Pain management programmes for adults

Information for patients

Prepared on behalf of the British Pain Society

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Is pain affecting your life?

This booklet may have caught your attention because you have persistent pain. If so, you will know that persistent pain can seriously affect the quality of your life. It affects your work and your home life. Often your family and friends can’t really understand what you are going through. You have probably tried various treatments and now you wonder if you are going to have to live with pain forever. Your doctor may even have said this to you. You may be wondering how you are going to cope when you are in such pain.

This booklet tells you about pain management programmes. These focus on how pain is affecting your life and show you how to overcome the effects step by step. These steps can help, but you will have to work at putting into practice what you learn. More and more people are finding that pain management programmes help them begin to live normally again.

What is persistent pain?

Persistent pain – also called chronic pain – is pain that continues even if you have had treatment for the condition causing the pain or for the pain itself. Although many people have persistent pain, it is not always recognised as a serious cause of disability in a person’s life. Sadly, many doctors and other health-care workers do not yet accept that pain itself is the problem, whether a cause can be found or not.

Recently, persistent pain has begun to be treated as a condition in its own right, by trying to reduce the pain and to help with the problems it causes. Like many people with persistent pain, you may find that trying pain management is better than having more and more tests and treatements
which don’t help. One of the best ways to improve how you manage your pain is by going to a pain management programme.

**What is a pain management programme?**
A pain management programme aims to help you become better at managing your pain in the long-term.

- It uses a combination of psychological, physical and practical methods to work on your problems of pain, physical difficulties, distress and poor quality of life.

- Pain management programmes are run by a team of health-care professionals for a group of people with persistent pain. There are usually six to 12 people in a group. Pain management programmes are mainly for a set period, for example, one day a week for eight weeks, or four days a week for three weeks.

After you have been to a pain management programme, you should find your pain easier to manage and be able to do more of the things you want to do. Also, you should feel more optimistic and confident about the future despite continuing pain. You should find you need to visit your GP and hospitals less.

**What about other treatments?**
There are other treatments which offer help to people with persistent pain. **Back School** and **Functional Restoration Programmes** focus on physical rehabilitation. They include little discussion of the broader aspects of living with pain. For most people they are not as good as pain management programmes for longer-term improvement. **Expert Patient Programmes** deal with aspects of living with long-term
medical problems, not just pain. They have not yet shown that they help people make the changes they want. **Return to Work Programmes** may help you get back to work or retrain for different work.

**How can a pain management programme help?**
Pain management programme staff usually include clinical psychologists, physiotherapists, nurses, occupational therapists and doctors. They work together as a team to provide a thorough approach to tackling persistent pain and the effects it has on many parts of your life.

How can a physiotherapist help?  
Some people wonder why they need physiotherapy when it has not worked in the past. Physiotherapy provided on a pain management programme is different. The physiotherapist is there to help you to find ways to increase your strength and improve your fitness in a way that suits you. So even if physiotherapy and exercise haven’t helped you before, you should still find this part of the pain management programme helpful.

How can a psychologist help?  
Anxiety, frustration, depression and feeling low can have a significant effect on the levels of your pain. The psychologist will work with you to reduce these problems. Obviously, being in pain for a long time is distressing and the psychologist aims to work out with you how to tackle this. Seeing a psychologist certainly does not mean that the pain is ‘all in the mind’, but recognises how difficult it can be to manage persistent pain.
Is a pain management programme for me?
If you are living with persistent pain which makes your life difficult, and medical and other treatments have not helped, it is quite possible that a pain management programme could offer you hope.

A pain management programme could help you if you:

- find it difficult to do everyday things (such as work, household tasks or leisure activities), because of the pain;

- feel worried and stressed by the pain, and probably feel low and sad at times;

- understand what the programme involves and are open-minded about trying to do things differently;

- are willing to take part in a group.

Does a pain management programme suit everyone?
You will not be excluded from a pain management programme because you are elderly, you have an ongoing court case or claim related to pain, or because you are not able to read or write very well.

But, group pain management programmes don’t suit everyone. Some people need more individual help, especially:

- people with a rapidly deteriorating condition, a severe mental illness, or dementia, as these make it hard to follow the programme;
• people with serious psychological problems such as severe depression or drug or alcohol problems (they should not start a pain management programme until these problems are sorted out); and

• people who cannot speak or write in the language in which the programme is run.

What about children and young people?
There are very few programmes for young people with persistent pain. Specialist treatment in these programmes involves family members, schools and colleges, and so suits their needs in a way an adult group is unlikely to do.

What do I have to do?
You can be referred either by your GP or by a hospital consultant. You have the right to ask to be referred, and you can ask your GP or hospital doctor whether a pain management programme would help you. If you are not sure, it is best to be referred and talk to the programme staff about whether they can help you. You should be able to choose the programme that you prefer.

What happens when I have been referred to a programme?
Once you have been referred, the staff at the pain management programme will offer to assess your needs, to make sure that they can help. They will explain the pain management programme to you in more detail so that you can decide whether or not to try it.

You will usually go to a pain management programme as an outpatient, although there are a few intensive programmes where you stay in hospital. Outpatient programmes are held
in a variety of places, including hospitals, community centres and GP surgeries.

- You usually start at the same time as other people and stay in the same group for the whole programme. Many people find it very encouraging and supportive to meet other people with similar problems.

- Most days are a mix of information and group discussion, learning new exercises, and trying out things which the pain makes difficult. The areas you will look at include home life, friends, family, work, hobbies, sleep, how you feel about yourself and how you feel about others.

- The exercises and stretches which you learn help you become stronger and more flexible, which makes it easier to manage physically and to prevent further pain.

- Many people use the programme as an opportunity to get support and guidance in reducing their medication, and to improve their sleep and mood. Many also find they can stop using walking sticks and other aids.

**Measuring your progress**

At the beginning and end of the programme, and possibly at follow-up appointments, you will be asked to fill in questionnaires and perhaps do physical tests (such as a timed walk) to measure your progress. This also helps staff to assess the programme and make improvements where necessary.
What happens after a programme?
What you learn on the programme can change how you manage pain day-to-day, in what you do and how you do it. You will benefit most if you continue to use what you have learned, applying it to new situations and needs as they arise.

Some people who have been in a group together enjoy keeping in touch with one another or with other people who have been through similar programmes, but you can decide what you want to do.

You, your GP and the doctor who referred you (if that is not your GP) should get a letter when you end the programme, describing your achievements, what you still need to work on, and in what areas you might need more support. This is to help you and your GP to work together on managing your health.

Is it easy to get on a pain management programme?
Pain management programmes have been developed by teams of staff who have recognised how useful the programmes are, but not all areas of the UK have pain management programmes, so your nearest programme may be quite far away. For some programmes there are more people than places available and you may have to wait a long time after being referred.

Where can I find out more?
Your GP may know about pain management programmes and be able to discuss these with you and whether they would help. But remember, these programmes are fairly new in the UK and not all GPs know about them. If your GP
cannot help, you can find out more information at www.britishpainsociety.org or at www.dipex.org. Or you can write to the British Pain Society at:

The British Pain Society
Third Floor
Churchill House
35 Red Lion Square
London
WC1R 4SG.

How we developed this information
This booklet accompanies guidelines on pain management programmes for providers and referrers, describing good practice. It was written by members of the working group below and includes professionals who work with people in pain, and patients who live with pain and are familiar with pain management programmes.

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We would also like to thank Mrs Jean Gaffin and Mrs Nia Taylor for their help.