



Persistent pain

A guide to self-management

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Introduction

One in five people in Scotland have persistent pain. Persistent pain is sometimes called long-term or chronic pain.

The Pain Management Service is a team of professionals who are all specialists in the management of persistent pain. This includes consultants in pain management, a specialist physiotherapist, clinical psychologist and specialist nurses. You may see some or all of these people while you are attending the pain service.

Persistent pain is often difficult to cure. Most people attending the Pain Management Service find that treatments aimed at relieving their pain help to some extent, but do not take the pain away completely.

Working with you, our aim is to help you to reduce the impact that persistent pain can have on your life, allowing you to get back to doing things that you enjoy and becoming more active. Following an assessment, a plan of care will be proposed which aims to help you manage your pain and symptoms more effectively and so improve your quality of life. We ask that you work with us and take an active role in managing your pain. It is your efforts that make a big difference and not someone or something else.

For more information about any of the subjects in the booklet and how they may help you, please ask any member of the Pain Management Team.

1. Understanding pain

Almost every area of our body is supplied by nerves that are sensitive to pain. These nerves keep us safe from injury - for example, if we touch something hot, pain tells us to take our hand away. This pain is called acute pain and usually goes away once an injury has healed.

However, persistent pain is pain that has been going on for three months or more. It continues after an injury has healed and is unlikely to be a result of ongoing damage.

How can it affect my life?

Persistent pain can have an effect on all areas of a person's life. Pain can affect work, sports, interests, social life, relationships and mood. It is normal for people to feel angry, frustrated, anxious or depressed about what is happening to them.

However, there is a great deal that people can do to help themselves, to help their symptoms, such as staying active, gentle exercise and relaxation.

Why am I still in pain?

Even if your doctor tells you that your x-ray and scan results are normal and that there is no further damage to your joints, you may still be in pain. Unfortunately, for some people, their pain does not go away. We don't know why this happens and it is

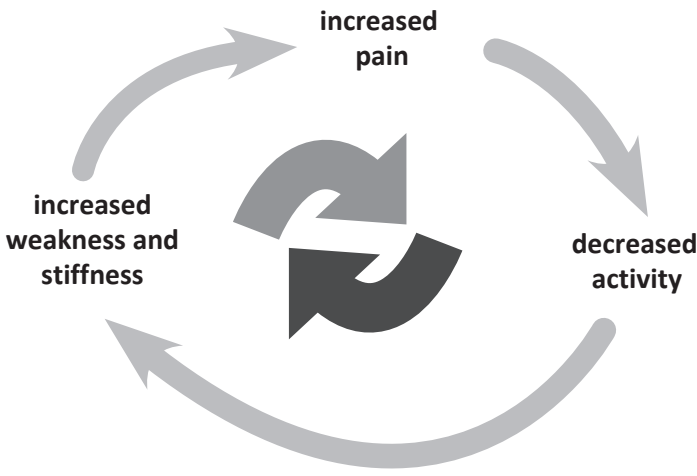
common to have normal results despite high levels of pain. What we do know is that there are changes in how our pain system works and it seems to become very sensitive.

As a result, sensations that would not normally be painful can become so.

Does increasing pain mean there is more damage?

Sometimes pain may mean that we don't move normally and we might try to protect the affected area. With time, lack of movement means that the area can become stiff and weak.

As a result, pain can get worse and a vicious circle of increasing pain and reduced activity follows. The more pain you get, the less you do and your muscles become stiffer and weaker. The less you do the more the pain increases.



Many people want to do more exercise but feel unable to do so because movement increases their pain. Despite this, people often push themselves to do more and their pain may flare up. This often results in a cycle of good days and bad days. You may recognise that you do this without realising it.

2. Pacing

People with persistent pain often learn to recognise when they are having good spells or bad spells. During a bad spell you may rest more, which means that you lose some fitness and achieve less. During good spells it is natural for you to try to do all the things that you were unable to do, and as a result may become sore and tired and have to rest again.

This can become a vicious circle of over activity and rest. It may feel as if the pain is becoming worse and limiting your activities more and more. This may mean that you give up things that you enjoy. Using a technique called pacing may help you to get back to doing some of the things that you want to do. Pacing is a way of planning your activity to avoid making the pain worse and helping you to achieve your goals. It is one of the key tools that you can use to help you manage your pain.

How does pacing work?

There are three main principles.

Prioritise

Every day think:

- What has to be done today?
- What are the most important things that need to be done or are there other things I would really like to do?
- Do I really need to do this?
- Can someone help me to do any of these jobs?

It may help to make a list of all the things you have to do during the week and spread these jobs out so you do something every day rather than doing them all at once.

Plan

Can the job be broken down into different stages? For example, if you plan to spend 30 minutes preparing a meal, do it in 10 minute sessions rather than all at once. If you have a job you want to do, ask yourself if there is a different way you can do this which will make it easier for you to manage.

Pace

Pacing can help you to try and increase your activity gradually. It's about practising doing things for a time that it is comfortable, but doing this every day.

You will slowly find that you are able to do more and your fitness will improve. For example, during a good or bad spell, if you are able to walk for three minutes without becoming sore, you could start to practice this every day. You can then gradually start to increase this time. Make sure that you are doing this in steps that you can manage. It doesn't matter how small these are.

Basic rules of pacing

- Don't set yourself targets that are too high.
- Remember to build up gradually.
- Progress can be slow and frustrating at times, but try not to become discouraged, and remember that even if it is slow, it is still progress.

3. Reaching your goals

By now you will understand that you gradually need to become more active and able to relax.

You can achieve this by taking a slow and paced approach over weeks and months, not days. You may feel that it is easy to lose track of what you're trying to do when the pain gets in the way, especially when progress seems so slow. If this happens then you may find that it will help to set yourself goals to aim for. This can give you something to work towards by pacing your activity.

What is a goal?

Think of something that you would like to be able to do – this is a goal. When you have thought about a goal, think about how you might be able to achieve it. This could be anything from walking your dog, going to the cinema or out for a meal with friends.

Make sure that your goal is achievable, enjoyable and something that you want to do.

How can I reach my goals?

Once you have thought about a goal, think about how you might be able to achieve it.

- Remember to pace yourself. Plan how you might gradually work towards achieving your goal.
- Try to do the amount you plan each day, no more and no less.
- Tell your family and friends what you are going to achieve, they will be able to help and support you.
- Praise yourself for any progress - no matter how small.
- Reward yourself when you have achieved your goal.

4. Flare-ups

Many persistent pain sufferers will experience flare-ups of pain. Although these flare-ups are not usually something to worry about, they can be frustrating and a nuisance, or make you feel that you have little control over your pain. However, there may be some simple things that you can do to either reduce the number of flare-ups you have or help you to cope better with them.

What triggers a flare-up?

Sometimes there will be a particular activity that will cause a flare-up.

Could you get help with this or change the way you do it to stop this happening? This could be as simple as breaking the activity down into shorter sessions (see the section on pacing) or planning how you will do it.

How can I manage the pain?

Try to think of things that help your pain. This could be as simple as a heat pad or a warm bath or shower. Sometimes lying down for short periods may help. You may have to rest in bed for a short time, but this should never be for more than two days. Taking your painkillers regularly may also help. More advice is in the section on medication.

Is it good to relax?

If your muscles tense up during a flare-up this may increase your pain.

Trying to relax may help and there are lots of ways that you can do this. Read the section on relaxation in this booklet.

What about activities?

Reduce your activities slightly but do not stop them altogether. There is a chance that you could lose some of your fitness if you do this. Don't be afraid to ask for help from your family, friends or work colleagues to let you reduce your activity for a short period.

Remember that this is only temporary and as the flare-up settles you will gradually get back to your normal level of activity.

5. Medication

Your doctor may have prescribed different types of medication to help your pain.

These may include drugs that you may not think of as pain killers, like some anti-depressants or anti-epileptic medications. These drugs are prescribed because we know that the way that they work can also help persistent pain. If you are worried about

taking these discuss this with your family doctor (GP) or community pharmacist. We may also give you an appointment with the pain clinic to review this medication.

You may have to gradually increase the dose of your medication before you are likely to experience any benefit, and you should be given instructions on how to do this. If you are unsure of this do not increase the dose yourself but discuss this with your doctor or pharmacist.

If you are experiencing side effects that you are unable to tolerate or you are concerned about, then seek advice from your GP or pharmacist.

What should I know about my medication?

Following a few simple instructions will make sure that your medication will have the best effect possible.

- It is important that you take your painkillers as instructed by your doctor.
- Take your painkillers regularly throughout the day.
- Do not take more of your medication than is prescribed. If you feel your painkillers are not working discuss this with your GP or pharmacist.
- If you are having a flare-up of your pain, do not wait until the pain has become severe before you

take the painkillers. Trying to wait a little longer only allows the pain to get worse and may mean it will be more difficult to control.

- Do not stop any of your pain medication suddenly; seek advice from your GP or pharmacist.

6. Dealing with emotions

Pain can affect the way that you feel. You may feel depressed, anxious or frustrated if you cannot do the things that you enjoy. Often people become angry about what is happening to them and how it affects their lives. You may have very negative thoughts about yourself and your situation may appear to be hopeless. It is common to feel like this and many people who suffer from persistent pain do so.

How does this affect me?

We know that what you feel and think can also affect your pain. If you are depressed or anxious, you may focus on the negative aspects of the situation and forget about the positive things. As you continue to do this everything appears to be so much worse than it actually may be.

You may be doing this without even realising that you are. This can affect your general mood and how you get on with your family and friends.

As well as this, your pain may feel worse and you may do less, which in turn affects your mood. Do you see how this can become a vicious cycle, often without you realising it is happening?

What can I do if I feel like this?

- Remember that you are not the only one feeling like this.
- Many other people with persistent pain experience these emotions.
- Talk to your family or close friends about how you feel.
- Try not to focus on the negative aspects of the situation -think about the things that you can achieve, or that you enjoy doing, not those you cannot.
- Plan how you can do the things that you enjoy.
- Try to be realistic when you think about your life and not let yourself make things worse than they are. Friends and family may be able to help you to do this.
- Look at the section on relaxation again. Practising your relaxation skills can help you to clear your mind of negative thoughts and see things more positively.

7. Family and friends

We know that persistent pain can have an impact on relationships with your family and friends. Those close to you usually give much needed support, but the things that you experience, like disturbed sleep, mood swings, irritability or sexual difficulties can also affect them. There is also a danger that, although meaning well, partners or family can become over-protective and try to do too much for you.

How can I make the most of my friends and family?

- It is important that you continue to be actively involved in family and social life.
- Concentrate on the things you can do with your family or friends - not the things that you can't.
- Try not to take those close to you for granted. It is nice if you can do something for them as well.
- Plan social outings that you will all enjoy and try to break it down into manageable stages, just as you would do if you were pacing activities. For example, if you were going out for a meal, choose a restaurant that is near by, has comfortable seats and room for you to walk about if necessary.
- Prioritise. Sometimes it may be nicer to do something with your children or partner than to do a chore that can wait.

- Persistent pain can make sex difficult and this can put a strain on some relationships. Try to talk about this with your partner. Pain Concern (details in the self-help section) publish a leaflet called 'Sex and chronic pain' which may be helpful.
- Help your family to understand that doing things for you all the time may not be helpful.

8. Sleeping

People with persistent pain often have problems sleeping. You may find that pain wakes you at night or you have difficulty getting off to sleep.

What keeps me awake?

There may be things that you can do which could keep you awake without you realising it.

- Do you drink coffee, tea, fizzy drinks or alcohol in the evening or if you are awake during the night?
- In order to catch up on your sleep do you sleep late or nap during the day?
- Do you lie awake worrying about not getting enough sleep?

What can I do to help me sleep?

If you have been able to recognise what keeps you awake, here are some simple things that may help you sleep:

- Gradually increase your daytime exercise.
- Try not to nap during the day.
- Do not drink tea, coffee, fizzy drinks or alcohol for at least four hours before bedtime. Even smoking cigarettes can act as a stimulant.
- Try to establish a quiet time before going to bed. A warm bath helps to relax your mind and your muscles. This may be a good time to do your relaxation exercises.
- Make sure your bed is comfortable and you are not too warm.
- Use pillows for support if necessary.
- Only go to bed at night when you feel sleepy.
- Wherever possible go to bed at the same time every night and get up at the same time each morning, regardless of how much time you slept during the night. Set your alarm clock.
- If you cannot sleep, after 30 minutes get up and do something relaxing - for example, reading or listening to music, until you feel sleepy.

9. Relaxation

Tension is a common problem for people with persistent pain. It is natural to tighten your muscles as a guard against the pain, but when we are stressed for long periods, muscles in the body can

become tensed up all the time. You may not even recognise that this happens. This is a bit like holding a heavy book with an outstretched arm, sooner or later your arm gets tired and sore. This is why tense muscles can make your pain worse.

How do I know if I am tense?

If you are in pain it can sometimes be harder to notice tension in other parts of the body. For example:

- Are your eyes screwed up?
- Perhaps your eyebrows are pulled together as if you are frowning.
- Check for tension around your shoulders by pulling them gently up and down.

How do I relax?

Being able to relax means that you ease the tension in your muscles, which may help to lower your pain levels. There are various ways of doing this:

- You can buy special audio CDs from bookshops. Pain Association
- Scotland has some good audio tracks that you can download. Look under Relaxation in the video library section of their website.
- Some people find that playing music can help.

- Taking up a hobby can have a gradual relaxing effect, and may help to distract you from your pain.

It is likely that you will have to practise any type of relaxation by doing a little bit every day. You could begin with five minutes, and try to do a little more each week. Relaxation can take time to learn, but the more you practise the better you will get and it is worth persevering with. Remember that you will feel the benefits of relaxation in the long term and that it is worth practising.

Try to plan times for regular relaxation and find a quiet warm place where you won't be disturbed. Choose a time of day when you do not feel pressured to do anything else. Lie down on your back, or sit in a well supported chair if you are not able to lie down. Try to get comfortable and close your eyes.

The routine is to then work on each of your muscle groups. With each group of muscles, firstly tense the muscles as much as you can, then relax them fully. Breathe in when you tense the muscles, and breathe out when you relax.

To start with, concentrate on your breathing for a few minutes. Breathe slowly and calmly. Then start the muscle exercises working around the different muscle groups in your body.

- Hands - clench one hand tightly for a few seconds as you breathe in. You should feel your forearm muscles tense. Then relax as you breathe out. Repeat with the other hand.
- Arms - bend an elbow and tense all the muscles in the arm for a few seconds as you breathe in. Then relax your arm as you breathe out. Repeat the same with the other arm.
- Raise your shoulders to your ears, hold them there for a few seconds and relax them down.
- Face - try to frown and lower your eyebrows as hard as you can for a few seconds, then relax. Then raise your eyebrows (as if you were startled) as hard as you can, then relax. Then clench your jaw for a few seconds, then relax.
- Chest - take a deep breath and hold it for a few seconds, then relax and go back to normal breathing.
- Stomach - tense the stomach muscles as tight as possible, then relax.
- Buttocks - squeeze the buttocks together as much as possible, then relax.
- Legs – bend your toes and feet up and then relax, then tense up and relax the muscles in your legs.

Then repeat the whole routine three to four times. Each time you relax a group of muscles, note the difference of how they feel when relaxed compared

to when they are tense. Some people find it eases their general level of ‘tension’ if they get into a routine of doing these exercises every day.

You could also use this quick, simple relaxation exercise whenever you feel tense. You can use it anytime or any place – when you’re sitting down or even in crowded places.

Take a good, deep breath.

Breathe slowly and deeply.

Let your shoulders droop.

Relax your hands.

10. What about work?

You may be working, finding it difficult to stay at work or have been unemployed for some time. Not being able to work can change the way that you feel about yourself. You may feel as if you have nothing to offer or have lost the skills that would help you to return to work and you can feel quite isolated. You may also be experiencing financial difficulties.

If you are still working, you can become frustrated if you think you are not able to do your job properly and we know that some employers may not be very understanding. All of this can be another cause of stress or worry.

What can I do to help at work?

Some of these may help you at work:

- Try to stay at work! If you have to take time off try to make it as short as possible. If you are off try to stay active.
- Think about the parts of your job that you can and cannot do or those parts that you find difficult. Think about different ways to do things to make them easier. Read the section on pacing your activity again.
- Talk to your employer and discuss any problems that you have and how they might be able to help you with these.
- Try to get advice from either an occupational therapist or a physiotherapist who specialises in workplace assessment. Details of groups that may be able to help are given at the end of the booklet.

These may help if you are out of work at the moment:

- Try to stay as active as possible. This will help you to maintain your fitness.
- Think about the skills that you do have. Disability employment or career advisors at your local job centre will be able to help you with this.
- Consider re-training or going back to further education. For example, if you had a manual

job you may be able to find a less physically demanding occupation that you can do. Local colleges will advise you on courses.

- Work does not have to mean paid employment. Think about voluntary work. The hours may be shorter and more flexible and there are many organisations that may need a wide variety of skills. This may help give you the confidence to get back to work.

At the end of this booklet you'll find details of some organisations that may be able to help you or give advice.

11. Things to remember

- Persistent pain is unlikely to be a warning of injury or a sign of increasing damage.
- There are lots of things that you can do yourself that will help your pain.
- Think about how you could plan and pace your activity.
- Practice some form of relaxation every day.
- Try to focus on the things that you can do, not the things you cannot.
- Talk to your friends and family about what you are trying to do.
- They will be able to help and encourage you.

- Think about what you have achieved and be proud of yourself when you reach your goals.
- If you do have a flare-up, think about how you can manage this and remember that it is only temporary.

12. Self-help

Pain Association Scotland 0800 783 6059

www.painassociation.com

Pain Association Scotland is a unique organisation that has pioneered the development and delivery of self-management training for people with persistent pain.

A local community based self-management group for people with persistent pain is run by Pain Association Scotland at Biggart Hospital, Prestwick and at Nethermains Community Centre Kilwinning. It is advisable to contact Pain Association Scotland before attending these groups.

The group aims to improve quality of life and wellbeing for those with persistent pain by developing and maintaining skills in pain management. It is a rolling 12 month programme covering a number of different topics.

Pain Association Scotland have been endorsed by the Scottish Government and receives support from

NHS Ayrshire & Arran health board. If you would like to attend, you can just go along. You can get a list of group dates and times on their website or by contacting the Freephone number above.

A range of excellent on-line self management videos are also available on the website.

Ayrshire and Arran Pain Management Service Website



www.nhsaaa.net/services-a-to-z/pain-management-service/

A resource updated by the pain service with information leaflets, mindfulness audio tracks and some condition specific information.

The Pain Toolkit

www.paintoolkit.org

An information booklet which will support you in managing your pain.

Sleep Council

www.sleepcouncil.org.uk

A website with information about improving quality of sleep and sleep patterns

Arthritis Research Campaign **www.arthritisresearchuk.org**

Arthritis Research have an extensive range of excellent information booklets, including 'Living with long-term pain: a guide to self-management' and 'Fibromyalgia'.

Scottish NHS Chronic Pain Website

www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/chronic-pain

This Scottish government website provides information and advice for people with pain.

Active Scotland

www.nhsinform.scot/healthy-living/keeping-active

Local Exercise Schemes

Vibrant communities and Chip project in East Ayrshire 01563 576717

Activity for Health in South Ayrshire 01292 269793

KA Leisure in North Ayrshire 01294 558020

Provide an accessible community based physical activity programme to encourage and support individuals in making the transition to an 'Active Healthy Lifestyle'. Can also direct people to ayrshire's weight loss support programme 'Weightogo Ayrshire' and Invigor8 classes for those over 60 who have concerns about mobility and falls.

Benefit Enquiries

Job Centre Plus 0800 055 6688

Access to employment provides training, advice & guidance, sources training opportunities and pathways to work.

Employability

East Ayrshire 01563 503000

South Ayrshire 01292 612301

North Ayrshire 01294 324949

Access to employment provides training, advice & guidance, sources training opportunities and pathways to work.

Living Life Guided Self Help – NHS 24

0800 328 9655

A free confidential service based on a cognitive behavioural therapy approach is available to anyone suffering low mood, mild to moderate depression and/or anxiety. It can be accessed either by GP referral or by contacting the number above.

Mood Juice

www.moodjuice.scot.nhs.uk

This site is designed to help you think about emotional problems and work towards solving them. It has a section on chronic pain.

All of our publications are available in different languages, larger print, braille (English only), audio tape or another format of your choice.

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