



Managing pain: A guide for people living with a terminal illness and the people close to them

Introduction

If you have a terminal illness or care for someone who does, this booklet explains how to manage pain. Each person's experience and response to pain is unique, influenced by their illness and treatment. However, with proper treatment and support, pain can usually be managed effectively.

What causes pain?

Pain is a physical sensation that occurs when damaged areas of your body send signals to your brain. Not everyone with a terminal illness experiences pain. It can be caused by the illness itself, treatments, operations, or pre-existing conditions like arthritis or old injuries. Other factors like stress, anxiety, worry, fatigue, and isolation can also intensify pain.

How pain may affect you

Everyone experiences and responds to pain differently. Pain can affect just about every aspect of your life. It can stop you from moving around doing day-to-day activities. It can also affect your sleep and concentration. Pain can have a big impact on your emotions, mood and thoughts too. People often say that pain affects their confidence, optimism, quality and enjoyment of life, and relationships with other people.

Managing your pain

There are various treatment options available depending on the cause of your pain and your preferences. There are also self-help strategies that you can employ to manage the pain.

Effective pain management is an important aspect of palliative care. For a full pain management plan, we consider your physical, psychological, social, and spiritual needs, as addressing all these areas provides the best outcomes when managing pain.

Pain assessment

Your palliative care team will discuss with you to understand your pain and determine the right treatment options. This may involve asking you questions about your pain and doing a physical examination.

In some cases, they may need to arrange tests to identify the underlying cause of the pain. For example, a blood test might be done to guide medication choices. Your team will also consider your preferences and collaborate with you to determine the most effective approach for managing your pain.



Questions your doctor or nurse might ask

Your doctor or nurse might ask questions about your pain, including:

- Where is the pain in your body?
- Does the pain travel to other parts of your body?
- What does the pain feel like? For example:
 - tingling
 - burning
 - aching
 - tender to touch
 - dull
 - sharp
 - shooting
 - throbbing.
- Can you rate the pain on a scale of 0 to 10, with 0 being no pain and 10 being the worst pain you can imagine?
- How often do you get the pain?
- Does anything make the pain better, such as resting or pain medicines?
- Does anything make the pain worse, such as moving, eating or taking a deep breath?
- How is the pain affecting your life?

Talking about your pain

Everyone feels pain in their own way and everyone responds to it differently. This means you are in the best position to say what your pain is like, rather than those around you.

Try to describe any pain you're experiencing to your healthcare team. This can be difficult, but it helps them find out what's causing your pain and what the best treatment will be.

Keeping a pain diary

Keeping a pain diary can be helpful. A pain diary is when you write down when you feel pain, what it feels like and what you were doing at the time. You can then use this when you talk to your healthcare team so they know what you're feeling. You can use pen and paper or type it into your smartphone or tablet.

Information for friends and family: helping someone communicate

If you're caring for someone who has trouble communicating, it can be hard to know if they're in pain or what type of pain they have. Ask the palliative team for other ways to tell if they're in pain. They might suggest a visual chart or picture cards to help the person express what their pain is like.

If they cannot communicate at all, you should watch out for signs that they are in pain.

There are several signs to look out for, including:

- frowning
- changes in their mood
- changes in their routine such as refusing food
- change in their posture
- agitation or distress
- not being able to concentrate
- becoming withdrawn or not making eye contact
- changes in their breathing.

If you notice any of these things or feel worried that your friend or family member is in pain, speak to their healthcare team.

Types of pain

There are lots of different types of pain. You might hear your medical team using some of these words to describe pain. It can help to know what they mean:

- **Acute pain** is pain that lasts for a short time – normally less than six months. It often comes on suddenly and is usually caused by damage to your body such as an injury or a tumour.
- **Chronic pain** is pain that lasts a long time. It can be constant, or it can come and go. It is treated differently to acute pain.
- **Neuropathic or nerve pain** is pain caused by damage to the nerves themselves. It often feels like stabbing, burning, sharp pain, or tingling.
- **Visceral pain** occurs when the internal organs are damaged or inflamed (swollen). This includes colic, which feels like waves of squeezing pain in your tummy. The pain comes from the bowel, bladder or gall bladder.
- **Bone pain** can happen if there is damage to bones, including damage from bone cancer. It often feels like an intense aching pain. Bone pain is sometimes worse at night.

- **Breakthrough pain** is when you have pain even though you're taking regular painkillers. The pain 'breaks through' the painkillers. It might be brought on by doing something like eating, moving, sneezing or coughing. This is sometimes called **incident pain**. It may also mean that your painkillers are wearing off.
- **Referred pain** is when you feel pain in one part of your body even though the damage is happening to another part of your body.
- **Total pain** is the term for all the pain you have. It includes physical, emotional and spiritual pain. It also includes any struggles you have with practical issues or worries about coping with your illness.



Pain relief medicines

Your healthcare team will work with you to get your pain under control. There are lots of different medicines for treating pain. Some are for different types or how bad the pain is.

It can take a while to find the medicines that work best for you. Tell your healthcare team if your pain gets worse or feels different, and they can increase your dose or try a new medicine or drug-free technique.

Common painkillers

The three main types of painkillers are:

- simple painkillers for mild pain
- weak opioids for moderate pain
- strong opioids for severe pain.

It’s common to take simple painkillers alongside opioids for moderate or severe pain.

Opioids Addiction in people with terminal illness is very rare.	What it’s for and how it works Opioids can be given as tablets, injections, liquids, in a patch on your skin or through a syringe driver	Common side effects
Weak Opioids include: <ul style="list-style-type: none"> • Codeine • tramadol 	Weak opioids can be used for mild to moderate pain.	All opioids can cause constipation, nausea and vomiting, and drowsiness and sleepiness.
Strong opioids include: <ul style="list-style-type: none"> • morphine • methadone • oxycodone (oxynorm and oxycontin) • fentanyl 	Strong opioids can be given for many types of moderate and severe pain.	Constipation can be eased by taking laxatives regularly (they help you go to the toilet). Nausea and vomiting usually wear off after a few days. Anti-emetic (anti-sickness) medicines can help with this. If you feel extremely drowsy, have jerking movements or find it hard to take a deep breath, contact your doctor or nurse. These might be signs of taking too much opioid.



Other medicines used to treat pain

Type of medication	What it's used for	Common side effect
Antidepressants: <ul style="list-style-type: none">– amitriptyline– Nortriptyline– Mirtazapine	These are also very good at treating nerve (neuropathic) pain.	Side effects are usually mild and improve after a few days. You might get nausea, dizziness or a dry mouth.
Anticonvulsants (anti-seizure) <ul style="list-style-type: none">– Gabapentin– Pregabalin	These can relieve nerve (neuropathic) pain.	They can sometimes cause weakness, tiredness and blurred vision.
Antispasmodics <ul style="list-style-type: none">– Hyoscine butylbromide (buscopan)– Hyoscine hydrobromide	These can relieve colic (crampy pain in the tummy). They work by relaxing the bowel.	Commonly cause a dry mouth. Drinking water and sucking boiled sweets can help. They can also cause constipation.
Steroids <ul style="list-style-type: none">– Dexamethasone– Prednisolone	These can reduce swelling that causes pain. For example, a headache due to a brain tumour. They also help with pain caused by pressure around nerves.	They can cause difficulty sleeping and increased appetite. High doses can increase your blood sugar. Steroids need to be monitored and regularly adjusted.

Drug-free pain relief

There are ways of relieving pain that do not involve drugs. You can try these on their own, or along with taking medication. See our information sheet “Complementary Therapies and Drug-Free Interventions”.

Emotional and spiritual support

It's normal for people with a terminal illness to feel emotionally or spiritually distressed, whether they're religious or not. Your state of mind can affect the amount of pain and discomfort you feel. You may find that it helps to talk to a professional. This could be a:

- counsellor
- psychotherapist
- spiritual adviser or faith leader.

Speak to your healthcare team about getting this kind of support.

Occupational therapy and physiotherapy

Occupational therapists (OTs) and physiotherapists can help you adjust your home and daily activities to manage your pain. Mobility aids can make moving around less painful. Changing positions regularly or using special cushions can help ease pain too.



Complementary therapy

Complementary therapies can be used alongside your medical treatment. They might be able to help you relax, sleep and manage your pain. Talk to your palliative team for services they might be able to support you with. Common therapies include:

- TENS (Transcutaneous Electrical Nerve Stimulation)
- Massage
- Reiki
- Breathing Exercises
- Counselling
- Cognitive Behavioural Therapy, Acceptance and Commitment Therapy
- Meditation, Mindfulness and Thought Diffusion
- Sleep Hygiene Support
- Nurturing Touch/Self-Massage
- Wheat packs
- Hand-held Fan (helpful for shortness of breath)
- Music therapy
- Art therapy
- Non-sleep deep rest
- Aromatherapy
- Reflexology
- Hypnotherapy
- Acupuncture
- Pet Therapy

Information for friends and family: supporting someone in pain

As well as giving medicines, there are other ways you can help the person to manage their pain. People feel less pain when they feel relaxed and supported. They can also be distracted from their pain when they have meaningful activities to do:

You can help them to feel more comfortable by:

- spending time with them
- listening to their worries
- helping them to talk about their feelings
- helping them to relax by playing music, or reading to them
- helping them to do their favourite activities such as reading or seeing friends.

Ask the nurse if there is a carers support group in your local area where you can get more support with this.