



Using an experience-based co-design approach to create a pain management patient information leaflet

Types of Pain

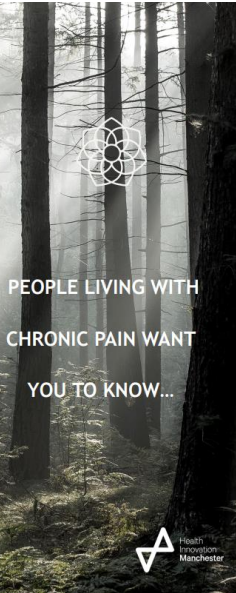
- **Chronic pain** - pain that continues for longer than 3 months, either as part of another health condition, or despite investigations and treatment.
- **Acute pain** - pain that happens suddenly, starts out sharp or intense, and serves as a warning sign of disease or threat to the body.
- **Neuropathic pain** - a neurological disorder in which people experience intense chronic pain due to nerve damage. It often results from an injury or disease of the peripheral or central nervous system.
- **Cancer pain** - can take many forms. It can be dull, achy, sharp or burning. It can be constant, intermittent, mild, moderate or severe. How much pain you feel depends on several factors, including the type of cancer you have, how advanced it is, where it's situated and your pain tolerance.

Factors that affect chronic pain

- Age
- Alcohol
- Anxiety
- Changes in the weather / seasonal factors
- Diet and nutrition
- Employment status and occupation
- Ethnicity and cultural background
- Gender
- Genetics
- Physical activity
- Sleep problems
- Smoking
- Trauma
- Weight



This person is living with pain



PEOPLE LIVING WITH CHRONIC PAIN WANT YOU TO KNOW...



Why don't my painkillers work?

- This is a commonly asked question, and often one without any easy answers.
- Long-term pain arises through many different mechanisms, and most drugs only work for one of these.
- Some pains do not seem to respond to any painkilling medicines.
- You can get used to painkillers, including opioids, so that you need more and more to have the same effect. This is called building up tolerance. However, we know that high doses of opioid medicines taken for long periods are unlikely to give better pain relief and are associated with several problematic adverse effects.

Where to go for support

- If you find you're having difficulty managing your pain, ask the GP for a referral to a specialist pain clinic. Pain clinics offer a wide range of treatments and support. They aim to support you in developing self-help skills to control and relieve your pain.
- The **Pain Toolkit** is a collection of helpful tips and strategies to manage persistent pain, developed by someone with long-term pain.
- **Ten Footsteps to Living Well with Pain** created by a partnership of clinicians together with people who are living with persistent pain.
- **24/7 Helpline** - free 24/7 mental health crisis helpline - 0800 953 0285



This person is living with pain

Reviewing your pain medication

- It is important to have your medication reviewed regularly by your clinician.
- Doses of medication may need to be altered as your body changes, to prevent side effects and tolerance to medication.
- Other options to help manage pain may help improve your pain, such as physiotherapy, support networks, improvement in mental health and well being services. Distraction from thinking about pain can help, anything you find enjoyable (subject to your physical limitations) is a form of distraction.
- Specialist investigations may be needed before long term options are discussed.

Long term effects of opioid medication

- Addiction
- Constipation
- Difficulty in breathing at night
- Feeling sick, dizzy, sleepy, confused
- Increased levels of pain
- Itching
- Lack of sex drive, erectile dysfunction, reduced fertility
- Reduced ability to fight infection
- Weight gain



This person is living with pain

Treatment for chronic pain

- Medicines work best if you combine them with other ways of managing symptoms such as regular activity and exercise (as much as your body can tolerate, do not exert yourself to your bodies detriment).
- Specialist intervention - physical therapy and rehabilitation, psychological interventions, interventional procedures (nerve blocks, joint injections, or spinal cord stimulation) complementary and alternative therapies.

Tips

- Always read the leaflet provided with your prescribed medicine to ensure you are aware on how to administer and are aware of any precautions and potential side effects. Take medication as prescribed and ensure you finish the course.
- Branded medications are no better than unbranded. Brand-name and generic drugs contain the same active ingredients in the same amounts.
- Do not take someone else's medication. When you take medicine from someone else, you can't always confirm its safety or ingredients.
- Pharmacists can do much more than just prescribe. They can often be just as useful and effective as a GP.
- Everyone's pain tolerance is different, there is no shame in admitting you are in pain.

How can I help control my pain at home?

- Keeping active, with regular movement, using support such as physiotherapy or community exercise services.
- Understanding your pain, when is it worse, what makes it better?
- Healthy lifestyle choices, such as weight management, stopping smoking, reducing alcohol intake, having a healthy diet, good sleep hygiene.
- Using medication only when needed, so you do not build a tolerance.
- Talking about your pain to a clinician or family and friends.
- Relaxation, meditation and yoga.

This document has been developed by people living with chronic pain with support from Health Innovation Manchester.

Situation

Opioids are a highly effective class of analgesics and, when used judiciously, are of great benefit to many people living with pain. However, in the case of 'chronic non-cancer pain', when the source of long-term pain does not have a cause that can be treated, opioids can do more harm than good, particularly when used at higher doses.

Greater Manchester has one of the highest opioid prescribing rates in England, with opioid use (as defined daily dose/1000 GP registrants/day) of 53.1 compared to 13.9 in London and 36.9 nationally. In addition, opioid-related deaths and harms, such as dependency and addiction, have become increasingly prominent in the UK.

There is existing information about pain management, which has been produced by clinical specialists, to inform and support people living with chronic pain. We wanted to understand what information experts by experience would include in patient information and what they felt were key messages to share with others.

Action

We recruited four people living with chronic pain to join an experience-based co-design group. The aim of this group was to create a patient information leaflet based on what information those experts by experience wanted to share with others who may be facing the same challenges.

To create the patient information leaflet, the working group took the following steps:

- Review of a draft patient information leaflet developed by a pharmacist
- Group co-design sessions facilitated by the programme team to share experiences and ideas
- Group co-design sessions facilitated by the programme team to agree the content and look of the patient information leaflet
- Accessibility checks completed and a review from the Health Innovation Manchester Communications & Engagement Team
- Review of the final version for final thoughts and tweaks

Result

The [Patient Information Leaflet](#) has been successfully co-designed by people living with chronic pain.

The leaflet is available on [Greater Manchester Pain Management Resources Hub](#) and has been shared widely with Greater Manchester stakeholders. It has lots of useful content including:

- Factors that affect chronic pain
- Why don't my painkillers work?
- Long term effects of opioid medication
- Reviewing your pain medication
- Where to go for support

Read about [Debra's experience](#) of working with Health Innovation Manchester to develop the patient information leaflet.

Feedback from the lived experience working group on the final patient information leaflet:

"I like it very much. The colours are striking and the images are good. It is well ordered, neat and understandable."



"Wow. Great piece of work. Looks very good indeed and is very informative along with being factual!"

