The British Pain Society

Understanding and managing pain: information for patients

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1 Who should read this booklet?

We all know what pain is. We have all suffered from it. Sometimes, we hardly notice it. Sometimes, it's unbearable. Usually, it goes away on its own. Sometimes, it goes away with treatment. Rarely, it doesn't go away at all, but becomes persistent (sometimes called chronic) pain.

There are many different causes for persistent pain. The aim of this booklet is to help you understand the difficulties associated with persistent pain, and how it can best be treated. In this booklet, we do not specifically cover pain caused by cancer, but much of what we describe here can 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 persistent pain, and how it can best be treated.

There are things that you can do to reduce the effects of pain on your life, such as appropriate exercise, pacing your activity (not doing too much when you feel better) and relaxation. These things may not be obvious and they do not come easily. They take practice to get the most out of them. However, they can be as effective as taking medication (See page 29 for more information.)

2 Why doesn't my pain go away?

Some pain is easy to understand because, for example, there is an obvious injury such as a cut or a bruise. Some is less obvious. 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 a sprained ankle, is called 'acute' pain. Long-term pain, such as back pain, is called 'persistent' or '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.

Many acute pains are a useful alarm signal that something is wrong. Most minor ones get better on their own or with simple treatment. Others may be a sign of something more serious, such as 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. On the other hand, persistent pain appears to serve no useful purpose, but has a huge effect on the lives of many people.

"I have had to give up work, which obviously not only cuts down the social contact I have with others, but leads to feelings of failure that I am no longer able to provide a wage to the household. My husband and children now do most of the housework and gardening, which were always my jobs, and although only in my thirties I now rely on their help for mobility and dressing. As you can imagine, my self-esteem is very low and the pain limits where I can go and what I can do."

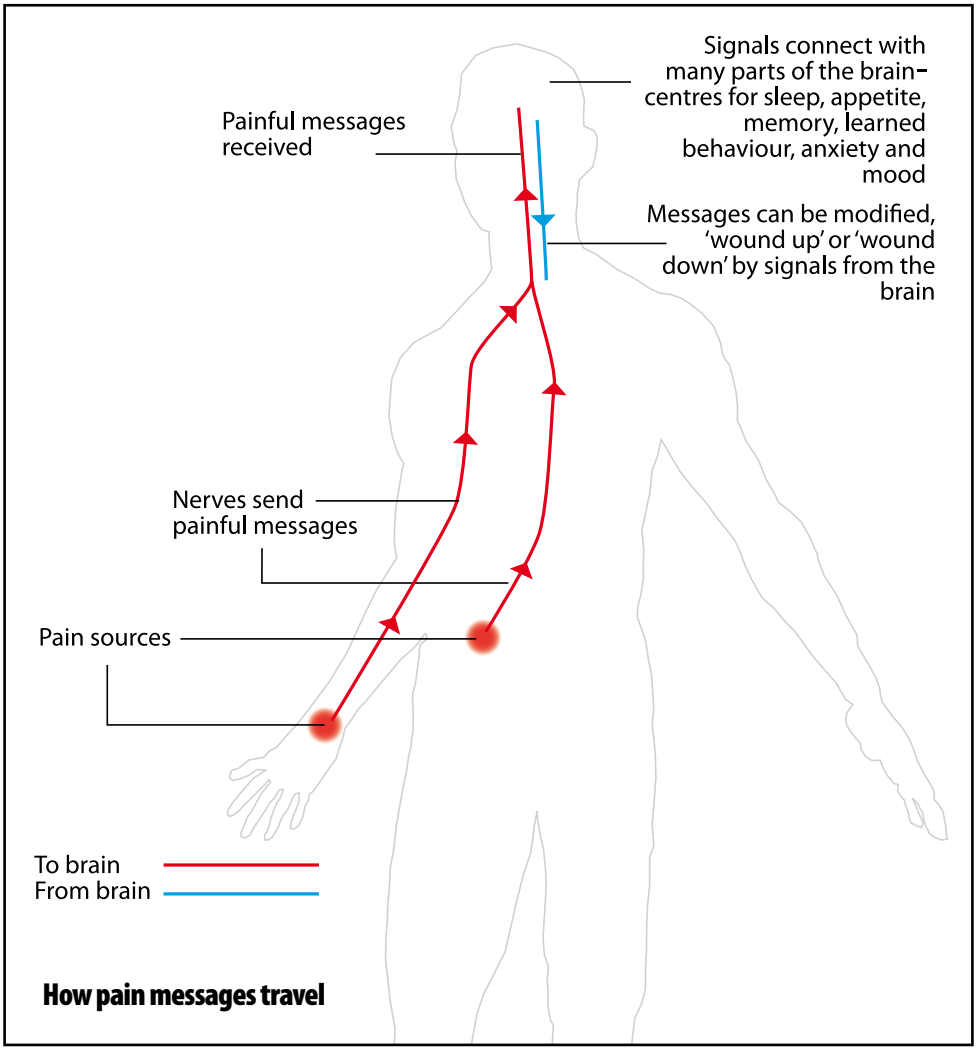
Pain can come from any part of your body : skin, muscle, ligaments, joints, bones (nociceptive pain), injured tissue (inflammatory pain), nerves (neuropathic pain), internal organs (visceral pain) or a combination of these types of pain (mixed pain).

Pain signals normally travel from the painful part of the body along thousands of specialised nerve fibres, through 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 itself can start the pain sensation.

"You and medical professionals need to work together with skill, time and patience to improve the problem."

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, either reduce or increase the pain further. Cells at the nerve endings, in the spinal cord and in the brain can become over-sensitised as a result of constant pain input. This is called 'wind-up' and is one of the reasons why persistent pain does not go away easily, even if the cause of the pain is discovered and treated.

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, distressing problem. You and the medical professionals need to work together with skill, time and patience to improve the problem.

Although medical technology is improving all the time, some pain is very complicated. It may involve so many factors that we will never be able to find the precise cause of it accurately with machines, or make it show up in any tests. However, not knowing the cause of the pain does not mean it is not a very real problem.

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

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 to the sensory experience. This means that the only way of deciding whether someone has pain is by asking them, or watching them.

Unfortunately, there is more to persistent 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 in 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 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 or measured. The challenge for both you and those treating you is to understand the complicated nature of persistent pain and the best way of managing it.

3 What might this mean for me?

Persistent pain is complicated and is not easily 'fixed'. You need to work alongside health professionals involved in the case and be patient and willing to try things to work out what is best for you.

Unfortunately, you may still suffer from some level of pain because there may not be a complete cure. However, this does not necessarily mean that it will get worse, nor does it mean that continuing damage is being done.

Understanding the pain, as far as possible, is important.

You should ask the health-care professionals who are helping you to explain – as far as they understand – the things that worry you.

Common worries are shown below.

- What is causing my pain?
- Is it something which is likely to get worse?
- What are the investigations (X-rays, scans and so on) looking for, and what do my results mean?
- If my painkillers do not work, can I have stronger ones or what else can be done?
- If a painkiller works, will I still be able to feel any pain that might be telling me that something else is wrong and needs attention?
- Why can pain not be switched off?
- Could a surgeon not 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 period of time?

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 too much?
- What do you not do because you are worried you might damage yourself?
- Does the pain prevent you from getting off to sleep? Does the pain wake you from your sleep?
- Does your mood or stress affect your pain?
- If you are taking a painkiller, 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 and 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.

4 What help is available?

Who can help me and what might they do?

There is a great deal that can be done to help you. The best results come when you understand that you need to play an active role in treating your condition, alongside those who are treating you. We cover 'How can I help myself?' in the next chapter of this booklet.

While your GP may be able to help with your pain by prescribing medication, for some patients a more specialist approach may be needed.

Help in managing persistent pain can come from a wide variety of health-care professionals. Most patients will get to see these people through the National Health Service (NHS) after being referred by their GP, although you can use some services privately.

You will find those health-care professionals with most experience of managing persistent 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.

At the pain clinic, 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.

You may not always see a doctor on your first visit to the clinic. Specially trained nurses or physiotherapists may see you first and can decide what type of treatment is best for you – this is often known as triage. They may later be involved in following the progress you make with the treatments the pain specialist will start you on, or they may supervise treatments.

The pain specialist will listen to your story and ask many questions to piece together a picture of your pain, how it is linked in with other medical problems that you might have and how it affects you as a person. This is called a 'holistic assessment' and is a very important part of understanding your pain. Answer any questions as fully and thoughtfully as you can. Sometimes you will be asked to fill in a questionnaire about your pain or about your feelings. Again, do this as honestly as you can to help the professionals understand you and your pain.

The doctor will talk to you about the types of pain that you may have, and will try to explain why this has happened. He or she will examine you to look for any causes for the pain that might have been missed, and to assess your overall state of health. They will then discuss a management plan with you, sometimes after you have seen other members of the pain team (a multidisciplinary consultation).

Doctors may prescribe drugs that are unusual or new – treatments with which your GP may have little experience. They may also use injections or other pain-relieving procedures and often need to use X-rays or other specialist equipment. They will also probably try more than one treatment – this is part of your management plan.

You may need more advanced investigations (such as MRI scans) than your GP can arrange. 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 clinical psychologist at an early stage after your first visit to the pain clinic. This does not mean that people feel you are imagining your pain or that you are 'mad' – far from it.

Psychologists may be very helpful in looking at ways to help you manage your pain so that you can live a more normal life in spite of the pain. This usually involves a discussion of how you understand your pain and how you feel about it. This is because this is what guides you in day-to-day life. Trying different ways of seeing things and different ways of doing things can help you when you cannot see a way forward. Psychologists may also identify other stresses which are adding to your pain and may need to be looked at.

Physiotherapists use a wide variety of treatments for persistent pain. Although physiotherapy services for pain are most often based in physiotherapy departments in large hospitals, they also are now becoming more available in GP surgeries and health centres. Physiotherapists offer exercise, manual therapies, electrotherapy, advice on posture and advice on how to manage your activity levels and improve your fitness. This means you can now achieve more from life. Some specialist physiotherapists have received extra training in complementary therapies such as acupuncture.

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.

Specialist pain nurses are employed in the NHS in pain clinics, with a few working in the community. The role of the specialist pain nurse varies from place to place. However, they are normally involved in providing information, advice, acupuncture and other treatments, as well as helping in using drugs for pain.

Occupational therapists (OTs) working with people who have persistent pain can give expert advice on how you can best manage your day-to-day activities despite your pain. They can also assess you, your home and your place of work to identify helpful devices such as stair rails, bathing aids and other alterations to your home and workplace.

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

Despite the huge amount of progress that modern medicine has made, pain specialists cannot cure or relieve all pain. However, they can make a real improvement to the quality of your life by involving all the members of the pain team in a multi-disciplinary approach. It is not uncommon for some patients to be offered the opportunity to join a structured pain management programme (PMP) to make best use of this approach. We cover this in a later section of the booklet.

What treatments might be offered?

There is a range of treatments available – not all will be suitable for everyone, and it is important to discuss your options with your health-care professional.

There are many types of treatment available which have no scientific evidence that they either benefit or harm people. You can spend a lot of money on treatments that have not been proven to work, and may even make matters worse.

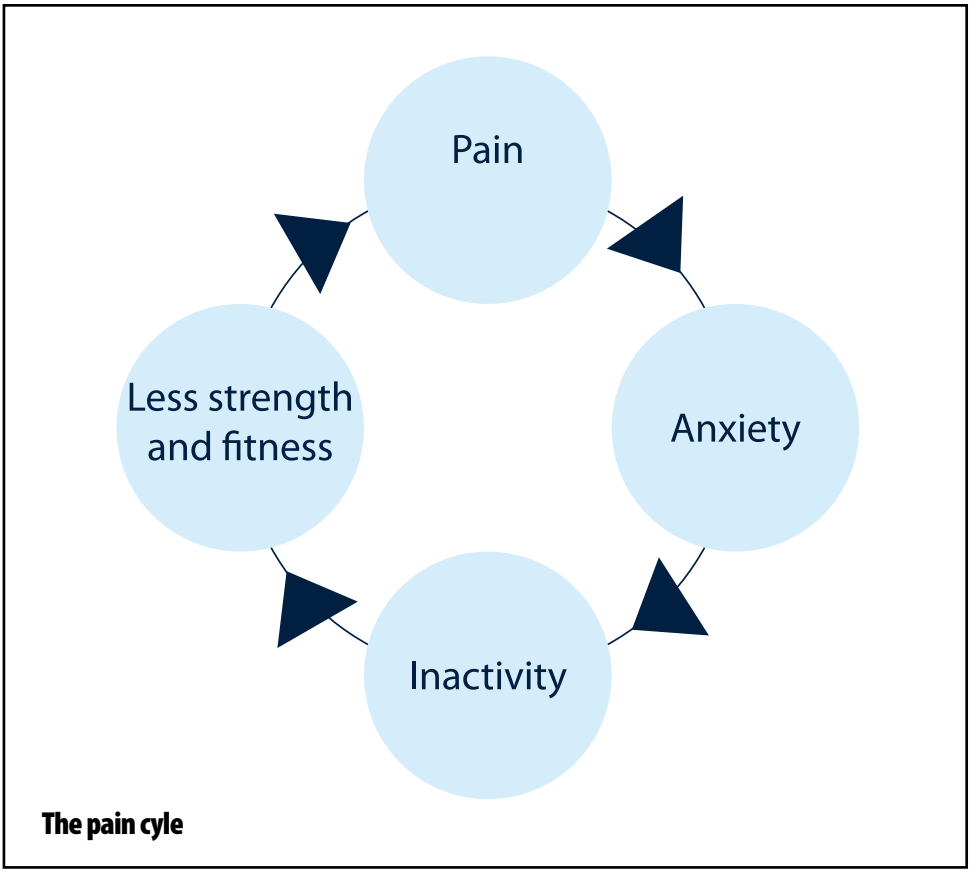
Before starting any treatment, ask your health-care professional whether it is likely to do you any good, and whether it might do you harm. Then discuss with the therapist how the treatment works, what it might achieve, how long it will take and how much it will cost if it is not available on the NHS. Make sure that the therapist is registered with a reputable professional organisation and has appropriate liability insurance. Do not feel you have to keep having any treatment or to continue with it if you do not like either the treatment or the therapist, or if you don't feel it is working.

Exercise

To many people with persistent pain, 'exercise' is a word which strikes them with fear. Their previous experience of exercise has often been painful, and they may believe that movement will cause damage, so it is understandable that many do not want to try it.

However, there is a difference between exercise which would help you recover from acute pain and exercise for persistent pain. Exercise for persistent pain is designed to help you best use and build on what you can do. Pain may mean that you are not very active, which can lead to stiff joints, increased weight, poor fitness, weak muscles and getting breathless more easily. A lack of exercise can also lead to other problems such as heart disease and diabetes.

People with persistent pain face a dilemma – activity can increase pain in the short term, but a lack of activity leads to problems in the long term. These problems can then, in turn, cause an increase in pain.



The pain cyle

Exercise is vital to help deal with persistent pain, but getting started is difficult. Remember that 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. The advice of a physiotherapist is very helpful in drawing up a specific activity and exercise programme that you are likely to stick with.

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

"I have suffered with arthritis in my fingers and my doctor advised me to keep my hands busy and use the fingers as much as possible to keep them flexible, as there is no cure, just gradual deterioration of the joints into old age. So I take as much exercise as I can, since I easily gain weight, and when relaxing I try to keep busy with some handicraft, to prevent the unnecessary eating (and drinking) that arise from boredom and idle hands in the evenings!"

Manual therapy

Manual therapy falls into three main areas – mobilisation, manipulation and massage. It is performed mainly by physiotherapists, chiropractors and osteopaths.

Mobilisation is a gentle form of physical treatment where the joint is moved as much as possible within the existing range of motion.

Manipulation is a more forceful movement of a joint, possibly beyond what it could normally do.

Both of these can help to improve the range of movement and reduce pain, allowing increased exercise and activity.

Massage is a gentle, hands-on treatment which can help muscles to relax and can distract you from the pain. The effects of massage may only be short term, but may help you get over a difficult period.

TENS

Transcutaneous electrical nerve stimulation (or TENS for short) aims to 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 stick-on electrodes. This helps to reduce the pain in a similar way to 'rubbing it better'.

TENS machines are often available through your GP, pharmacy, local physiotherapy department or pain clinic. It is important to be taught how to use it properly, and it may take a little while to adjust the treatment to gain the most benefit. Some people can find this a useful alternative to taking medicines, which do not work for everyone or may have side effects. However, the evidence for long-term benefit is weak.

Acupuncture

Acupuncture may be available in many GP surgeries, NHS pain clinics and physiotherapy departments, as well as from private practitioners. The effect is very variable between patients: it is often short-lived, but can be more beneficial for some people. You may need to continue to have 'top-up' treatments for a long period of time.

You should check that your acupuncturist is trained and registered with a recognised professional organisation – see the relevant section in 'More Information'.

Drugs (medicines)

'Painkillers' are possibly the treatment that most people expect to be given when they have pain.

'Why don't my painkillers work?' is a commonly asked question, and often one without any easy answers. Persistent pain can arise through several different mechanisms, and most drugs only work for a few of these. Some pains do not seem to respond to any painkilling drug. You can get used to painkillers, so that you need more and more to have the same effect. (This is called building up tolerance.)

Treatment should always start with small doses of weak drugs that can then be gradually increased or changed to stronger drugs until you have the best possible pain relief. The correct dose of any medication is the minimum dose that produces the maximum benefit. It is rarely possible to relieve pain completely by using painkillers. You should discuss, with your doctor, what you expect from the treatment.

Medicines for pain relief	
Paracetamol	
Non-steroidal anti-inflammatory drugs (NSAIDs)	Aspirin Ibuprofen Diclofenac Naproxen Celecoxib (called a Cox II inhibitor)
Weak opioids	Codeine Dihydrocodeine Tramadol
Strong opioids	Morphine Oxycodone Fentanyl Buprenorphine

Standard painkillers

We are all familiar with using paracetamol for everyday aches and pains. Far from being just a weak painkiller that can be bought from pharmacies or supermarkets, it is a very safe and useful drug for many persistent pains and, taken regularly (normally two 500mg tablets four times a day), helps many patients.

Non-steroidal anti-inflammatory drugs (NSAIDs) are also widely used. Aspirin, ibuprofen and naproxen (which are types of NSAID) are available without a prescription. 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 up the bottom), NSAIDs may help with joint and muscle pain, but they do need to be used carefully – especially if you have had a stomach ulcer or asthma, or heart, liver or kidney problems.

Stronger painkillers

These are normally drugs related to morphine and are, as a group, known as 'opioids'. They 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 in your body by your liver changing it into morphine. This means large doses of codeine become a strong opioid and you can become addicted to them.

Tramadol, which is widely used, is an intermediate opioid.

Strong opioids, such as morphine and oxycodone, are often used to treat the pain from cancer but are now being used more and more to treat other forms of pains. Some drugs (such as fentanyl and buprenorphine) are available as a patch to wear on the skin, and can reduce the number of tablets that you need to take.

You should make the decision to start on strong opioids very carefully after discussing it with your GP and pain specialist – and then only when you have tried all other ways of relieving your pain. They can lead to problems with 'dependency', which means you find it very hard to live without them. And, in some people, it can lead to addiction. If you have used them for more than a few weeks, you should reduce your dose gradually and follow a carefully supervised programme. You could experience withdrawal symptoms if you stop using them suddenly. If you take them for long periods of time, they may affect your hormones, sex drive and immune system. It is important to discuss these things with your doctor before regularly starting to take strong opioids.

It is also important to set yourself goals, such as being more active or returning to work, and to use the pain relief produced by these strong drugs to achieve those goals. If they do not work, you should talk to your doctor about reducing and stopping them.

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

Combination painkillers

Combination painkillers	
Co-Codamol	Paracetamol and codeine
Co-Dydramol	Paracetamol and dihydrocodeine
Tramacet®	Paracetamol and tramadol

Sometimes using two painkillers together that work in different ways can be more effective. Paracetamol 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, remember that paracetamol is a common ingredient of cold and flu remedies.)

Non-standard medications

Some pains, such as nerve damage (neuropathic) pain, are not helped by 'normal' painkillers. In these cases, other drugs may be used instead of or in as well as standard painkillers.

Non-standard medications used for pain	
Anti-depressants	Amitriptyline Nortriptyline Imipramine Venlafaxine Duloxetine
Anti-epileptics	Gabapentin Pregabalin Carbamazepine Sodium valproate Topiramate

Some drugs that are used today to reduce pain were originally created to treat other illnesses – such as antidepressants and anti-epileptics. It is now quite common to use these medicines to treat some types of pain. 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'*.

Antidepressant drugs are commonly used in neuropathic pain, where they act to improve the effect of some of the chemicals in the brain and spinal cord that reduce when you suffer from either depression or persistent pain. Many of these drugs can cause drowsiness and, when used at night, can help you to sleep. The doses needed for pain relief are usually much lower than those needed to treat depression.

Anti-epileptic drugs are also often used for nerve damage and for other pains where the nerves involved have become oversensitive. 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. They do this by affecting nerve activity.

Topical medicines

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

Many creams, gels and sprays are widely available from pharmacies without prescriptions. Some act by producing warmth and some by producing a cooling effect. Some contain active anti-inflammatory medications such as ibuprofen and diclofenac that you would normally swallow as a pill. How effective all of 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.

Side effects

Any medication may give side effects or may interact with other medicines that you are taking. This will vary from one patient to another. 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, weight gain from anti-epileptics and constipation from opioids. Sometimes there can be more serious side effects, such as bleeding of the stomach lining or breathlessness.

Many side effects reduce with time or can be treated effectively. Remember that if you have concerns about the side effects of your medication, particularly when you start a new one, you should contact your doctor or pharmacist as soon as possible.

Injections

Many people hope that there is a 'magic injection' that will cure their pain, but sadly this is rarely true. However, injection treatment may be helpful for some pains.

Short-term injections of a local anaesthetic (often mixed with a steroid drug) are commonly used. These injections may be given direct into a painful joint or area (trigger spot), or may be used to temporarily deaden the nerves supplying the painful area. Epidural injections of steroids may be used when there is pressure on a nerve root in your back which is giving you severe leg pain (sciatica). These injections may produce a benefit for a few days or months. You may also need to repeat them if this is appropriate.

It may be possible to achieve *longer-term* results by using special injections which partially destroy the nerves involved. These treatments are called 'denervation'.

It is important to understand that not all pains can be treated in this way. Your pain specialist will explain which injections are likely to benefit you, and the risks involved. You will be given an information leaflet about the injection. Read this carefully and ask any questions you have before you have the procedure.

Long-term devices

For certain types of pain, other, more complicated, treatments may be suggested.

Intrathecal pumps 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 in a very effective way. The low drug doses may reduce some of the side effects produced by larger doses of the same drug given by mouth.

Spinal cord stimulation (SCS) involves electrically stimulating specific pathways in the spinal cord which 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 adequately control your pain.

These treatments are performed only in very specialist centres and for patients who have been carefully chosen because of their suitability. They are very expensive and may not be suitable for everyone. Our website has information for patients on both intrathecal pumps and spinal cord stimulators.

5 What can I do to help myself?

This is a very important question, as it can help you to improve control of your pain.

Persistent pain often causes disability and distress. The distress can involve feeling depressed, anxious, tense or worried. This can often make the pain even worse. This may in turn increase your distress and, with worsening pain, this creates a downward spiral.

Developing strategies to manage your pain can help to reverse this and bring the pain and distress back to bearable levels.

It can be useful to think of managing persistent pain as being like using a toolbox. Inside this toolbox there are strategies which may give some relief when used alone. However, when chosen carefully and used together, they can give better long-term relief.

Your pain is very personal, and what works for you may not work for everyone. Until you try something, you cannot know whether it will work for you. Ideally, your pain team will help you to become more independent in the long term. Some of the skills are described in detail in the books suggested under More information (see page 39), or on our website.

Many people who are suffering with persistent pain find it very hard to accept that there is no cure for the pain. The hardest part of having persistent pain is to realise that life cannot go on exactly as it would have done without the pain.

"I was away from work completely for a year, and have returned — in a sustained way — to part-time working. It is hard going as all my main previous interests are no longer available to me because they are too tiring. I can no longer do the high profile 'responsible' job I did in the past and all of this has led to a great deal of frustration and unhappiness. I'm having to come to terms with a complete shift in focus and the realisation that it is unlikely that I will ever make a full recovery."

Accepting persistent pain involves a journey through denial, anger, resentment and sadness, until life finally becomes possible again, although in a very different form. You may have to adjust your lifestyle as a result.

Case study

Molly is disabled and has constant pain as a result of an accident. Molly says: "My husband and I spent three fruitless years searching for a cure, but the grim reality is that there is no 'magic scalpel' and my condition is permanent. The effect on my family and myself was devastating. I had juggled a full-time career with parenthood and caring responsibilities for older family members, and now everyone was caring for me. My daughters were working hard towards 'O' and 'A' levels and suddenly found themselves running the house, while my husband did not have a holiday for three years as every day off was used to take me to different hospital appointments.

Needless to say, I am extremely proud of my family. We have discovered coping mechanisms, wonderful friends and both daughters are now well on their way to graduation. The turning point for us was when we all accepted that the elusive cure was never going to happen and that pain management was the way forward."

Molly has taken up knitting again and joining a local knitting group has been a great help to her.

She says: "I met so many great people, learned to knit socks and gradually began to claw my life back together. I used the technique of pacing myself, and the successful drug regime allowed me the opportunity to gradually push myself a little further every time. When I am knitting I feel that I can cope with the pain more easily; it's still there but I have something better going on, so I can ignore it. I can talk to people, some of whom share similar problems and others who have problems I certainly wouldn't want. It seems as though we can talk about more intimate things when knitting, which may not happen with other activities - although it's not all doom and gloom believe me!!

"I feel like a contributing member of my family again. I feel less of a burden and have become 'the mum' again. I am more independent and, although they found it difficult at first, my family treat me less like an invalid.

"I am still in pain and I still have awful days, but now I know that I can get through them because I have a reason to live and beat the damned thing."

These are some of the strategies which, used together, can help to give better long-term relief.

Setting goals

Setting targets for each day, and for the longer term, can help keep the body and mind active. This also helps give direction to your recovery. As with any recovery, it is important to choose goals that matter to you – for example, being able to do the shopping or driving the car. In time, these goals can become more challenging, but you have to break them down into small and manageable steps.

Pacing

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. Taking regular breaks in activities, changing position, resting briefly between activities or doing stretches throughout the day can all help.

Practising and regularly setting goals and using pacing techniques can together help you to achieve many of the activities that persistent pain may initially have 'stolen' from you.

Relaxation

Practising relaxation techniques regularly can help to reduce persistent pain. It is a useful skill to have, and 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 technique and it is important to know that these are different from, for example, reading a book quietly or watching TV. There may be classes available locally that can help teach relaxation, or these may be available at your pain clinic. There are also many books, CDs or videos on relaxation techniques.

Keeping active

Research shows that people with persistent pain who keep active tend to feel better and can do more. To do this usually involves improving general fitness.

When in persistent pain, movements or activities that can make pain worse do not necessarily involve further damage or injury. It is very important to understand this, as it means that being active may hurt but this does not mean you are getting injured or harmed. Understanding this can help you recover and get back some of the life you may have lost to persistent pain.

Socialising

Having contact with people can play an enormous part in helping you feel better. Pain can make it hard to get out to see people or to join in with what they are doing, but social contact can be at home, over a cup of tea, within whatever limits you have. It has been shown that keeping in touch with friends and family is good for our overall health.

Enjoyment

Sometimes you may concentrate on what you must do, and forget the enjoyable activities. Try to find the time to phone a friend or go out to the cinema, even if you have to leave halfway through. Be pleased with the things that you have accomplished. Try to include at least one enjoyable activity in your list of things to do every day

Medicines

Medicines are often used for persistent pain and may give valuable relief. They are just one of the many tools in our 'toolbox' and you should use them alongside all of the other tools. The aim should be to use the minimum amount of medicines needed to allow you to increase your general activity and exercise.

It takes time and a great deal of effort to learn these self-help strategies – but they can often 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 need to go on a pain-management programme.

Hobbies

Getting involved in activities or hobbies which take the focus of attention away from your pain can be helpful. A hobby like sewing, photography or model-making, which you can do even when your activity is restricted, can fill time when you might otherwise feel that you are 'being lazy' or 'sitting around doing nothing'. Hobbies can also give you something to talk about with other people, other than your pain and problems.

"You musn't let this condition take over your life. You can pace yourself, so when you feel tired, stop and rest. If you stayed indoors, life can become very lonely, so you must get out to meet different people."

6 What is a pain management programme?

Pain-management programmes (PMPs) involve a number of different treatments delivered by a number of health-care professionals. These usually include a psychologist, physiotherapist, occupational therapist, nurse and doctor.

The length of the programme varies, but it usually takes place over between two and eight weeks, taking up either half or whole days. The programmes are normally run for groups of about eight to 10 people as outpatients, but are sometimes run as a residential course.

PMPs are not a cure for pain, and anyone starting a programme needs to understand that the aim is to improve the quality of life despite pain, not to reduce the pain (though you may find your pain does reduce slightly).

They are usually offered after the medical and physical treatments described above have been tried and have not worked well enough, or are not suitable.

The focus is mainly on increasing activity in your social life, work, family life and hobbies despite ongoing pain. 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 the programme varies between centres, but they generally all aim to:

- improve your ability to manage your pain and related problems;
- help you increase your level of physical activity;
- help you use your medication more effectively;
- improve your mood and reduce worries about activity and pain; and
- help you achieve your 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 a few weeks.

7 Summary

Persistent pain is difficult to understand and is challenging to treat.

Managing pain is not something that a doctor does to you or for you. You and the doctor (or other health professional) work together to find what works best to control your pain.

Medicines, physical treatments, psychological support, injections and other interventions may help to manage pain. However, they will not be the whole answer.

You can bring your skills to work too, by doing things like:

- gradually increasing your level of activity;
- improving your fitness; and
- changing the way you think about your pain.

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.

8 More information

Other societies and organisations

There are many organisations, most of them charitable, whose aim is to support people with pain or painful conditions. A few organisations are broad in what they focus on, relating to pain in general, but many are related to a specific condition such as arthritis or shingles. Our website — www.britishpainsociety.org.uk — has information leaflets that you can download, as well as a list of addresses and links to other websites. Remember that computers are often available in your local library. If you don't have access to the internet, we can send you a printed copy of the contacts.

On the internet

The internet also has a huge amount of information and much of it is excellent. However, it is always worth checking with your own doctor or specialist before you rely on any information.

Good starting points are the NHS website, www.nhs.uk

www.healthtalkonline.org and www.youthhealthtalk.org

The healthtalkonline website lets you share other people's experiences of health and illness. You can watch or listen to videos of interviews, read about people's experiences and find reliable information about conditions, treatment choices and support. Youthhealthtalk is a website about young people's real life experiences of health and lifestyle.

Books and leaflets

As well as the information available electronically, there are many books and leaflets available. A quick look at the Amazon catalogue showed over 500 books relating to persistent pain. Like information you find on the internet, books can also be rather variable in their standards. Here, we have chosen just three which are good quality and written by well-known people who are currently working in the area of managing pain.

- *The Pain Survival Guide: How to Reclaim Your Life* by Dennis W. Turk, PhD and Frits Winter, PhD. Published by the American Psychological Association, 2007. ISBN 1-59147-049-8

  The recommendations in this book are based on research into what works. Workbook exercises, behaviour logs and suggested readings help you include these lessons into your daily life and learn to live well despite pain.

- *Overcoming Chronic Pain: A Self-Help Guide Using Cognitive Behavioural Techniques* by Frances Cole, Helen Macdonald, Catherine Carus and Hazel Howden-Leach. Published by Constable Robinson, 2005, ISBN 1841199702

  This book provides a self-help approach to managing pain based on the authors' work with patients at Bradford Hospital.

- *Manage your Pain* by Michael Nicholas, Allan Molloy, Lois Tonkin and Lee Beetson. Published by Souvenir Press Ltd 2003. ISBN 0285636790

  This book includes basic exercises to help increase your mobility, and talks about pacing so that you can gain some control over your pain flare-ups.

We have details of many other books on our website, along with some comments about each of them. We try to update this regularly, and the books are recommended either by health-care professionals or members of our patient liaison committee. Apart from general books about pain, you will also find some which relate to specific pains such as back pain.

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