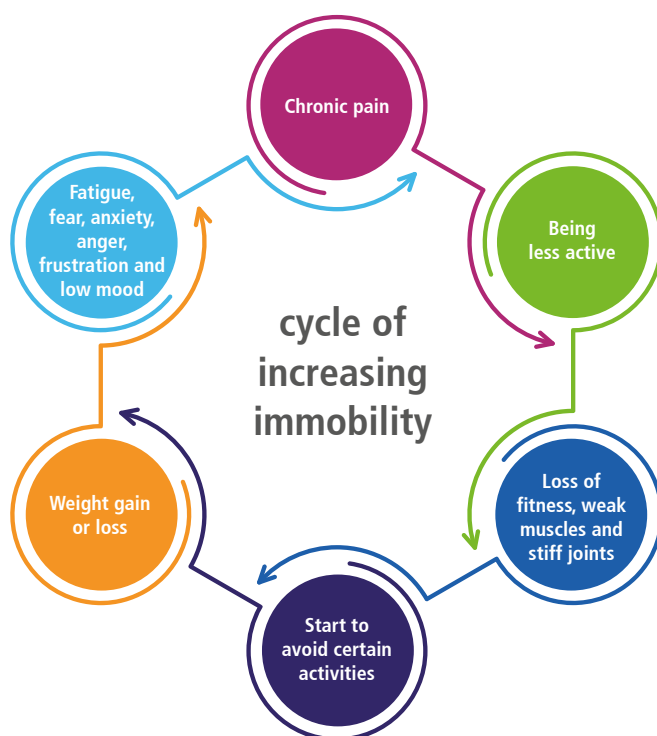


People living with chronic pain may find it difficult to believe that any exercise, which so often worsens symptoms at the start, will have a good outcome for pain management.

However, many have found that **careful exercise progression can be very helpful in managing chronic pain in the long-term.**

Useful facts about exercise and chronic pain:

- People with chronic pain who exercise regularly may require less pain medication for the same amount of pain relief.
- Gentle strengthening can help maintain or add to your muscle strength. Strong muscles support and protect joints. Weight-bearing exercises include using resistance bands or weighted wristbands.
- Endurance exercises make the heart and arteries healthier and may lessen swelling in some joints. Low-impact endurance exercises include swimming and cycling.



- Flexibility exercises help to keep joints moving, relieve stiffness and allow for more freedom of movement for everyday activities. Flexibility exercises include upper and lower body stretching, yoga, and tai chi.
- Stronger muscles are less prone to micro-trauma, meaning less daily pain.
- Exercise done on a regular basis improves sleep and provides more energy.
- Being able to manage chronic pain has a significant psychological impact as well, since you no longer feel like you have no control over your body.

One of the many reasons exercise is an effective pain management tool is because it releases endorphins – brain chemicals that improve mood and act as natural painkillers. It is important to remember that the typical endorphin release experienced by the general population is often not present in chronic pain patients who exercise.

This particular group of people may go many months before exercise typically begins to feel good. Therefore, **patience and perseverance are key to exercising when living with a chronic pain condition.**

Tips for exercising with chronic pain

- Choose exercise you enjoy – everyone is different and enjoys different types of activities.
- Consider some aerobic exercise in all exercise programmes, for example, swimming or walking.
- Some discomfort with exercise is acceptable, however, it is likely that you are overdoing it if you regularly experience flare-ups that last for more than a few hours after exercise.
- Try to avoid doing more on good days and less on bad days.
- Don't overdo it initially and accept that there will be obstacles along the way. Some days may seem impossible due to pain or fatigue.
- Slowly pace up the exercise programme by increasing the number of repetitions or duration of an exercise, for example three repetitions to five repetitions.
- Seek the support and advice of a healthcare professional or exercise specialist that is aware of the particular needs of someone living with chronic pain.

Improvement won't happen overnight, so get started with gentle, slow movement like a few simple stretches, a few widths in a pool or a two-minute walk that you increase gradually for instance.

Steadily increase the length or frequency that you exercise over the course of several weeks or months.

Relaxation

Diaphragmatic Breathing

Learning how to breathe correctly is probably the easiest and most effective method of learning how to relax, while training yourself to breathe in a way that helps you relax and reduce your pain.

1. Find a quiet place where you will not be disturbed (take the phone off the hook; tell others not to disturb you).
2. Sit with your feet flat on the floor, in a chair that provides good support.
3. Place one hand on your abdomen and one on your chest. Take a normal breath in and notice which hand moves the most. Most likely it will be the hand on your chest. Now try to take a breath from your abdomen – you might feel as though you are pushing your stomach out and this is the way it should feel. As a visual reference, imagine you are filling a jug of water from the bottom up.
4. Now close your eyes. Take a slow deep breath in through your nose (count to three) and then exhale (count to three) through your mouth. Breaths should be of equal length (count to three) or your out-breath should be a little longer.

It is sometimes helpful to guide yourself with a few statements, such as:

“With each breath I take, I feel myself becoming more relaxed, more at peace, more calm...”

“With each breath I take, I feel myself letting go of tension.”

“With each breath I take, my body feels heavier, warmer, softer...”

Breathing from your diaphragm may be very different to your normal pattern of breathing, so it is important to practice this technique regularly to get the most benefit from it. In addition, diaphragmatic breathing should not only be used when you notice stress but as part of your daily routine. Try to secure at least five to 10 minutes a day where you can practice deep breathing on its own, or in combination with other techniques.

Don't give up too soon if you don't see an immediate benefit, your body needs time to adjust.



Progressive muscle relaxation

The following exercise in progressive muscle relaxation (PMR) will look at how to help manage the physical impact of stress. The purpose of PMR is to help you to develop awareness of when your muscles are becoming tense and learn to relax them before the tension becomes great. This technique not only decreases muscle tension, but also induces a general state of mental calm and deep physical relaxation.

Note: If you feel pain in specific areas following this exercise, do not tense that muscle group, or perform only mild-tensing in that area next time.

1. Make yourself as comfortable as possible in a seated position. Hands resting gently in your lap. Start with a few minutes of diaphragmatic breathing.
2. When you are ready, begin tensing and relaxing specific muscle groups:

Feet

- Flex your foot by pulling your toes up toward your knees while your feet are flat on the floor.
- Feel the tension building in your foot and hold it there for three seconds.
- Take a deep breath.
- As you exhale say the word 'relax' and release the tension slowly, paying close attention to the different sensations.
- Perform this exercise twice and repeat with the other foot.

Calves

- Contract the calf muscle by lifting the heel of your foot.
- Feel the tension build and hold it for three seconds.
- Take a deep breath.
- As you exhale say the word 'relax' and release the tension slowly, paying close attention to the different sensations.
- Perform this exercise twice and repeat with the other calf muscle.

Knees and upper thighs

- Extend your leg out straight and tense your thigh muscle.
- Feel the tension building in your thigh and hold it for three seconds.
- Take a breath.
- As you exhale say the word 'relax' and release the tension slowly, paying close attention to the different sensations.
- Perform this exercise twice and repeat with the other thigh.

Abdomen

- Observe your abdomen rising and falling with each breath.
- Inhale deeply and tense the abdomen (stomach muscles).
- Feel the tension and hold it for three seconds.
- As you exhale say the word 'relax' and release the tension slowly, paying close attention to the different sensations.
- Perform this exercise twice.

Hands

- Tightly clench your fist for about five seconds.
- Focus on the sensations in your hand and examine the feelings of muscular tension.
- Take a deep breath and as you exhale release the tension slowly and gradually, allowing your fist to open and your fingers to move.
- Take a few moments to allow feelings of relaxation to develop.
- Focus on the contrast between relaxation and tension.
- Perform this twice and repeat using other hand.

Forearms

- Turn your palm face up, make a tight fist and curl it towards you.
- Feel the tension build and hold for three seconds.
- Take a deep breath.
- As you exhale say the word 'relax' and release the tension slowly, paying close attention to the different sensations.
- Perform this exercise twice and repeat with the other forearm.

Biceps

- Bring your fist in toward your shoulders and tighten your bicep.
- Feel the tension build and hold it for three seconds.
- Take a deep breath.
- As you exhale say the word 'relax' and release the tension slowly, paying close attention to the different sensations.
- Perform this exercise twice and repeat with the other bicep.

Shoulders

- Draw the shoulder blades together (to midline of body).
- Contract the muscles across the upper back.
- Feel the tension and hold it for three seconds.
- Take a deep breath.
- As you exhale say the word 'relax' and release the tension, letting the shoulder blades return to their normal position, almost as if weight had been placed on them.

Jaw and facial muscles

- Clench your feet together.
- Tense the muscles in the back of your jaw.
- Turn the corners of your mouth in a tight smile.
- Wrinkle the bridge of your nose and squeeze your eyes shut.
- Take a deep breath.
- As you exhale say the word 'relax' and release the tension slowly, paying close attention to the different sensations.

Forehead

- Raise your eyebrows up and tense the muscles across the forehead and scalp.
- Feel the tension build and hold it for three seconds.
- Take a deep breath.
- As you exhale say the word 'relax' and release the tension slowly, paying close attention to the different sensations.

Whole body muscle relaxation

- Focus on relaxation flowing from the top of your head.
- Over your face.
- Down the back of your neck and shoulders.
- Over the chest and abdomen.
- Flowing through your hips and buttocks.
- Into your thighs, knees and calves.
- Into your ankles and feet.
- Continue to breathe quietly for a few minutes.

Take a few seconds to empty your mind and to allow the feelings of relaxation to spread throughout your body. Scan your body and if you find any remaining tension allow yourself to let go of it. Count backwards in your head from three to one.

Become aware of your surroundings. Move your feet, legs, hands and arms. Turn your head to either side, or in a circle. Open your eyes slowly, feeling refreshed and relaxed.

Reference: J. D. Otis, *Managing Chronic Pain: A Cognitive-Behavioural Therapy Approach*. Oxford University Press, Inc. New York, 2007.

Flare ups

Managing flare-ups

Flare-ups or dramatic increases in pain levels are a normal part of living with chronic pain and it can be helpful to accept that these episodes are bound to happen from time to time. How often they occur and how long they last varies from person to person. **It is important to learn ways of managing your pain in order to experience fewer flare-ups and to be able to cope with them when they do happen.**

Flare-ups are often triggered by overdoing things, although the effects might not be felt until later. Moving or sleeping awkwardly, or changes in the weather can also sometimes trigger flare ups. A flare up of pain could also be experienced before, during or after stressful events such as illness or family functions. Women, particularly those with pelvic pain, might have more pain at the time of their period.

Flare ups may also just happen with no identifiable trigger.

Flare-ups often lead to cancelled arrangements or disrupted plans for doing things, which can be frustrating. Concentration, sleep and personal care may also be affected. During flare-ups many people want to be on their own, while others feel it is important to let those around them know that they are having

a bad day. Others call on family to help care for children or to take over the daily chores until they are back to normal.

A good metaphor for a flare-up is a storm. Storms cannot be stopped, instead they have to be weathered. What you can do is to seek shelter, prevent damage, survive and stay as comfortable as possible whilst the storm is raging. When the storm ends there may be a sense of relief.

It can sometimes feel like pain is taking over, which can be very frightening. Some people opt for professional help (seeing their GP or attending A&E) but this is often not useful. Others choose to manage their flare-ups themselves with techniques learnt along the way.

Medication is a central part of some people's flare-up plans although others might prefer to use it only as a last resort. Rest and relaxation are generally quite important, although many people often find it difficult to give themselves permission to stop. While resting often means lying down it is also important to keep active at some level, as mobility could be easily lost from stopping everything. Gentle exercise sometimes relieves pain – keeping mobile could involve gentle stretching, yoga or just pottering



about. Some people find hot water bottles, heat pads and electric blankets soothing, whereas others get more relief from cold packs or a pack of frozen peas.

Distracting the mind away from the pain is considered important, though people are not always able to do this without some effort. Reading could be a good distraction although some find it difficult to concentrate and prefer to watch television or listen to music, the radio or tapes. Some find it helpful to focus on pleasant thoughts such as grandchildren, good times or a challenging piece of work.

Remember that episodes of intense pain are time limited. It is easy to lose sight of this at the time of a flare-up. A flare-up can be viewed as having a beginning and an end; it may begin or end abruptly, or gradually. The one thing you can be fairly sure of during a flare-up is that it won't last forever.

Try not to give yourself a hard time when having a flare-up. Instead try to focus on coping with the pain and working towards getting better as soon as possible.

Remember that to deal with pain you need a good 'box of tools'. The more tools you have, the more likely you will find a tool to help with the task. If one tool is not effective on a particular occasion, do not get discouraged, try another tool.

At a time when you are not experiencing a flare-up, spend some time thinking about how you would manage one. What might you do, how might you react, what would be most helpful? What may be your best tools to deal with your pain?



Useful websites

The following organisations are used as health education resources by the Community Pain Service.

Able

www.ableradio.com

Acupuncture Association of Chartered Physiotherapists

www.aacp.org.uk

Addaction

www.addaction.org.uk

Age UK

www.ageuk.org.uk

Alexander Technique

www.alexandertechnique.co.uk

Arthritis Research UK

www.arthritisresearchuk.org

Backcare

www.backcare.org.uk

Big White Wall

www.bigwhitewall.com

Breathworks

www.breathworks-mindfulness.org.uk

British Acupuncture Council

www.acupuncture.org.uk

But You Don't Look Sick.com

www.butyoudontlooksick.com

Carers First

www.carersfirst.org.uk

Carers Support

www.carers-ashford.org.uk

www.carers-supportcdt.org.uk

Carers Trust

www.carers.org

Carers UK

www.carersuk.org

CFIDS and Fibromyalgia Self-Help

www.cfidselfhelp.org

Citizens Advice

www.citizensadvice.org.uk

CRPS UK

www.crps-uk.org/

Daoist Internal Arts

www.taichi.uk.com

DFL/Shaw Trust

www.dlf.org.uk

Disability Grants

www.disability-grants.org

Disability Rights UK

www.disabilityrightsuk.org

Dover Counselling Centre

www.dovercc.org.uk

Ehlers-Danlos Support UK

www.ehlers-danlos.org

EMDR UK and Ireland

www.emdrassociation.org.uk

European Pain Federation (EFIC)

www.europeanpainfederation.eu

Expert Patients Programme

www.kentcht.nhs.uk/epp

Faculty of Pain Medicine

www.fpm.ac.uk/faculty-of-pain-medicine/opioids-aware

<https://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware>

Family Lives

www.familylives.org.uk

Fibromyalgia Action UK

www.fmauk.org

Fit for Work

<http://fitforwork.org/>

Frantic World

<http://franticworld.com/>

<http://franticworld.com/free-meditations-from-mindfulness/>

Gardening for Disabled Trust

<http://gardeningfordisabledtrust.org.uk/>

GOV.UK

www.gov.uk

Headway

www.headway.org.uk

Healthtalk.org

www.healthtalk.org

Hypermobility Syndromes Association

<http://hypermobility.org/>

HysterSisters

www.hystersisters.com

International Association for the Study of Pain

www.iasp-pain.org

Kent Advocacy

www.kentadvocacy.org.uk

Kent County Council

www.kent.gov.uk
www.liveitwell.org.uk

Living Life

www.lttf.com

Living With Chronic Pain

www.paincd.org.uk

Mindful

www.mindful.org/meditation

Moodcafe

www.moodcafe.co.uk

Moodjuice self-help guide

www.moodjuice.scot.nhs.uk/chronicpain.asp

NHS Choices

www.nhs.uk

noigroup

www.noigroup.com/en/Home

Northumberland, Tyne and Wear NHS Trust self-help leaflets

www.ntw.nhs.uk/pic/selfhelp

Ofwat

www.ofwat.gov.uk/households/customer-assistance/watersure

Overcoming

www.overcoming.co.uk

Pain Concern

www.painconcern.org.uk
<http://painconcern.org.uk/sex-and-chronic-pain/>

painACTION

www.painaction.com

Pain-Ed

www.pain-ed.com

Painkiller Addiction Information Network

www.painkilleraddictioninformationnetwork.com

Patient

<http://patient.info>

Porchlight

www.porchlight.org.uk

Relate

www.relate.org.uk

Scoliosis Association UK

www.sauk.org.uk

Self Management UK

www.selfmanagementuk.org

Sheffield Aches and Pains

www.sheffieldbackpain.com

Stickman Communications

<http://stickmancommunications.co.uk/>

Stitchlinks

<http://stitchlinks.com/>

Thanet Support

www.thanetsupport.co.uk

The Association of UK Dietitians

www.bda.uk.com

The British Medical Acupuncture Society

www.medical-acupuncture.co.uk

The British Pain Society

www.britishpainsociety.org

The Conservation Volunteers

www.tcv.org.uk/greengym

The Ehlers-Danlos Society

<http://ehlers-danlos.com/>

The Migraine Trust

www.migrainetrust.org

The Money Advice Service

www.moneyadviceservice.org.uk

The Pain Toolkit

www.paintips.org
www.paintoolkit.org

The Sleep Council

www.sleepcouncil.org.uk

Think Action

<http://thinkaction.org.uk/>

Trigeminal Neuralgia Association UK

www.tna.org.uk

Turn2Us

www.turn2us.org.uk

Turning Point

www.turning-point.co.uk

UK Fibromyalgia

www.ukfibromyalgia.com

Understanding Pain: Brainman stops his opioids

www.youtube.com/watch?v=Ml1myFQPdCE

Windmill Community Gardens

www.windmillcommunitygardens.org

Contact us

Write to us:

Community Chronic Pain Service
Kent Community Health NHS Foundation Trust
3rd Floor, Mill Lane House
Mill Lane
Margate
Kent CT9 1LB

Email: kentchft.chronicpainpatients@nhs.net
Phone: 0300 123 1753

Referrals can be made via Choose and Book (indirectly bookable) to Chronic Pain Referral Point (east Kent).

For more information and our referral criteria, please visit www.kentcht.nhs.uk/chronicpain

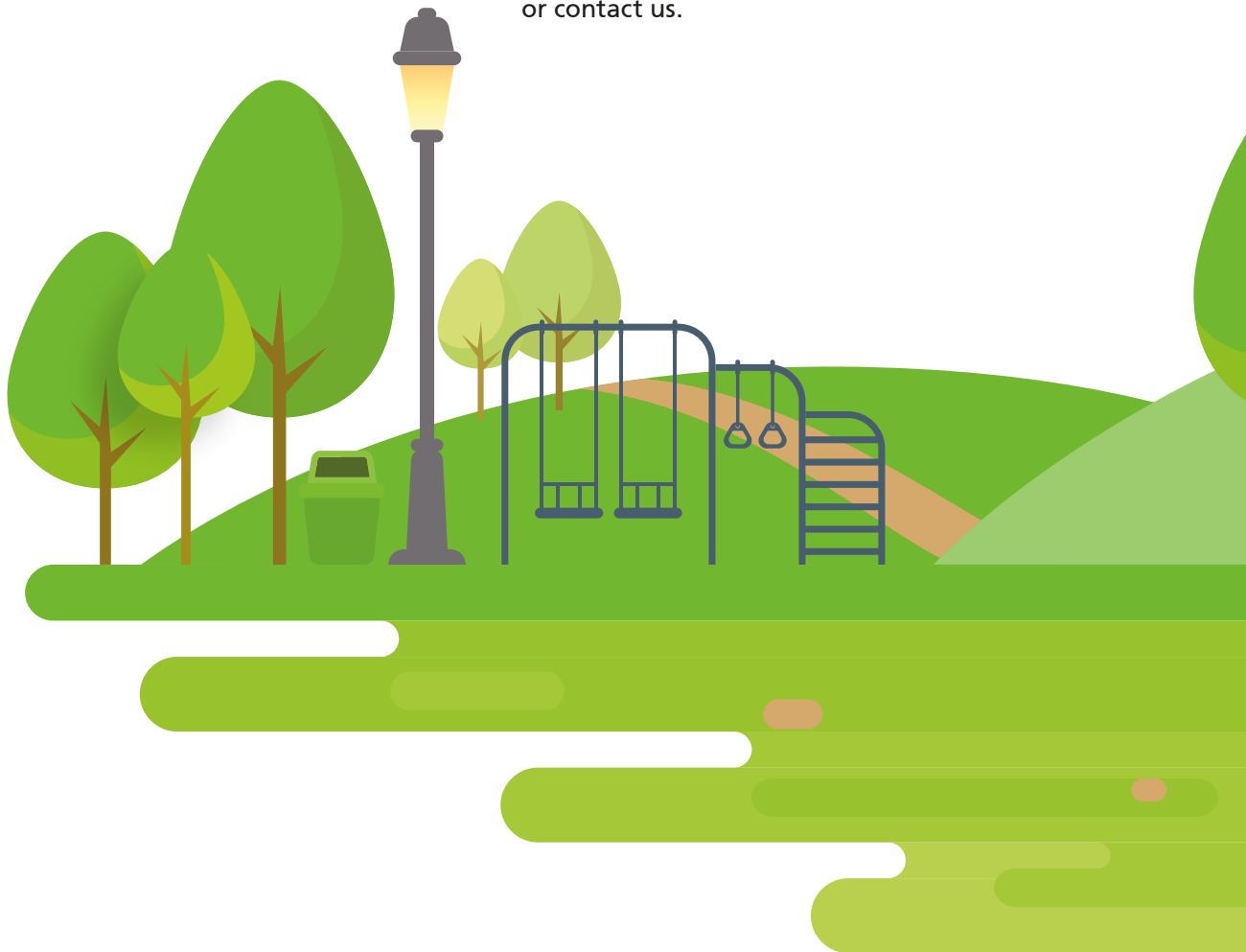
Do you have feedback about our health services?

Phone: 0800 030 4550, 8.30am to 4.30pm, Monday to Friday
Text: 07899 903499
Email: kentchft.PALS@nhs.net
Web: www.kentcht.nhs.uk/PALS

Patient Advice and Liaison Service (PALS)

Trinity House
110-120 Upper Pemberton
Ashford
Kent
TN25 4AZ

If you need communication support or this leaflet in another format, please ask a member of staff or contact us.



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