



Opioids Aware: Information for patients

About pain for patients

Most of us have experience of pain including headaches, pain from small injuries and muscle pain, for example following exercise. These pains do not last long and often do not need treatment. All pain we feel is affected by how we are feeling, our past experiences of pain and any worries we have about the cause of the pain. If we are worried and upset about how pain may affect us in the future, our pain will feel worse. Unpleasant thoughts, feelings and memories (even if these are not to do with pain) can affect how we feel pain. Anxiety, depression, Post-Traumatic Stress Disorder, previous emotional upsets or other mental health problems can worsen our experience of pain and make it more difficult to treat.

Types of pain

Pain is usually described as acute (short term) or chronic (long term or persistent, which is usually more than three months).

Acute pain (short term pain) is usually related to an obvious injury such as tooth infection, broken bone or operation. It can be severe but usually gets better quite quickly.

Chronic pain sometimes begins with an injury, but the pain does not get better as expected. Often it is not clear how a chronic pain has started. Chronic pain is usually not a sign of on-going injury or damage but may be to do with changes in the nervous system over time over time that make pain signals independently cause pain. It can cause low mood, irritability, poor sleep and reduced ability to move around. Common types of chronic pain include:

- ▶ low back pain
- ▶ pain related to arthritis
- ▶ pain related to injury to a nerve or other part of the nervous system (neuropathic pain)

Both acute and chronic pain can range from mild or severe.

Cancer pain is usually described separately and may be short or long lasting. The pain can be caused by the cancer itself or the cancer treatment. People with cancer may experience short or long term/persistent pain unrelated to their cancer.

Neuropathic pain is a type of chronic pain associated with injury to nerves or the nervous system. Types of neuropathic pain include:

- ▶ sciatica following disc prolapse
- ▶ nerve injury following spinal surgery
- ▶ pain after infection such as shingles or HIV/AIDS
- ▶ pain associated with diabetes
- ▶ pain after amputation (phantom limb pain or stump pain)
- ▶ pain associated with multiple sclerosis or stroke

Treatments for different types of pain

(You may have more than one type of pain)

Acute pain (short term pain): Treatments for acute pain usually only need to be given for a short time while healing of the injury begins. Acute pain is often easy to treat with a range of medicines and other treatments depending on how severe the pain is. Opioid medicines are useful for treating acute pain and usually only need to be given for a few days. The dose of opioid should be reduced as healing occurs.

Chronic pain is difficult to treat with most types of treatment helping less than a third of patients. Most treatments aim to help you self-manage your pain and improve what you can do. Different treatments work for different people. Medicines generally and opioids in particular are often not very effective for chronic pain. Other non-medicine treatments may be used such as:

- ▶ electrical stimulating techniques (TENS machine)
- ▶ acupuncture
- ▶ advice about activity and increasing physical fitness
- ▶ psychological treatments such as Cognitive Behaviour Therapy and meditation techniques such as mindfulness.

Helping you understand about chronic pain is important and in particular helping you understand that physical activity does not usually cause further injury and is therefore safe. It is important that you understand that treatments tend not to be very effective and that the aim is to support you in functioning as well as possible.

Neuropathic pain is usually severe and unpleasant. Medicines may be used to treat neuropathic pain but are usually not very effective and work for only a small proportion of people. You may not benefit from the first drug tried so you may need to try more than one drug to try and improve symptoms.

Cancer pain is usually caused by an obvious source of tissue damage (tissues include ligaments, muscles and tendons) and may be acute or chronic. Neuropathic pain can occur with cancer diagnoses and treatments (such as radiotherapy). Because cancer pain treatment, particularly at the end of life, is often for a short duration, it is usually more successful than chronic pain treatment. People who recover from cancer or who survive a long time with cancer may have pain that is more difficult to treat.

Thinking about opioid treatment for pain

Pain is complicated and effected by many things, including:

- ▶ how you are feeling in general
- ▶ your previous experience of pain
- ▶ your understanding of why you have pain
- ▶ any worries you have about your pain
- ▶ how you deal with your pain
- ▶ how your pain affects your life

Pain that doesn't get better can often cause distress, tiredness and irritability. Your sleep may also be affected, and it can cause problems with daytime activities and moving around. Because of this, it can also affect relationships with friends and family.

You should discuss, with your doctor, what you expect from the treatment. It is easier to treat pain after surgery or an injury with pain relieving medicines, however it is rarely possible to relieve long-term pain completely by using such drugs. The aim of treatment is to reduce your pain enough to help you get on with your life. In trials most medicines for long-term pain only benefit around one in every four or five people and on average only provide a 30% reduction in pain. Medicines work best if you combine them with other ways of managing symptoms such as regular activity and exercise, and doing things that are satisfying or enjoyable, such as work or study, and social activities. Setting goals to help improve your life is an important way to see if these drugs are helping.

Why don't my painkillers work? is a commonly asked question, and often one without any easy answers. Long-term pain arises through many different mechanisms, and most drugs only target one of these making it less effective. Some pain does 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. We know that high doses of opioid medicines taken for long periods are unlikely to give better pain relief and are linked with a number of problematic harmful or unpleasant effects.

Taking opioids for pain

How do opioids work?

Opioids provide pain relief by acting on areas in the spinal cord and brain to block the pain signals. They are considered to be some of the strongest painkillers available and are used to treat pain after surgery, serious injury and cancer. Opioid drugs can help manage some, but not all, types of chronic pain.

How are opioids taken?

Opioid medicines come in many different forms: injections, tablets, capsules, liquids, and patches.

When should I take my opioid medicines?

For continuous long-term pain you may be given a slow-release tablet or an opioid skin 'patch' which gives a steady level of medicine in the blood. Your healthcare team will find the best way to manage your pain and adjust the dose to give you pain relief most of the time. They'll also try to lessen the side effects. Fast-acting opioid medicines and opioids that can be injected are not very useful for managing continuous pain.

What dose of opioid should I take?

The correct dose of any medicine is the lowest dose that produces a noticeable benefit. It is unusual to get complete pain relief from opioids.

You should always take the correct dose of prescribed medicines. If you feel the dose is not enough, or if the side effects interfere with your life, you should discuss this with your healthcare team.

How long will it take to work?

This depends on the form that has been prescribed. Fast acting tablets may be used when you first start trying opioid treatment; these may work within an hour and last for around three to four hours. Slow release tablets or patches take longer, up to two days to begin to have any noticeable effect.

What are the possible side effects?

When you first start taking opioids you can get some side effects, which usually stop after a few days. These include:

- ▶ feeling dizzy
- ▶ feeling sick (nausea)
- ▶ being sick (vomiting)
- ▶ feeling sleepy
- ▶ feeling confused

Sometimes these side effects can go on for longer than a few days. Your health-care team may give you some other medicines to help, such as anti-sickness tablets.

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If pain has affected your sleep, opioids may help you to recover your normal pattern, but they should not make you drowsy in the daytime.

Opioid medicines can cause some problems when you take them for long periods of time. These problems include:

- ▶ constipation (not being able to poo regularly or having problems completely emptying your bowels). This is a common problem when taking opioids and does not tend to go away the longer you take opioid medicines. You may need to try laxatives to treat constipation. If you experience a lot of side effects your team may suggest changing to another opioid drug
- ▶ itching
- ▶ weight gain
- ▶ lack of sex drive
- ▶ difficulty breathing at night; this is most common if you are overweight and if you snore heavily. If you have a condition called obstructive sleep apnoea it may not be safe for you to take opioids
- ▶ Loss of immunity
- ▶ Hormone disturbance and loss of bone density

What if I forget or miss a dose?

Take it as soon as you remember!

However, if it is almost time for your next dose, skip the missed dose and take your medication as normal. **Do not take two doses together!**

Can I drive when I'm taking opioids?

Please see our patient information leaflet on Driving and Pain.

Can I take this medicine long-term?

Opioids can have a positive benefit for some people living with long-term pain, but they can have serious consequences when they are not providing sufficient benefit or being taken in a manner that was not intended. It is important to think about the risks and benefits of continuing opioids with your prescriber on a regular basis. Recent medical literature suggests that the risks to your health increase significantly when prescribing opioids at high doses for a long period of time. If you take opioid drugs for many months or years, it can affect your body in a few ways. These problems include:

- ▶ reduced fertility
- ▶ low sex drive
- ▶ irregular periods
- ▶ erectile dysfunction in men (the inability to keep an erection)
- ▶ reduced ability to fight infection
- ▶ increased levels of pain

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If you are worried about any of these problems, please discuss this with your healthcare team. Your team will be able to tell you whether you are at risk of developing these problems.

Everyone prescribed opioid medicines in the long-term should have them reviewed by their prescriber regularly. If this does not happen ask your GP.

If you want to try reducing your dose, you should discuss this with your doctor and bring the dose down slowly.

Many people can gradually reduce their opioid dose and find that their pain is no worse. As fewer side effects are experienced, quality and enjoyment of life can improve. All of this contributes to greater physical fitness.

Can I drink alcohol?

Both alcohol and opioids can cause sleepiness and poor concentration. You should avoid alcohol completely when you first start on opioids or when your dose has just been increased. If you are taking opioids, you should avoid alcohol if you are going to drive or use tools or machines. When you are on a steady dose of opioid, you should be able to drink small amounts of alcohol without getting any extra unusual effects.

Will my body get used to opioid medicines?

Opioids can become less effective with time (this is called tolerance). This means that your body has got used to the pain-relieving effect of the medicine. You can also become dependent on opioid medicines (dependence). This means that if you stop taking the drug suddenly, or lower the dose too quickly, you can get symptoms of withdrawal. If you run out of medicine, you can experience the same symptoms that include:

- ▶ tiredness
- ▶ sweating
- ▶ a runny nose
- ▶ stomach cramps
- ▶ diarrhoea
- ▶ aching muscles

What about addiction to opioids?

It is rare for people in pain to become addicted to opioids. We do not know exactly how many people get addicted when they are taking opioids for pain relief, but it is very uncommon. It is more common if you:

- ▶ have been addicted to opioids (including heroin).
- ▶ have been addicted to other drugs or alcohol before.
- ▶ have severe depression or anxiety.

This does not mean that if you have had an addiction problem before or you are very depressed and anxious you will become addicted. It only means that you are more likely to become addicted than someone who has not had these problems. If you have had a problem with drug

or alcohol addiction in the past this does not mean that you cannot take opioid medicines for your pain. However, your healthcare team will need to know about your past or current drug-taking to prescribe opioids safely and to help you watch out for warning signs. People who are addicted to opioids can:

- ▶ feel out of control about how much medicine they take or how often they take it
- ▶ crave the drug
- ▶ continue to take the drug even when it has a negative effect on their physical or mental health

What if I want to stop taking an opioid?

Do not stop taking your opioid medication suddenly, you may experience withdrawal symptoms. Speak to your healthcare professional (doctor, nurse, pharmacist) who will be able to supervise a gradual reduction.

Is there anything else my prescriber needs to know?

Your prescriber needs to know if:

- ▶ You are allergic to any drugs or medicines
- ▶ You are taking any other prescribed or over the counter medicines or herbal medicines
- ▶ You are pregnant or breast feeding, or if you are planning to become pregnant in the future
- ▶ You have a kidney problem

You have or have had a history of excessive alcohol use, recreational drug use or addiction to prescribed or over-the-counter medication.

I am on a high dose of Opioid pain killer and my doctor wants me to stop the medication. What can I do?

If you are on a high dose opioid, even if it is helpful for you, your doctor might want to reduce this. The long-term effects of opioids and in some cases other drugs such as gabapentin, pregabalin, diazepam can trigger a reduction. There are various services available to help with this. A discussion with your doctor might help finding the support you have local to your residence.

Examples of local support:

- ▶ GP-led medication review and optimisation.
- ▶ Advanced Nurse Practitioner, Specialist Nurse led review and optimisation.
- ▶ Community Pharmacist led medication review and optimisation.
- ▶ Community Multi-disciplinary Team (MDT) approach, in combination of the above
- ▶ MDT with liaison Pain Medicine Specialist in secondary care.
- ▶ Patient-led optimisation (with ongoing assessment and review by healthcare professionals)
- ▶ There are decision aids developed by NICE for chronic primary pain. These can also offer support