

# Supporting someone who has completed the Pain Management Programme

Pain Management Service

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Information for Friends and Family

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‘The aim of all Pain Management Programmes is to reduce the disability and distress caused by persistent pain by teaching physical, psychological and practical techniques to improve quality of life. It differs from other treatments provided in Pain Clinics in that pain relief is not the primary goal.’

**(taken from British Pain Society Guidelines for Adult Pain Management Programmes)**

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## Introduction

This booklet aims to help you support a friend or relative who is attending a Pain Management Programme.

Persistent pain affects not just the person in pain but also their friends and family. Every relationship is different. Living with persistent pain can change relationships in different ways. Persistent pain can have a major physical effect on people's lives, as well as many emotional, social and psychological effects. It can affect people in personal and domestic tasks, in work and leisure. People with persistent pain can often feel depressed, frustrated, worried, sad or helpless. As a family member or a friend of someone with persistent pain, you may have many of these feelings too.

While we cannot give you all the answers, we want to urge friends and family to support each other. The information here is a starting point. It is also a good idea to read the folder of information and hand-outs your friend or relative collects during the Pain Management Programme and talk about the information with them.

## What is persistent pain?

It is very important to know there is a difference between sudden (**acute**) and lasting (**persistent**) pain.

**Acute pain** can be a warning sign. We get it when we injure ourselves or if we are tired, run-down, stressed or over-worked. We may need to change what we are doing and take action, such as take some rest and/or medication or see the doctor if needed. This pain will normally go away in time.

**Lasting (persistent) pain** is different. This is long-term pain that has lasted longer than the expected time for recovery. About 43% of people in the country have some form of persistent pain and it has many different causes. Research now shows us that in many people the nervous system can become oversensitive. This can result in pain persisting (data from [www.britishpainsociety.org](http://www.britishpainsociety.org)). This is not because there is ongoing damage.

## The Pain Management Programme

Pain management is a self-management approach to help people live well with persistent pain. We offer many different kinds of sessions from an experienced team of physiotherapists, clinical psychologists, occupational therapists, nurses and medical consultants.

The fact that a psychologist is involved **does not** mean the person's pain is imagined or not real. Psychological techniques can help the person to cope with their thoughts and feelings in relation to their pain. Our Pain Management Programmes aim to:

- Offer people information and education about pain
- Teach many different kinds of techniques, strategies and skills. These can be used to help people manage their pain or to feel more in control of it.

The pain management approach is not seen as a 'treatment' or 'cure' for pain. It is a way to help people make their pain more manageable so it interferes less in their day to day activities. This can lead to an improvement in their quality of life.

By the time the person has finished the programme, you may have already seen some positive

changes. But it is important to realise that a Pain Management Programme is about how the person can take responsibility for managing their lives. There will be further changes and progress to be made. They will need your on-going support, encouragement and understanding. It is important to remember that despite the changes the person has made, it does not mean the pain has gone away.

As you support your relative or friend in managing their pain, you will find it useful to learn some of the key areas (or tools) taught on the programme. These are as follows:

- Thinking about activity levels and how to plan and pace
- Setting goals
- Exercise
- Managing unhelpful thoughts and feelings
- Communication with others
- Relaxation and distraction techniques
- Flare-up plans

## Thinking about activity levels

When someone is in pain they are often unable to do so much: at home, at work or socially. They may give up certain activities completely, or they may battle on but feel frustrated or unhappy that they are limited in what they are doing because of the pain. As friends and family, you may have had to change your routines and activities too, which can add to distress and frustration for both you and the person with pain.

It is important that the person with pain continues to do the things that are important and meaningful to them, even if this is in a different way to how they did them before. They will think about how they might do this whilst on the programme.

## Planning and pacing: avoiding the ‘boom and bust’ cycle

People with persistent pain may do more on ‘good’ days (when in less pain) and may overdo it, leading to more pain. This then leads to the person having to rest. We call this a **‘boom and bust’ cycle**. This can lead to frustration and upset for all involved. It can also lead the person to avoid activities which caused the pain to worsen, which then can have longer-term effects.

On the Pain Management Programme we talk about how to go about activity in a more measured and planned way, to avoid the above example. We talk about learning to stop an activity before it becomes ‘too much,’ at a pre-planned point. For example, saying “I will stop cleaning after 15 minutes, when I still feel fairly OK”. This will vary with the person and the activity. The benefits of this approach might include having less ‘bad’ days, less stress, and less tiredness. This can help with controlling the pain.

It is also important to try to do a measured amount of activity even on bad days. It is not helpful to do nothing. Achieving something, however small, is good for our mental and physical health. It may help to break activities into smaller and more manageable parts.

## Ways you can help:

- Help to develop the habit of pacing by checking how long the person spends doing something. Some people ask their family or friends to be their 'clock,' for example, reminding them to take a break.
- Talk about if it would help if you did less or more on joint tasks with the person, for example completing housework, mealtimes, childcare, etc. It can mean trying out different routines, beginning new activities or changing habits.

## Set goals

Persistent pain changes your life. Many people want to get back to things they used to do or to try something new. Setting goals is a way to achieve this.

People on the Pain Management Programme are given lots of information about goal setting. Briefly, it involves breaking the goal down into 'smaller' or 'mini-goals' to achieve a step at a time. This makes it more achievable and realistic. A goal should be motivating and important for the person.

## Ways you can help:

- Setting new challenges can be scary, this is where your support comes in.
- Listen to what the person is trying to do and encouraging them can really help.
- Remember, the person will be working towards their goal in a step by step way and this may take time. Each step is progress forwards.
- Setbacks can often happen on the way to achieving a goal. If the person experiences a set-back, it is helpful to remind them that this does not mean failure in achieving the goal. Set-backs can be useful events to learn from. You could help get the person back on track and re-motivated to achieve their goals.
- Think about ways you could be involved in any rewards of progress along the way or celebrating the achievement of their goals.

## Daily exercise

Keeping to a regular exercise routine is important for everyone, but we know it's not always that easy to do. Having persistent pain can make trying to exercise regularly even harder.

It is **safe** for people with persistent pain to exercise. The gradual loss in activity which is typical for a person with persistent pain also affects the body as a whole. It may harm their general health and mood. Your friend or relative will have detailed information about the pain cycle. They should understand that with persistent pain, **hurt does not usually mean harm**. With persistent pain, we do not follow a 'let pain be the guide' rule. Instead we help people to focus and engage with exercise and movement where they are in control.

## Ways you can help:

- You could urge the person to do their daily routine of relaxation or stretches and strengthening exercises.

- If you would like to, you could also join in with them or guide them through the handout detailing all their stretching and strengthening exercises.
- You could share a walk with the person and go at their own pace.
- You could do a joint exercise programme or class together.
- Remind the person that hurt does not mean harm when exercising.

## Thoughts and feelings

One thing we look at on the programme is how to challenge the unhelpful thoughts people tend to get when they are in pain.

For example, if someone has a few 'good' pain days and then wakes up with a return of very intense pain, they may think "Oh no, I knew the pain would be back again. It was not worth doing all those exercises as nothing helps. This pain is never going to get better!" This in turn is likely to make them feel low, fed up or frustrated. They may then set back their progress by losing the motivation to do the exercises or activities that have been helping them.

On the programme we encourage everyone to try to check their unhelpful thoughts and challenge them. They need to look for evidence to support or contradict their thoughts. We also try to help people notice when they are trying to mind-read or predict other people's reactions to them.

Talking about feelings of fear, sadness, loss or anger is healthy. Bottling feelings up can make health worse.

## Ways you can help:

- Listen to the person if they want to talk about how they are thinking or feeling.
- Give the person space if they need it.
- Plan and do something nice together.
- Encourage the person to 'catch', 'check' and 'change' their thoughts.
- Encourage the person to use helpful self-talk.
- If the person is struggling with their mood, encourage them to use their flare-up plan or self-soothing box if they have one.

## Communication with others

Often, people on the programme say they feel that people close to them are bored with hearing about their pain. Others worry about burdening people. They may then try to hide their pain, doing more than they can cope with at that time or holding on to their feelings of pain, distress and frustration. They may not ask for the help and support they need.

Because pain is unpredictable, people may have to cancel activities at the last minute. This may trigger unhelpful thoughts, worrying that friends may think they are unreliable or feel let down or angry. This can lead to people with persistent pain deciding not to bother arranging activities, which restricts their social contact. This can lead to an increase in unhelpful thoughts and low mood.

Through the programme we urge people to think about the way they talk with others and if this way is helpful to them.



## Relaxation and distraction techniques

We urge everyone to try to practise relaxation every day.

- For some people it can be helpful to have someone to do this with them, or to make sure that they have time to do the relaxation exercises without any interruptions.
- Activities that we enjoy and which take our attention away from the pain can be very helpful. We encourage everyone to think of ways to distract themselves.
- You may have an important role in helping the person to divert their attention away from the pain through activities you both enjoy and are able to do. This can be anything from a funny film to a trip out.

## Refer to the flare-up plan

As well as good days and bad days, every now and then, someone with persistent pain may have a 'flare-up'. A flare-up can be described as the usual experience of pain, but with the volume turned up. Flare-ups are not a new pain and are not a sign of new injury.

Everyone copes with pain and flare-ups in their own way. Dealing with flare-ups can often be a scary and lonely experience. It can often limit activity. Dealing with the distress of increased pain can make it difficult to focus. Some people have unhelpful thoughts and feelings, that at other times, they would be able to cope with. All these things can affect relationships.

It may help for you to talk about the experience of flare-up times together, ideally at a time when the person is not having a flare-up. We advise people on the programme to come up with a detailed plan of what would be most helpful during this time. This not only helps to manage and limit the distress flare-ups can cause, but also how best to build back up to a more normal routine and mood. Many people with persistent pain say having this detailed plan can give a sense of control and perspective and help stop distressing thoughts and feelings get on top of them.

## Further help and advice

Visit the websites [www.painconcern.org.uk](http://www.painconcern.org.uk) and [www.paintoolkit.org/](http://www.paintoolkit.org/) for more information. You can get support for your own mental health by seeing your GP or visiting [www.leicspart.nhs.uk/mental-health](http://www.leicspart.nhs.uk/mental-health).

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔  
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