# Living well with Chronic Pain: the role of Pain Management Programmes

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**Key Words:** 

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## Key points

- Chronic pain conditions may not be adequately managed by medications alone
- Chronic pain states are driven by well understood neurophysiological mechanisms and are not 'psychosomatic'
- Patient behaviours and coping styles will determine functioning and quality of life, more significantly than pain intensity
- Pain Management Programmes (PMPs) help individuals to focus on functioning and quality of life through self-management, and to broaden the agenda away from pain control alone.
- Multidisciplinary input is essential; doctors can help by effective preparation of the patient and timely referral, and by avoiding re-medicalisation

The clinical management of long-term, non-malignant chronic pain can be challenging. The limited number of pharmacological treatments available only help a proportion of patients, often resulting in tolerance and side effects with long term use. Patients can be left with substantial functional disability, poor quality of life and with their condition causing substantial health-related economic burden<sup>1</sup>.

In this challenging context, many patients approach pain services hoping for pain elimination, or enduring pain control. They are often searching for an explanation for their pain and may feel that the severity of their symptoms has not been taken seriously<sup>2</sup> ( unhelpful clinical approaches detailed in Table 1). Clinicians will use evidence-based pharmacological and interventional methods to help; where these are effective in sustainably reducing pain and restoring function, Pain Management Programmes (PMPs) have no role. However, patients who have less long-lasting treatment responses will benefit from a shift in clinical approach. It can help to move away from an emphasis on pharmacological and interventional treatment to a focus on self-managing pain in the long term, and to achieving good functioning and quality of life even if pain persists. This is not easy to achieve, but PMPs can teach the skills to attain this, even where patients' pain remains poorly controlled by medicines. It is important to introduce patients to selfmanagement philosophy relatively early in their clinical journey, rather than to wait for treatment failure first. Understanding the remit and approach of PMPs allows judicious referral and preparation of patients for this approach.

The rationale and philosophy of PMPs rest on (1) a proper understanding of chronic pain states, (2) realising the limits of medical treatment, and (3) an understanding of what true 'self-management' of a chronic condition can look like.

Clinicians and patients need to appreciate an understanding of chronic pain often being driven by central sensitisation and altered descending control of nociceptive input<sup>3</sup>. Failure to understand this can explain why patients, and often clinicians, cannot make sense of chronic pain conditions that persist in the absence of ongoing pathology. This can lead to some clinicians labelling pain as 'psychosomatic', and the patient contesting this in a way that impedes treatment and sours clinical relationships.

Extensive research (including in animal models) shows how the pain system can become sensitised, resulting in high levels of pain being evoked spontaneously, or from minimal stimuli. The concept of pain being caused by negative emotions ('psychosomatic') has been shown to have poor coherence and validity in the pain literature<sup>4</sup>. Of course, there is a significant role for emotions in an individual's behavioural response to chronic pain, described below, but it is not causal. Instead, chronic pain can be seen as an example of a condition where intense emotional responses can directly worsen symptoms (like psoriasis) or where negative emotions can make a condition worse by disrupting necessary selfmanagement (such as depression causing poor glycaemic control in diabetes).

Understanding chronic pain correctly allows the patient to make sense of their experience of severe pain in the absence of corresponding tissue damage, and allows them to realise that they are not be harming themselves by moving. Much research has shown that fear of pain sensations, and the belief that movement is harmful because it is painful (kinesiophobia) results in worse functioning and outcomes<sup>5</sup>; reduced movement results in physical deconditioning and loss of life roles. PMPs can work against this destructive cycle, when the unpleasant but non-damaging nature of chronic pain sensations are properly understood.

PMPs reframe the clinical approach to chronic pain. An understandable approach to pain is to try control and reduce it, hoping that this will resolve the difficulties in mood and functioning that came after pain onset. In chronic pain states, this logic can break down, and can become a barrier to progress. Pain control is not always possible and does not always lead to better functioning. For example, taking a high dose of opioid medication and lying down may result in some pain relief, but not necessarily better long term functioning<sup>6</sup>.

Thus, PMPs shift the clinical agenda away from pain control, towards using techniques that allow individuals to function and live well in the face of ongoing pain. A patient's physical and psychological difficulties in the face of pain can be addressed directly, rather than waiting for pain relief to happen first. Patients are shown how to self-manage their lives, using psychological and physical techniques, in the face of pain, and that this may be more effective than escalating analgesics or repeated interventional techniques. Self-management means a person autonomously being able to become more physically active, manage their moods and behavioural responses, and to set goals and to restructure their

lives. It is more than, for example, being 'given a set of home exercises' by a professional who is in the 'expert' role; true self-management teaches patients to set their own goals, solve their own problems, and achieve such personal effectiveness in the face of their condition that they no longer need regular input from clinicians (Table 2).

Content and techniques involved in a PMP

PMPs are regarded as the 'treatment of choice' for chronic pain that has a significant physical, psychological and social impact<sup>1</sup>. National guidance has established the core components required of a PMP<sup>17</sup>.

Cognitive and behavioural methods

Mood disturbance is common in chronic pain (depression prevalence estimates vary between 30 – 60%8). It is easy to see how the experience of chronic pain can be frightening and intimidating, and how the associated loss of function can lead to sadness. Also, the base rate of emotional struggles in the general population, irrespective of pain, is high; patients may well have experienced mood disturbance prior to their pain condition. Nonetheless, even understandable emotional reactions can become an independent problem, and can also inhibit effective rehabilitation; people who are low in mood and fearful of movement often struggle to sustain an exercise programme. Thus, psychological techniques, including thought-challenging, exposure to difficult tasks, mindfulness and acceptance, can be used to help an individual's mood directly, and also to facilitate the application of the other PMP skills.

Skills training and activity management

In chronic pain conditions, personal skills that an individual might have 'taken for granted' – for example their ability to plan their day, know their physical limits, and to communicate

around their needs – can become problematic. PMPs commonly train skills such as relaxation, mindfulness and communication. However, Activity Management – the examination of how people deploy their effort and energy – is probably the most critical aspect of skills training<sup>9</sup>. It is understood that people with chronic pain can fall into patterns of avoidance of activity, overexertion, or highly cautious 'pacing' where they structure their exertion around minimising pain levels. None of these are an ideal approach to flexible activity management with pain. PMPs now train various approaches to activity engagement that emphasise self-awareness, realistic approaches to goal-setting and the establishment of a sustainable and increasing level of daily activity.

### Physical activity

Exercise or graded activity increase is a central part of PMP treatment; indeed, there is evidence that exercise alone is beneficial for chronic pain conditions (e.g. Fibromyalgia<sup>10</sup>). However, exercise is also a challenging proposition for people with chronic pain; it can hurt and not be immediately rewarding. To help an individual learn to self-manage their own exercise programme, there are a range of skills to be taught, including the ability to establish an effective yet sustainable level of exertion, and how to modify and progress exercises to improve functioning. However, nearly all research also emphasises that sustaining self-guided exercise is a psychological challenge, and that it requires attention to issues such as motivation and an individual's beliefs and fears about their pain condition. For example, one model of behaviour change emphasises that sustained habit change requires Capability (exercise skills), Motivation, and Opportunity (supportive context)<sup>11</sup>; most PMP approaches also find that addressing pain-related fear is essential. Thus, exercise training requires a broad focus. To help an individual maintain a higher level of activity in

the long-term, PMPs teach exercise in the context of self-awareness, motivational techniques, and applied problem-solving.

### Education

PMPs can usefully give patients information on topics such as medication (and medication reduction), the nature and physiology of chronic pain, issues around sleep and other topics such as diet, sex, and the use of aids and adaptations. However, it is widely agreed that education and the provision of information alone is seldom sufficient to achieve behaviour change. It is likely that valuable clinical change comes from individuals changing their attitude and approach to pain (decreasing fear of pain, increasing acceptance and a focus on valued goals) rather than from being in the possession of more accurate information <sup>12</sup>.

#### Outcomes and evidence

There is some consensus on desirable outcome criteria in clinical trials for analgesic agents; domains include pain, physical functioning, emotional functioning, participant-rated improvement and adverse effects<sup>13</sup>. Large surveys show that patients particularly value improvements in functioning and emotional-wellbeing<sup>14</sup>. All of these domains, and particularly those favoured by patients, are targeted by PMPs. However, pain reduction is not usually seen as the primary outcome, in contrast to the usual goal of analgesic trials. The evidence supporting PMPs has been evaluated over decades and is regarded as strong, though a recent Cochrane Review has shown that effect sizes are in the small to moderate range<sup>15</sup>. As chronic pain is a long-standing condition, evidence for enduring treatment effects is particularly valuable; one study of intensive residential PMP treatment has shown that positive effects hold up well, three years after treatment<sup>16</sup>. There are strong arguments for the health economic benefits of PMPs, at least when applied relatively early in the

course of the condition, where a de-medicalising self-management approach may obviate the need for expensive interventions such as surgery or the implantation of a Spinal Cord Stimulator. A review has indicated that the cost required for functional improvement – measured by the number of dollars required to return an individual to work – favour PMPs above all pharmacological and interventional methods<sup>17</sup>.

PMPs also, perhaps obviously, have a lower rate of serious medical side effects than interventional pain management procedures. Of course, patients can fail to benefit, and even get worse, in the context of the substantial physical and psychological challenge of the PMP. One study of particularly disabled patients undergoing intensive (thus demanding) residential treatment calculated rates of 'clinically reliable worsening' at 0% - 3.4% <sup>18</sup>. However, it remains clear that PMPs entail less medical risk for patients than any interventional approach, and cannot – unlike medication – incur greater side effects with long term use.

### Design and staffing

It takes a certain 'dose' of PMP input to reliably achieve good results; the components of this 'dose' are the number of hours of input, the range of professional delivering the programme, and their levels of skill and specialism in pain management. PMPs require a multidisciplinary team; national surveys show that availability of this provision varies widely.

The British Pain Society states that PMPs should be a minimum of 12 half-days of input (36 hours). Minimum staffing includes a Doctor, a Psychologist and a Physiotherapist; programmes also often incorporate input from Occupational Therapists, Nurses,

Pharmacists and Clinical Support Workers (e.g. Health Care Assistants, Assistant
Psychologists). Specific pain management expertise is required; psychologists should either
have this expertise, or be supervised by someone who has, and the Physiotherapy Pain
Association has set out core competencies for PMP Physiotherapists. Whilst some pain
interventions for specific groups of patients can be effective as a unidisciplinary treatment
(for example, Physiotherapist-delivered CBT for subacute back pain<sup>19</sup>), it is recognised that
patients with the full picture of pain-related disability and distress require the full package
of PMP treatment. In general, more intensive programmes have better outcomes, and there
is a recognised danger of 'watering down' their delivery, in terms of hours of treatment and
staff mix and specialism, such that they become ineffective.

Outpatient PMPS can be delivered in primary or secondary care settings. For the most disabled, complex and refractory patients, specialist residential or inpatient PMPs can be considered. Studies have shown that they are more effective than outpatient programmes<sup>20</sup>, but this comparison is not necessarily useful. Instead, it is best that patients with different patterns of difficulty are directed to the different types of approach. For example, where a patient's physical disability is so severe that they might struggle to attend an outpatient programme, residential referral may be a good choice. Conversely, a residential programme can be disruptive and unnecessary for a patient who is functioning well enough to benefit as an outpatient.

### Referral and preparing the patient

PMPs are an effective, evidence-based treatment for chronic pain; however, to the patient with pain they can initially seem counterintuitive, or like an admission of the failure of

medical treatment. Embracing PMP philosophy requires, to a degree, acceptance of the fact that pain will persist, that medical treatment will be of limited value, and willingness to practice demanding physical and psychological self-management techniques. Many patients feel that their pain has not been taken seriously, and they have experienced a history of unhelpful clinical treatment such as detailed in Table 1. Thus, when their treating physician attempts to direct them away from medical solutions to self-management based on the likely persistence of pain (and with a psychological emphasis), it is not hard to see why some resist. Doctors need to be able to explain the rationale of PMPs well, and to refer to them at the right time.

Most PMPs will assess patients for readiness to participate, and PMP staff can provide advice and guidance about potential suitability. However, it is useful for referring doctors to have some knowledge of positive indicators for referral, beyond the obvious (i.e. absence of treatable disease, safety to exercise). The key factors are readiness to experiment with the PMP agenda, and absence of practical barriers to engagement in a group-based self-management treatment. It is not required that patients should relish the idea of self-management or completely give up their hopes for pain control; rather, they must be willing to try things out, even if they entail emotional and physical challenge. There are practical issues that may render PMP approaches unwise, or ill-timed. For example, although PMPs regularly treat patients with depression, there are states of acute psychiatric need (e.g. active psychotic illness, severe PTSD, certain personality disorders) that would make it unwise for a particular patient to attempt a challenging PMP. Severe cognitive impairment and states of profound physical disability or fatigue may make it impossible for a person to access effective PMP treatment that requires consistent group attendance (though

residential treatment may be an option). Children and adolescents should not be included on adult PMPs, and young adults (e.g. 18 – 30 years) may get better results from programmes that target their developmental stage (available at some specialist centres). In contrast, several factors are no longer seen as barriers to treatment, despite having been historically seen as problematic. Older adults, for example, can benefit from treatment, and whilst litigation can have a complicating impact on PMPs (better treatment outcomes may result in less compensation), it is not a necessary reason for exclusion.

Proper explanation and good rationales can prepare patients for PMP treatment. PMPs should be presented as a positive choice that legitimately addresses the long-term challenge of pain, rather than a default response after a period of medical treatment failure. The psychological aspect of PMPs can require careful explanation as patients are understandably resistant to the idea that their pain is 'in their heads'. However, a proper explanation of the nature of chronic pain (as above) can explain why pain persists in the absence of damage without being 'psychosomatic'. Also, it easy to explain how any distressing chronic condition, which entails functional limitation and change to life, can come to have an emotional component. Most patients will understand that achieving substantial behaviour change (for example, losing weight or giving up smoking) is not simply a matter of 'knowing what to do'; rather, habit change requires an understanding of motivation, beliefs, and patterns of coping that help or hinder. Establishing an exercise habit in the face of pain will be similar. Such analogies can help to explain the psychological aspect of treatment.

It is likely that pain doctors will carry on seeing patients during and after PMPs, as symptoms are chronic. Doctors can support the efforts of PMP teams, yet it helps to be aware that medical actions can inadvertently undermine them. It is particularly important to take the correct approach in the period immediately after the PMP. The PMP team will have made efforts to help patients adopt a more active role in their treatment, to reduce their dependence on healthcare professionals, and rely more consistently on their own coping resources. This is a challenging philosophy, and hard to sustain in difficult moments. It is common for patients to have setbacks or flare-ups after PMP treatment. Most of the time this represents the natural course of the condition, plus the physical and emotional provocation of PMP treatment; it is not necessarily evidence of PMP failure. The best approach for such setbacks is to refer back to the PMP philosophy and to use selfmanagement techniques to approach them. However, the patient may revert to hoping that an expert will step in and resolve the problem, and the doctor may inadvertently undo PMP work by offering to 'take charge' with new medical approaches. This usually undermines self-management treatment and re-medicalises the problem. Of course, sometimes PMP treatment simply does not work. However, in the post-PMP period, it is best to see setbacks as opportunities to practice PMP techniques; doctors should redirect patients to their existing skills, allowing these to have the chance to be practised and to work, and should take care not to re-medicalise matters unless it is clearly indicated.

\*\*\* 3000 words of max 3000.

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