Understanding and Managing Long-term Pain

Information for People in Pain

THE BRITISH PAIN SOCIETY

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Why you should read this booklet

We all know what pain is. We have all suffered from it. Sometimes we hardly notice it. Sometimes it may be unbearable. Usually it goes away on its own but, at other times, it may need treatment. Unfortunately, there are times when it doesn't go away at all, becoming long-term pain. (Health professionals often use the terms 'chronic pain' or 'persistent pain'.)

There are many different causes of long-term pain and we do not know them all yet. The aim of this booklet is to help you make sense of long-term pain, understand the difficulties associated with it and how it can best be managed. We do not specifically cover pain caused by cancer, but much of what is described can also apply to cancer pain.

Whether your pain is recent or long -term, severe or less severe, this booklet explores the best ways of managing it. We look at what pain is, what can be done about it, who can help you with it and how you can help yourself.

The aim of this booklet is to help you understand the difficulties associated with long-term pain and how it can best be managed.

Why doesn't my pain go away ?

Some pain is easy to understand because there is an obvious injury such as a cut or a bruise. Other pains are less obvious. For example, you cannot see the pain of appendicitis, but anyone who has had it will tell you that it is real enough.

Health professionals use different terms for different types of pain.

- Short-term pain, such as when you suffer a sprained ankle, is called 'acute' pain.
- Long-term pain, such as back pain that persists for months or years, is called 'chronic' pain.
- Pain that comes and goes, like a headache, is called 'recurrent' pain.

It is not unusual to have more than one sort of pain or to have pain in several places

> Pain is defined by the International Association for the Study of Pain (IASP) as "*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*" (www.iasp-pain.org).
>
> The definition is important because it links emotion and past experience to the sensory event. This means that the only way of deciding whether someone has pain is by asking them or picking up clues from the way they behave.

Many acute pains are a useful alarm signal that something is wrong. Most minor pains get better on their own or with simple treatment. Others may be a sign of something more serious, as with a broken leg. This pain is helpful because it means that you get treatment and rest your leg until the break has had a chance to heal. Long-term pain, on the other hand, appears to serve no useful purpose and has a huge impact on the lives of many people.

Why doesn't my pain go away?

Pain can be experienced in any part of your body and involve a number of different mechanisms:-

- The pain most commonly felt when pain mechanisms are 'switched on' is technically known as 'nociceptive pain'.
- When body tissues are injured, inflammatory changes can occur leading to 'inflammatory pain'.
- If sensory nerves are damaged and malfunction the result is nerve pain or 'neuropathic pain'.
- When our internal organs are affected we may experience 'visceral pain'.
- It is possible to have pains involving more than one mechanism. These are referred to as 'mixed pains'.

Normally, when we feel pain, signals travel from part of the body along particular nerve fibres via the spinal cord to the brain. However, in some cases (for example, pain after a stroke) damage to the brain or to the spinal cord can cause pain to be felt in parts of the body which are not actually damaged. This type of neuropathic pain (see above) can be likened to a faulty burglar alarm—the alarm is sounding but there is no intruder.

Pain signals are initially processed in the spinal cord and then in the brain where there are connections with centres associated with anxiety, emotions, sleep, appetite and memory. This creates a very personal experience of pain for each person.

The brain sends signals back to the spinal cord which can, in turn, reduce or increase the pain further. Nerve endings and parts of the spinal cord and brain can become over-sensitised as a result of constant pain input.

Why doesn't my pain go away?

One reason is a process called 'central sensitization'. This is a type of 'learning' by nerve cells in your spinal cord and brain which means that that the pain does not go away even if the original cause is discovered and treated. It may result in pain experience that seems out of proportion to the initial injury.

In simple terms the body's warning system becomes more sensitive, producing an increased feeling of pain even though there may no longer be any continuing damage to the body. This can lead to a long-term and challenging problem. You and the healthcare professionals need to work together with skill, time and patience to improve things.

Although medical technology is improving all the time, some pain is very complicated. It may involve so many factors that we may never be able to find the precise cause with X-rays, scans or laboratory tests. However, not knowing the cause of the pain does not mean it does not exist and the problems it creates are also very real.

Only the person in pain can really say how painful something is. Because pain is always personal, no two people experience it the same way. This can make it very difficult to define and to treat.

Unfortunately, there is more to long-term pain than simply hurting. This is unpleasant enough by itself, but when it continues for a long time it can affect every part of your life and how you cope with it. It may affect your ability to work, your relationships with family and friends, your activity levels and your sleep. All of this may become overwhelming at times and can cause a vicious circle of increasing pain and distress.

Pain is never 'just in the mind' or 'just in the body'. It is a complicated mixture of signals from the body and how the brain interprets them. You know your pain, even though it cannot be seen. The challenge for you and those treating you is to understand the complicated nature of long-term pain and the best way to manage it.

What might this mean for me?

Long-term pain is complicated and not easily 'fixed'. You will need patience to work alongside your health professionals to work out what works best for you.

Unfortunately, you may have to continue to live with some level of pain because there may not be a way to get rid of it. However, this does not necessarily mean that it will get worse or that continuing damage is being done. This is why health professionals often refer to pain *management* rather than talking about treatment or cure.

You should ask the health-care professionals who are helping you to explain— so far as they understand—the things that puzzle, concern or worry you.

Common questions are:

- *What is causing my pain?*
- *Is it likely to get worse?*
- *What are the investigations (X-rays, scans and so on) looking for, and what do my results mean?*

- *If my pain medicines don't work, can I have stronger ones or what else can be done?*
- *If a pain medicine does work, will it hide other pains which might be telling me that something else is wrong and needs attention?*
- *Why can't my pain be switched off?*
- *Could a surgeon see something if he or she looked inside me, even if it doesn't show on a scan?*

- *If I take morphine or other similar drugs for my pain, will I get addicted?*
- *What are the side effects of the drugs I am taking?*
- *What is the effect on my body of taking drugs for a long time?*

What might this mean for me?

It will help those looking after you if you can give them the answers to the following questions:

- *What makes the pain worse? Is this straight away or after a while?*
- *What eases the pain, even a little?*
- *What does the pain stop you doing?*
- *What can you still do, but avoid doing because it hurts?*
- *What don't you do because you are worried you might damage yourself?*

- *Does the pain stop you getting to sleep? Does the pain wake you up?*
- *Does your mood or stress affect your pain?*
- *Does your pain affect your mood or stress levels?*
- *If you are taking a pain medicine, how well does it reduce the pain and for how long?*

To find the best treatments for you, it is often necessary to try various options to see if they help. This is not because the health-care professionals do not know what they are doing, but because pain is complicated and every pain and every person is different.

What help is available?

Who can help me and what might they do?

There is a lot that can be done to help you. The best results come when you play an active role in treating your condition alongside those who are treating you. How you can help yourself is covered in the next chapter of this booklet.

While your GP may be able to help with your pain by prescribing medicine, for some patients a more specialist approach may be needed. Help in managing long-term pain can come from a variety of healthcare professionals. Most patients will meet these people through the National Health Service (NHS) after being referred by their GP, although some services can be accessed privately.

You will find the health-care professionals with most experience of managing long-term pain in specialist pain clinics in hospitals. However, the NHS is changing and more specialist services are now available outside these clinics and even outside the hospitals.

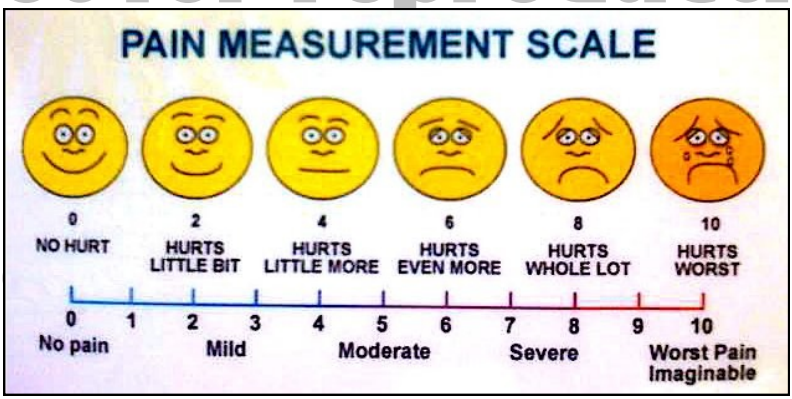
Pain clinics are often 'multi-disciplinary', which means you may be seen by a number of specialists – for example, doctors, nurses, physiotherapists, psychologists and occupational therapists. Each has a different part to play in managing your pain though their roles often overlap.

SPECIALIST PAIN DOCTORS can normally be found in pain clinics. They are usually anaesthetists who have undergone specialist training in pain medicine. They are likely to play a key role in relation to diagnostic questions and in advising on and delivering medical and interventional treatments.

What help is available?

You may not always see a doctor on your first visit to the clinic. Another member of the team may see you first. The healthcare professional who assesses you will listen to your story and ask questions to piece together a picture of your pain, how it is linked to other medical problems that you might have and how it affects you as a person.

This is called an 'holistic assessment' and is a very important part of understanding your pain and the impact it is having. Your answers and your own thoughts and views are an important part of the assessment. Sometimes you will be asked to fill in a questionnaire about your pain and how it is impacting on you and your life. It can be helpful to take along a list of your current medicines as well.



Pain measurement is one part of an holistic assessment

The assessing clinician will talk with you about the types of pain that you have and will try to explain why this has happened. He or she may also examine you to look for any causes for the pain that might have been missed and to assess your overall state of health. Then they will discuss a management plan with you. Sometimes this may be after you have seen other members of the pain team.

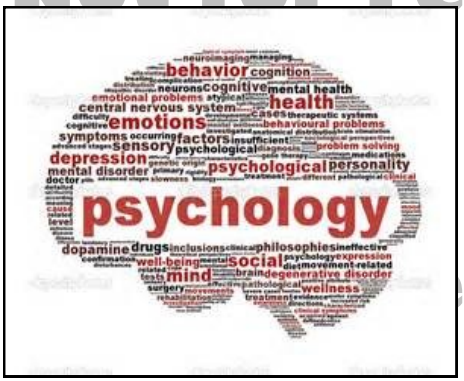
You may be prescribed drugs that are unusual or new to you. Your GP may also be unfamiliar with these. The pain clinic may also use injections or other pain-relieving procedures, often requiring X-rays and specialist equipment. They may well offer more than one treatment.

What help is available?

It is possible that you may need more specialist investigations (such as an MRI scan) than your GP can arrange. It is possible too that the pain specialist may decide you need to be referred to another hospital consultant: for example, a rheumatologist, neurologist or surgeon.

You may be asked to see a pain psychologist as part of the team assessment. This does not mean that the professionals advising you think you are imagining your pain or that you are 'mad' - far from it.

PSYCHOLOGISTS can be very helpful in looking at ways to help you manage your pain so you can live a more normal life. This usually involves a discussion of how you understand your pain, how you feel about it and what you think will happen in the future. This is because this is what guides you in your day-to-day life.



Trying different ways of seeing things and different ways of doing things can help when you cannot see a way forward. Psychologists might also identify other stresses that are adding to your pain.

PHYSIOTHERAPISTS are important in a pain team because pain can impact on your ability to move normally. Although physiotherapy services for pain are usually based in physiotherapy departments in large hospitals, they are becoming more available in GP surgeries and health centres.

Physiotherapists may use a variety of approaches for long-term pain. In the early stages you may be offered treatments to try to relieve your pain. This could include manual therapy, electrotherapy or acupuncture. In a pain clinic, however, you are more likely to be given information and advice to help you to lead an active life and maintain your quality of life.

What help is available?

Pain may increase when you first try new exercises. This is normal but do tell the physiotherapist or doctor if the flare up in your pain is more significant. The exercises may need to be adapted. Additional pain relief may also be required.

OCCUPATIONAL THERAPISTS (OTs) can also be found in some pain teams. Their roles may overlap with others such as the physiotherapist or psychologist. They can often give expert advice on how you can best manage your day-to-day activities despite your pain. They may also assess you, your home and your workplace to identify helpful adjustments

SPECIALIST PAIN NURSES are normally employed in the NHS in pain clinics, with some working in the community. The role of the specialist pain nurse varies from place to place. They are normally involved in providing information and advice, often helping with trials of pain medicines. They may also offer treatments such as acupuncture or TENS (see page 18).

PHARMACISTS are experts in medicines. If you have not fully understood or remembered all the details of how to take your medicines, your pharmacist will help explain this to you.

CHIROPRACTORS AND OSTEOPATHS mainly use manual therapies such as manipulation and massage to treat pain. This treatment is not normally available as an NHS treatment.

In spite of the huge progress that modern medicine has made, pain specialists cannot cure or relieve all pain. But they can make a real improvement to the quality of your life by involving all the members of the pain team in a many-pronged (multi-disciplinary) approach. You may be offered the chance to join a structured pain management programme (PMP) to make best use of this approach (see page 34).

What help is available?

What treatments might be offered?

It is not uncommon to hear people with long-term pain conditions say that they are prepared to try anything to be free from pain. Even if you have never said this yourself, you will probably understand those who do. In searching for effective treatments, however, you may come across many types of treatment that have no scientific evidence. They may help but they could harm. It is possible to spend a lot of money on treatments that are not proven to work and which could possibly make matters worse.

Most treatments offered to you by pain clinics will have undergone an assessment process through formal research or by examining outcomes of treatment in other patients with similar problems. Healthcare professionals use this knowledge to advise you as to which treatment or combination of treatments is likely to help. This is called evidence-based medicine.

Before starting any treatment, it is worth asking about the possible benefits as well as any risks. You may also ask the clinician how the treatment works, how long it will take and how much it will cost (if it is not available on the NHS). You may also like to make sure that the therapist is registered with a reputable professional organisation.

Do not feel you have to accept any treatment or continue with it if you do not wish to.

Treatments

* Exercise
* Manual Therapy
* TENS
* Acupuncture
* Drugs
  - Side effects
  - Standard pain medicines
  - Stronger pain medicines
  - Combination pain medicines
  - Non-standard medicines for pain
* Topical medicines
* Injections
* Long Term Devices

What help is available?

- **Exercise (or being active)**

For many people with long-term pain, exercise is a word that strikes them with fear. Their previous experience of exercise has often been painful and some may believe that movement will cause damage. It is understandable that many are reluctant to try it. A physiotherapist is likely to be able to help you learn safe and effective exercises for your specific condition.

There is a difference between exercise that would help you recover from acute pain and exercise for long-term pain. Exercise for long-term pain is designed to help you best use and build on what you can do. Because of pain, you may be less active, and that can lead to stiff joints, increased weight, poor fitness, weak muscles and getting breathless more easily. In the long run, a lack of exercise can also lead to other health problems.

What help is available?

- **Exercise (continued)**

People with long-term pain face a dilemma: activity may increase pain' especially at first, but a lack of activity is likely to lead to long-term problems. This is particularly true for people who have joint pain associated with arthritis. These problems can then, in turn, cause an increase in pain. However, exercise is vital to help deal with long-term pain and live a meaningful life.

For any of us, getting started can be difficult. We all ache when we have not exercised for a long time. This is a sign that the body is rebuilding muscles and tendons, not a sign of damage. For people with long-term pain, however, these normal aches and pains can be more severe and more challenging but they are still not a sign of damage. It pays to start gently and build up slowly. A physiotherapist can help you draw up a specific activity and exercise regime that you are able to manage and likely to stick to.

Exercises can be divided into two types – general and specific. General exercise, such as walking, swimming, dancing, cycling and aerobics, improves your fitness and helps manage your weight. Specific exercises are performed to increase the strength or movement of particular muscles or joints.

It is important to find activities that you enjoy. This might be going to the gym or it might be walking, cycling, dancing, doing tai chi or gardening. Exercise should become an enjoyable part of life rather than a chore. If you can build it into a routine and do it with friends or family you are much more likely to keep it up.

What help is available?

- **Manual Therapy**

Manual therapy includes both mobilisation and manipulation and should be performed by registered health professionals: physiotherapists, osteopaths or chiropractors.

Mobilisation involves the therapist applying slow, passive movements to a joint. The patient cannot perform these movements independently but they are within the normal range of motion of the joint.

Manipulation is also a passive technique where the therapist applies a specifically directed manual thrust to a joint, at or near the end of the normal range of motion. This may be accompanied by an audible 'crack' or 'pop'.

Both of these can help to improve the range of movement of a joint which may lead to short term pain relief allowing increased exercise and activity. However, if you have enhanced pain sensitivity (sensitisation), often found in long-term pain conditions, manual therapies may actually aggravate your pain.

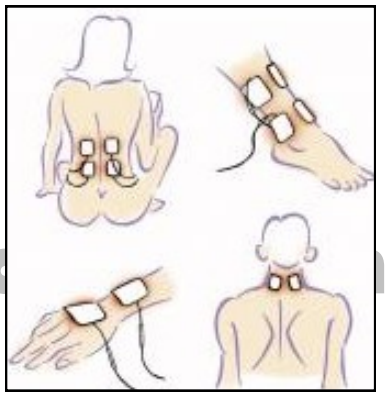
Massage is a gentle, often relaxing, hands-on treatment which can help muscles relax and it may distract you from the pain. The benefits of a massage are likely to be short term, but it could help you get over a difficult period. If your pain condition has been previously assessed by an appropriate doctor or health professional, massage is unlikely to cause any harm.

Registered health professionals may offer massage, but many other therapists and individuals also offer massage therapies. If you are seeking therapy outside of the NHS, it is advisable that you check that your therapist is appropriately trained. If in doubt, you should seek advice from your doctor or physiotherapist.

What help is available?

- **TENS**

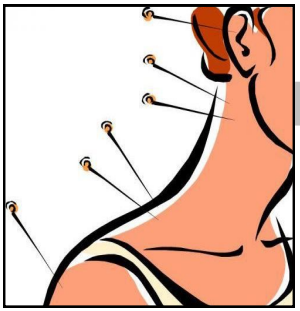
Transcutaneous electrical nerve stimulation (TENS) aims to block, or partially block, pain signals as they pass through the spinal cord on the way to the brain. It does this by passing a mild electrical current through the skin via sticky pads. The sensation of vibration produced by the TENS machine makes it more difficult for nerves in the spine to pass pain messages up to the brain. It is a similar although more reliable way of reducing pain by 'rubbing it better'.



A TENS machine is often available through your GP, pharmacy, physiotherapy department or pain clinic. They are not expensive to buy from larger pharmacy stores. It is important to take time to learn how to use TENS and you may wish to seek professional advice. Some people find it a useful alternative to taking medicines, which do not work for everyone or which may have side effects. Some people find the benefit from TENS continues for as long as the device is used, others find it diminishes over time.

- **Acupuncture**

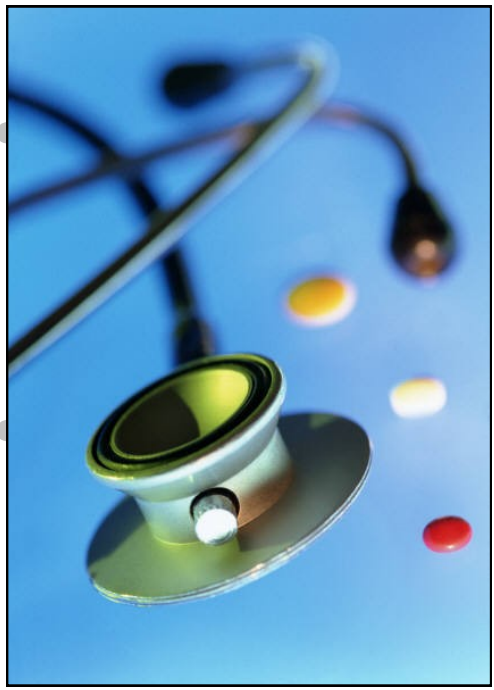
Acupuncture may be available in some GP surgeries, NHS pain clinics and physiotherapy departments as well as from private practitioners. The effect is very variable between patients and may depend on the type of pain condition. The benefits are often short-term rather than long-lasting. You may need to have 'top-up' treatments to maintain the benefits. You should check that your acupuncturist is trained and registered with a recognised professional organisation – see *More Information* on page 37.



What help is available?

- **Medicines (drugs)**

'Painkillers' are probably the treatment that most people expect to be given when they have pain. Many find, however, that 'painkillers' don't 'kill' the pain either in the short or long term. That can be disappointing and frustrating. You should discuss with your doctor what you expect from the treatment.



"Why don't my pain medicines work?" is a commonly asked question, and often one without simple answers. Persistent pain can arise through several different mechanisms, and most individual drugs only work on one mechanism. Some pains do not seem to respond to any pain-relieving drug. You can also develop a tolerance to some pain medicines, so that you need more and more to have the same effect.

The correct dose of any medicine is the minimum dose that produces the maximum benefit. Deciding whether to continue with a drug depends on balancing the benefits (in this case relief of pain) against the drawbacks (for example, unpleasant side-effects).

It is very helpful to keep a record of which medicines you have used, the dose, for how long, how you responded to it and why you stopped it. This can prevent you being prescribed the same drug a second time or alert the doctor to recommend changes to the way you use it.

What help is available?

SIDE EFFECTS

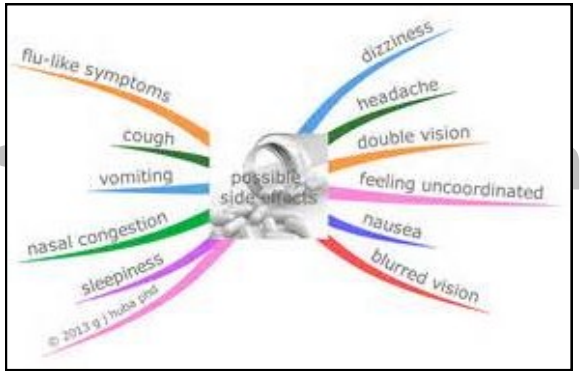
Any medicine can have side effects or interact with other medicines you are taking. This will vary from one patient to another. Many side effects reduce with time or can be treated effectively.

Some problems are common to many drugs, such as feeling sleepy, feeling dizzy, getting a rash or feeling sick. Other problems may be more specific, such as indigestion from NSAIDs (non-steroidal anti-inflammatory drugs), weight gain from anti-epileptics and constipation from opioids. Some medicines can be linked to more serious side effects such as bleeding of the stomach lining or breathlessness. This is why many medicines are only available on prescription.

The list of possible side-effects that are included on patient information leaflets is often quite long but each side-effect will normally only apply to a few patients. You may be fortunate and have none of the side-effects or you may be unfortunate and have a number of them. Similarly, if a medicine needs to be stopped, some people are able to do so easily with no withdrawal symptoms. Others, however, can find it difficult even when cutting down slowly.

Decisions about pain medicines are important and, often, not simple and straightforward. These decisions need to be shared, between you and your doctor or prescriber. You are the only one who can report on the benefits and the side-effects.

If you have concerns about the side effects of your medicine, particularly when you start a new one, contact your doctor or pharmacist as soon as possible.



What help is available?

STANDARD PAIN MEDICINES

We are all familiar with using paracetamol for everyday aches and pains. Far from being just a weak pain medicine that can be bought from pharmacies or supermarkets, it can be very effective in controlling pain for many patients. Taken regularly in the short term and when prescribed (usually one or two 500mg tablets four times a day), it is a safe and useful drug. However, as with other pain medicines, only take it if you are confident that it is contributing to your pain relief.

Standard Pain Medicines	
Paracetamol	
Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)	*Aspirin*
	Ibuprofen
	Diclofenac
	Naproxen
	Celecoxib (called a Cox II inhibitor)

Non-steroidal anti-inflammatory drugs (NSAIDs) are also widely used. NSAIDs such as aspirin, ibuprofen and naproxen are available without a prescription and some NSAIDs are available as creams or gels to rub on the painful part, which is a very safe way of using them. When taken by mouth or as a suppository (inserted in the bottom), NSAIDs may help with joint and muscle pain. However, they do need to be used carefully – especially if you have had a stomach ulcer or asthma, heart, liver or kidney problems.

In order to minimise the risk of serious side effects you should take the lowest dose for the shortest time.

It is important to be aware that you can get 'overuse' headaches from taking analgesics on a regular basis, particularly if you are a migraine sufferer. This includes over-the-counter medicines such as paracetamol and aspirin. Do discuss any concerns with your doctor.

What help is available?

STRONGER PAIN MEDICINES

These are normally drugs related to morphine and are, as a group, known as 'opioids'. Many people are uneasy about taking medicines from this group and doctors only recommend them when other drugs or pain relief methods have proved inadequate. However, if you follow specialist advice, you may find that the benefits are greater than any risks.

Problems can occur if you take more than the prescribed dose or if you use the medicine to manage problems other than pain. An example might be taking strong opioids to reduce anxiety. If you have pain most of the time, you are likely to be prescribed stronger pain medicines in a slow-release form. This can help ensure that you have fewer ups and downs in your pain.

These medicines are commonly divided into weak and strong opioids.

- Codeine is the commonest weak opioid and you can buy this in a low dose, combined with paracetamol, without a prescription. Stronger doses of codeine can only be prescribed by your doctor. Codeine works by your liver changing it into a smaller dose of morphine.

- Dihydrocodeine is a relative of codeine though normally considered to be somewhat stronger. It can be prescribed as slow-release, 12-hour, tablets.
- Tramadol, which is widely used as an intermediate-strength opioid, has recently been reclassified in the UK as a strong opioid. It is also available in a slow-release form.

- Strong opioids, such as morphine and oxycodone, are often used to treat the pain from cancer but are now being used to treat other forms of pains. All of the drugs in this group are available in a slow release format. Some of them (such as fentanyl and buprenorphine) are available as a patch to wear on the skin over a period of several days.

What help is available?

STRONGER PAIN MEDICINES (continued)

Stronger pain medicines	
Weaker opioid	*Codeine* *Dihydrocodeine*
Stronger opioids	*Tramadol* *Morphine* *Oxycodone* *Fentanyl* *Buprenorphine*

If you have used opioids for more than a few weeks and wish to stop taking them, you should reduce your dose gradually and follow a carefully supervised programme. You may experience withdrawal symptoms if you stop using them suddenly.

If you take them for a long time they may affect some of your body's hormones, your sex drive or your immune system. Taking strong opioids on a long-term basis is not a decision to be taken lightly. It may be the right thing to do if they help you to live a more active and better quality of life.

When making the decision to take strong opioids, it is important to set yourself goals to help you measure the benefits of the medicine. If they enable you to be more active or return to work, for example, you may well decide that they've done a good job. If they do not help you to live a fuller life, it may be appropriate to talk with your doctor about reducing and stopping them.

For more detailed information, see the British Pain Society leaflet *Opioid Medicines for Persistent Pain: Information for Patients*.

What help is available?

COMBINATION PAIN MEDICINES

Sometimes combining two pain medicines that work in different ways can be more effective. Paracetomol is frequently combined with codeine, dihydrocodeine or tramadol.

You should be careful if you add paracetamol to the drugs already prescribed or you may accidentally take too much paracetamol over the day. (For example, paracetamol is a common ingredient of cold and flu remedies.)

Combination pain medicines	
Co-Codamol	Paracetomol and codeine
Co-Dydramol	Paracetamol and dihydrocodeine
TramacetR	Paracetamol and tramadol

NON-STANDARD MEDICINES FOR PAIN

Some pains, such as nerve damage (neuropathic) pain, may not respond to 'normal' pain medicines. In these cases, other drugs may be used instead of or as well as standard pain medicines. These medicines were originally developed to treat depression or epilepsy but now they are often used to treat some types of pain. One drug may be effective in treating more than one illness.

• *Anti-depressant drugs* are commonly used to manage neuropathic pain. They act to improve the effects of some of the chemicals in the brain and spinal cord that reduce when you suffer from either depression or long-term pain. It does not mean your doctor thinks you are depressed (though that is not uncommon when you live with long-term pain). The doses used for pain are usually much less than those needed to treat depression.

Many of these drugs can cause drowsiness and, when used at night, can help you to sleep. But not all antidepressant drugs have a sedating effect.

What help is available?

NON-STANDARD MEDICINES FOR PAIN (continued)

• *Anti-epileptic drugs* are also often used for nerve-damage pain and for other pains where the nerves involved have become over-sensitive. They can reduce the pain produced by overactive pain nerves in the same way that they reduce over activity of the brain cells in patients with epilepsy.

Non-standard medicines for pain			
Anti-depressants	Amitriptyline Nortriptyline Imipramin Venlafaxine Duloxetine	Anti-epileptics	Gabapentin Pregabalin Carbamazepine Sodium valproate Topiramate Clonazepam

If you do have any concerns or worries about your medicines, you should always speak to your doctor or pharmacist. You may like to read our leaflet *Using Medicines Beyond Licence: Information for Patients.*

TOPICAL MEDICINES

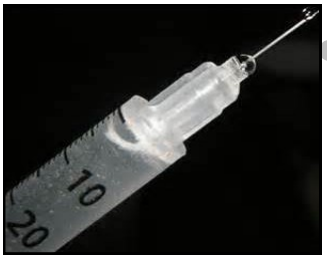
Some medicines for pain are available as creams, gels or patches. These can be as effective as tablets and may have fewer side effects.

Many creams, gels and sprays are widely available from pharmacies without prescription. Some act by producing warmth and some by producing a cooling effect. Some contain active anti-inflammatory medicines such as ibuprofen and diclofenac, which you would normally swallow as a pill. How effective these products are varies considerably from one patient to another.

Other creams are only available on prescription, such as stronger anti-inflammatory creams or gels and capsaicin cream.

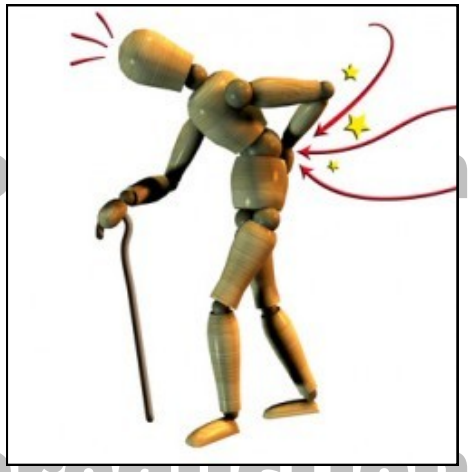
What help is available?

- **Injections**



Many people hope that there is a simple injection that will cure their pain, but sadly this is rarely true. However, injection treatment can be helpful in some cases and may mean you can manage some physiotherapy that may otherwise have been too painful.

Short-term injections of a local anaesthetic (often mixed with a steroid) are commonly used. These injections may be given directly into a painful joint or area (trigger spot), or may be used to temporarily deaden the nerves supplying the painful area. Epidural (spinal) injections of steroids may be used when there is pressure on a nerve root in your back that is giving you severe leg pain (sciatica).



These injections may help for just a few days or even for several months. In some cases it is possible for the injections to be repeated. It may be possible to achieve *longer-term* results by using special injections that partially destroy the nerves involved. These treatments are called 'denervation'.

Only some pains can be treated in this way. Your pain specialist will be able to explain if there are any injections which are likely to benefit you and the risks involved.

Normally you will be given an information leaflet about any injection therapy. Read this carefully and ask any questions you have before you have the procedure.

What help is available?

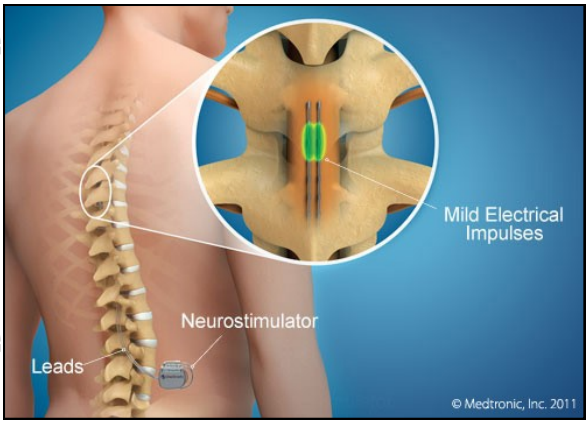
- **Long-term devices**

For certain types of pain, other, highly specialist treatments may be suggested. These treatments are performed only in very specialist centres and for carefully selected patients.

Spinal cord stimulation (SCS) involves electrically stimulating specific pathways in the spinal cord that reduce how you feel pain. This is usually done using a special electrode placed in your back. This is connected to an electronic stimulator, which is permanently inserted under the skin – a bit like a heart pacemaker. You can adjust the stimulator to produce the correct level to control your pain.

Intrathecal pumps, mainly used with cancer pains, allow a continuous dose of a drug to be injected direct into the fluid surrounding the spinal cord (the cerebro-spinal fluid). This method allows for very small doses of drugs to be used very effectively. The low drug doses may reduce some of the side effects produced by larger doses of the same drug given by mouth.

Spinal Cord Stimulator

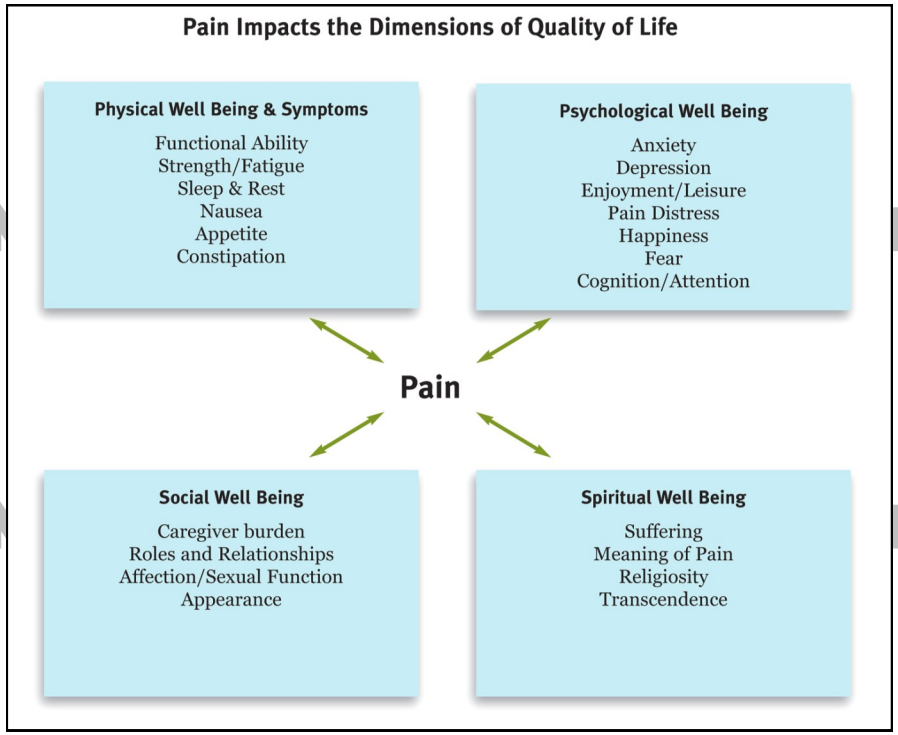


The website of The British Pain Society (www.britishpainsociety.org) has information for patients on both intrathecal pumps and spinal cord stimulators.

What can I do to help myself

Long-term pain often causes disability and distress. It also disrupts sleep, work and everyday activities. In fact, it can impact on most areas of your life. Some are fortunate and have found treatments and strategies to reduce the pain. However, even if you have not been so fortunate, you may still find ways to help yourself.

Most people with a long-term pain condition can recognise vicious circles and it can pay to work on these. You may feel depressed, anxious, tense or worried which can make the pain worse. This may in turn increase your distress and, with worsening pain, this can create a downward spiral. Developing strategies to reduce your distress can help to reverse this and bring the pain and distress back to more bearable levels.



What can I do to help myself

Another example is pain and sleep. Most people with long-term pain find it difficult to get a good night's sleep and poor sleep can impact on pain and many other areas of life. Sleep patterns and routines can spiral out of control making things worse.

It can be useful to think of managing long-term pain like using tools in a toolbox. These tools are strategies that can help you to improve your psychological wellbeing and quality of life. Even used individually they can be helpful, but chosen carefully and used together they can help you get back to a more normal life.

Pain is very personal and what works for you may not work for everyone. Some ideas may not work for you but, until you try something, you cannot know whether it will work.

Most people with long-term pain find it hard to accept that there is no cure for the pain. Living with long-term pain can involve a journey through denial, anger, resentment and sadness until life finally becomes more manageable and more worthwhile. However, it may well be a life that is different from the one you lived before your pain started.

These are some of the strategies which, used together, can help to build a better life. Hopefully, your pain team will be able to assist you to become more independent in the long term. Some of the skills are described in detail in the books suggested under More Information (page 39) or on our website www.britishpainsociety.org.

Keeping a pain diary

This can be a very useful exercise as a starting point. It can provide valuable information for you and the health professionals. A short summary of your pain at various times each day may reveal patterns in pain intensity as well as things that make the pain better or worse.

The diary summary can also be useful in conveying the *quality* of the pain to the clinician - burning, shooting, aching etc. This information can be valuable in helping with pain diagnosis and management.

What can I do to help myself

Keeping a pain diary (continued)

It may be an opportunity for patients to feel free to describe sensations that are very real to them, but may have been reluctant to mention in consultations as they feel they may not be believed.

A diary can also be useful to relate the benefits or side effects of medicines and other therapies. This information can really help in making a long-term and effective treatment plan.

A pain diary does not have to be complicated or necessarily kept for more than a couple of weeks, unless you find it helpful to do so. Your health professionals should be able to offer you further help and may be able to provide a diary that is easy to use.

Setting goals and managing activity

Setting targets for each day, and for the longer term, can help both body and mind, making life more worthwhile. It is important to choose achievable goals that matter to you. In time, your goals can become more challenging, but you may have to break them down into small and manageable steps (this is called 'pacing yourself').

Carrying on physical activity to the point of unmanageable pain or exhaustion is rarely helpful. It is tempting to try and finish things or 'push through the pain', but this usually makes pain or tiredness worse and is discouraging.

Setting goals and managing your activity with long-term gains in mind can help you resume many activities that your pain may have stopped you doing.

What can I do to help myself

Managing sleep

Sleep problems are common with long-term pain: you could even say they are normal. Many find it difficult to get to sleep or to stay asleep. It is not uncommon to find yourself napping in the day to try to catch up and the distinction between night and day can become blurred.

Some find that medicines can help with sleep but many do not. Self-help strategies may not completely restore your sleep to normal but they can definitely help. Try not to get overanxious about sleep problems because worry and sleep don't go well together. Adapting relaxation strategies (see below) can help stop your thoughts from keeping you awake.

Our sleep cycles are partly regulated by daylight and by our routines. It is a good idea to set an alarm for the same time every morning and to let in the light. It is also a good idea to make a regular bedtime for yourself.

As far as possible, the night-time should be free from daytime activities and your daytimes should be as free from naps. Even lying horizontally rather than sitting up can cause confusion to your sleep mechanisms. If you do nap, make it earlier in the afternoon rather than later on and try to limit your nap to about twenty minutes by setting an alarm.

Relaxation

Practising relaxation techniques regularly can help to reduce tension, stress and, in some cases, the pain too. It is a useful skill to have, but takes time to develop. Learning to relax can help you sleep, get good-quality rest and cope well with stressful and difficult situations.

There are many types of relaxation techniques and it is important to know that these are not simply the same as reading a book quietly or watching TV. These activities may be relaxing but deeper relaxation can give you more. There may be classes available locally that can help teach relaxation or they may be available at your pain clinic. There are also many books, CDs or DVDs on relaxation techniques.

What can I do to help myself

Keeping active

Keeping active when activity can be painful is not easy. Research shows, however, that people with long-term pain who keep active tend to feel better and enjoy a better quality of life. It is worth taking steps to maintain and improve your general fitness.

It is important to understand that movements or activities that can increase your pain do not necessarily mean further damage or injury. In long-term pain conditions, hurt does not mean that harm is taking place. It makes sense to take things gently but a small rise in pain in the short-term may be worth it if it helps you get back some of the life you may have lost due to pain.

Socialising

Pain can make it hard to get out to see people or to join in with what they are doing, but keeping in touch with friends and family is good for overall health. Worthwhile social contact can be at home, over a cup of tea, on the phone or via the internet. Every little counts.

Enjoyment and Hobbies

Try to include at least one enjoyable activity in your list of things to do every day. Sometimes you may concentrate too hard on what you must do and forget things that may give you some pleasure. Be pleased with the things that you accomplish even if that includes things which others might dismiss or take for granted.

What can I do to help myself

Getting involved in activities or hobbies that take the focus of attention away from your pain can be helpful. A hobby such as sewing, photography or model-making, which you can do even when your activity is restricted, can usefully occupy time when you might otherwise feel that you are sitting around doing nothing.

Hobbies can also give you something worthwhile to talk about. It helps to shift the focus away from pain and other problems.

Medicines

Medicines are often used for long-term pain and may give valuable relief. They are just one tool in the 'toolbox' and you should use them alongside all the other tools. The aim should be to use the minimum number and dose of medicines needed to allow you to stay active and maintain your quality of life.

It takes time and a great deal of effort to learn these self-help strategies – but they can help considerably in making life more manageable. It is difficult to do this on your own. You may need help from a pain clinic or a book about managing pain, or you may benefit from attending a pain-management programme.

What is a pain management programme?

Pain-management programmes (PMPs) are usually offered after the appropriate medical and physical treatments have been explored. They are not a cure for pain and anyone starting a programme needs to understand that the aim is to improve the quality of life, not to reduce the pain (though some may find that their pain does reduce a little).

PMPs involve a number of educational, training and treatment elements delivered by a team of healthcare professionals. This usually includes a psychologist, physiotherapist, occupational therapist, nurse and doctor.

The programmes are normally run for groups of about eight to 10 people as outpatients, but there are some regional centres which run more intensive residential courses. Some teams may work with individuals rather than groups. Some teams offer programmes to groups and individuals. The length of group programmes varies, but they usually extend over a period of about six weeks taking up one or two half or whole days each week.

What is a pain management programme?

The focus is mainly on how to increase activity in areas of your life which are important to you despite continuing pain; how to manage the thoughts and emotions which can hold you back. Many people who complete a pain management programme say that they can do more of what they want to do, despite their pain.

What happens in a programme varies between centres, but they generally aim to help you

- improve your ability to manage your pain and related problems
- increase your level of physical activity
- use your medicine effectively
- improve your mood and reduce worries about activity and pain and
- achieve important goals and return to daily activities

To be referred to a PMP you should ask your GP to refer you to the local pain clinic. There may not always be a PMP in your area. However, residential programmes are available in some parts of the country and so it is worth asking your pain specialist about these if you are prepared to stay away from home for two to four weeks. Online courses may also be available for you to work through at your own pace.

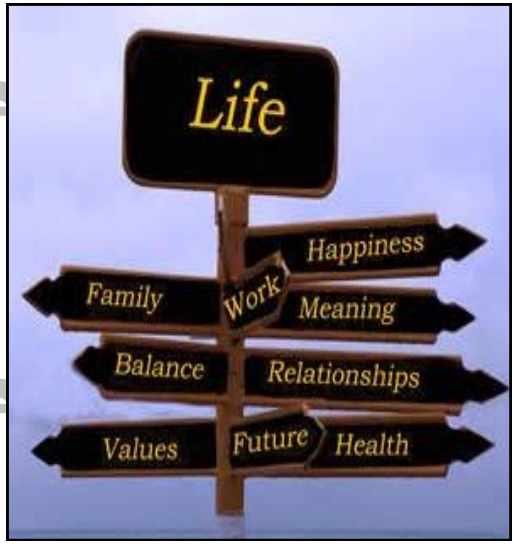
Summary

Long-term pain is difficult to understand and a challenge to live with. It is also a challenge for modern medicine and difficult to treat.

Managing pain is not something that a doctor does to you or for you. You and the doctor, alongside other health professionals, work together to find what works best to control your pain and help you live your life.

Medicines, physical treatments, psychological support, injections and other interventions may help to manage pain. But they will not be the whole answer. You can bring your skills to work too by exploring some of the ideas outlined in Chapter 5.

Being actively involved in managing your pain will mean that you have a better chance of working with your health-care professionals to improve your quality of life.



More information & support for patients & carers

Other Societies and Organisations

There are many organisations, most of them charitable, whose aim is to support people with pain or painful conditions. Some organisations focus on general pain but many offer help with a specific condition such as arthritis or shingles.

The website of The British Pain Society (www.britishpainsociety.org) has information leaflets that you can download plus addresses and links to other websites and contacts.

The internet is a huge source of information, much of it accurate and potentially helpful, but do run things past your doctor or specialist if you are uncertain. If you do not have a computer, try your local library as they often have internet access and can help you get started.

Below is a list of some websites, help lines and other resources which you may find useful.

Websites

www.britishpainsociety.org

www.nhs.uk

www.healthtalkonline.org — This website lets you share in other people's experiences of more than 60 medical conditions. Watch or listen to videos of interviews, read about people's experiences and find reliable information about treatment choices and support.

www.youthhealthtalk.org — A sister website to healthtalkonline.org featuring young people's experiences of health and lifestyle issues.

More information & support for patients & carers

www.painconcern.org.uk

Pain Concern is a charity for people living with long-term pain and those who care for them.

http://www.ableradio.com/podcasts.html

Airing Pain is a radio programme by Pain Concern broadcast on Able Radio. Previous podcasts can be downloaded from the website.

www.action-on-pain.co.uk

Support and advice for people affected by long-term pain.

www.paintoolkit.org

This website offers a Pain Toolkit - simple tips and skills in a 12-point plan to help you take control of your pain. It is also available as a booklet.

www.painrelieffoundation.org.uk

The Pain Relief Foundation is a charity that funds research into the causes and treatment of long-term pain and is concerned with the education of health professionals about pain management.

www.pain-uk.org

An alliance of charities providing a voice for people living with pain.

www.arthritiscare.org.uk

The UK's largest charity supporting people living with musculoskeletal pain.

www.rcoa.ac.uk/faculty-of-pain-medicine/patient-information

Approved patient information leaflets covering some non-standard pain medicines.

More information & support for patients & carers

Books and CDs

There are many self-help resources on managing pain. Like information you find on the internet, they vary in quality. Here are four books and a CD you can rely on, all written by well-regarded people working in the field of managing pain.

Overcoming Chronic Pain

Frances Cole, Helen Macdonald, Catherine Carus & Hazel Howden-Leach (2010) London: Robinson ISBN 978-1-84119-970-2

This book uses cognitive behavioural therapy techniques to help manage pain. Topics include practical ways to improve sleep and relaxation, how to get fitter and pace your activities and ways to maintain healthy relationships.

Manage Your Pain

L Beeston, A Molloy, M Nicholas & L Tonkin (2011) London: Souvenir Press. ISBN 978-0-28564-048-1

A very helpful book for people living with pain who want to learn more about using pain management techniques. It is informative, but the authors are Australian so it refers to their health service provision rather than the NHS.

Managing Pain Before It Manages You (third edition)

Margaret Caudill (2008) New York: Guilford Press. ISBN: 978-1-59385-982-4

This popular workbook teaches coping skills proven to decrease the discomfort, depression and anxiety associated with long-term pain. Through exercises and homework assignments, readers are helped to understand the pain process, learn about medicines and their effects, and recognise factors that exacerbate or relieve pain. Also included are a wealth of helpful ideas on coping with pain flare-ups, staying active, accomplishing personal goals and more.

More information & support for patients & carers

Explain Pain

David S. Butler and G. Lorimer Moseley (2003) Noigroup Publications, ISBN -10: 097509100X and ISBN-13: 978-0-97509-100-5. £44 from http://www.noigroup.com/en/Product/EPB or from libraries.

This book does exactly what it says in the title. It explains the science of pain in easy layman's terms using empathy, intelligence and humour.

Living with Chronic Pain

A self-help CD produced by consultant clinical psychologist Neil Berry. It is free to be listened to or downloaded at www.paincd.org.uk. CDs can also be purchased via the website.

This recording gives an outline of some of the things you might hear if you attend a pain-management programme. There are 10 tracks covering a variety of topics.

Notes

More information & support for patients & carers

Help lines

Action on Pain
www.action-on-pain.co.uk
Helpline: 0845 603 1593.

Arthritis Care
www.arthritiscare.org.uk
Helpline: 0808 800 4050
Helplines@arthritiscare.org.uk

Pain Concern
www.painconcern.org.uk
Helpline: 0300 123 0789

Pain Association for Scotland
www.painassociation.com
Phone: 0800 783 6059

Patients' Association
www.painassociation.com
Helpline: 0845 60804455

Notes

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This booklet was written by
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Patient Liaison Committee Working Group.
This group includes members of the
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Chair of Pain UK

Ms Jo Cumming
Trustee for Pain Concern; lay representative on the NICE OA Quality Standard Development Committee; Vice Chair OA and Crystal diseases clinical studies group Arthritis Research UK.

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https://www.britishpainsociety.org/can-you-help-fund-our-work/

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