



Overcoming Cancer Pain

A guide for people with cancer,
their families and friends

Practical
and support
information

For information & support, call

13 11 20



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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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Introduction

People with cancer don't always have pain. However, some people may have pain due to the cancer, its treatment, or other conditions that are unrelated to the cancer.

We hope this booklet will give you useful information to help you understand pain and manage it with different treatments. This booklet does not replace good communication between you and the health professionals caring for you. You need to talk to your doctor, nurse practitioner, nurse or pharmacist about pain relief.

You may also be interested in watching the *Overcoming Cancer Pain* DVD, available in some states and territories. Contact your local Cancer Council for details.

How this booklet was developed

This information was prepared by specialists working in pain management, oncology and palliative care. It is based on the Cancer Pain Education project, sponsored by The Friends of the Mater Foundation, and reflects clinical practice guidelines¹ for the management of pain in people with cancer. People affected by cancer also contributed to this resource.

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this booklet for more details.



**Cancer
Council
13 11 20**

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Key questions

Q: What is pain?

A: Pain is not just a sensation that hurts. It is an unpleasant sensory and emotional experience associated with actual or possible tissue damage.

People experience pain in different ways and even people with the same type of cancer can have different experiences. The way pain is felt is influenced by emotional, environmental and physical factors (see page 8). These factors act directly or indirectly on the body's nervous system (the brain, spinal cord and nerves). The type of cancer, its stage, the treatment you receive, other health issues, your attitudes and beliefs about pain, and the significance of the pain to you will also affect the pain experience. Health professionals assess all these factors to help treat the pain.

If left untreated, pain can lead to anxiety or depression, loss of function and changes to your day-to-day activities. Learning to control pain may allow you to return to many of the activities you enjoy and improve your quality of life.

Your experience of pain

Only you can describe your pain – it may be steady, burning, throbbing, stabbing, aching or pinching. Health professionals, family members and carers will rely on your description to work out the level of pain and its impact on your life. See the *Describing pain* chapter on pages 15–17 for different ways to let health professionals know how you're feeling.

Q: Does everyone with cancer have pain?

A: Cancer pain is a broad term for different kinds of pain that people may experience when they have cancer.

During treatment, about six out of 10 people (59%) say they experience pain. People with advanced cancer are slightly more likely to experience pain (64%). After treatment, about one in three people (33%) say they experience pain.² They may not be in pain all the time – it may come and go.

Q: What causes cancer pain?

A: People with cancer may have pain for a variety of reasons. It may be caused by the cancer itself or by the cancer treatment, or it may have another cause. Some reasons for pain include:

- a tumour pressing on organs, nerves or bone
- a fracture if the cancer has spread to the bones
- side effects from chemotherapy, radiotherapy or surgery
- poor circulation due to blocked blood vessels
- blockage of an organ or tube in the body, such as the bowel
- infection or swelling and redness (inflammation)
- muscle stiffness from tension or inactivity
- poor posture, which can lead to back pain, for example.

New pain or an increase in pain doesn't necessarily mean that the cancer has advanced or spread to another part of the body (metastasised). This is a common concern for people with changing pain levels.

Q: What types of pain are there?

A: There are many types of pain. Pain can be described or categorised depending on what parts of the body are affected or in terms of how long the pain lasts.

Acute pain – Pain that starts suddenly and lasts a short time, possibly for days or weeks. It may be mild or severe. Acute pain usually occurs because the body is hurt or strained in some way, but it generally disappears when the body has healed.

Chronic pain – Pain that lasts for three months or more. Chronic pain may be due to an ongoing problem, but it can develop even after any tissue damage has healed.

Breakthrough pain – A flare-up of pain that can occur despite taking medicine. It may happen because the dose of medicine is not high enough or because the pain is worse at different times of the day. Other causes of breakthrough pain include anxiety or other illnesses such as a cold or urinary tract infection. See page 36 for more information.

Nerve (neuropathic) pain – Caused by pressure on nerves or the spinal cord, or by nerve damage. It can come and go. People often describe nerve pain as burning or tingling, or the sensation of ‘pins and needles’.

Bone pain – Caused by cancer spreading to the bones, which damages bone tissue in one or more areas. It is often described as aching, dull or throbbing, and it may be worse at night.

Soft tissue pain – Caused by damage to or pressure on soft tissues, including muscle. The pain is often described as sharp, aching or throbbing.

Visceral pain – Caused by damage or pressure on internal organs. This type of pain can be difficult to pinpoint. It may cause some people to feel nauseous.

Referred pain – Pain is felt in a site away from the area of the problem (e.g. a swollen liver can cause pain in the right shoulder).

Localised pain – This occurs directly where there's a problem (e.g. pain in the back due to a tumour pressing on nerves in that area).

Phantom pain – A pain sensation in a body part that is no longer there, such as breast pain after the breast has been removed. This type of pain is very real to those affected. Phantom pain can be difficult to control with medicines and often non-drug strategies need to be used.

“ I had some numbness and pain in my hands from one of the chemotherapy drugs. Doing hand stretches and exercises, and soaking my hands in warm water, helped. The doctors stopped that drug so the numbness wouldn't become permanent. ” Ann

What affects pain?

As well as the cause of the pain itself, your emotions, environment and fatigue levels can affect how you feel and react to pain. It's important for your health care team to understand the way these factors affect you.



Emotions

You may worry or feel easily discouraged when in pain. Some people feel hopeless, helpless, isolated, embarrassed, inadequate, irritable, angry, frightened or frantic.



Environment

Things and people in your environment – at home, at work and elsewhere – can have a positive or negative impact on your pain.



Fatigue

Extreme tiredness can make it harder for you to cope with pain. Lack of sleep can increase your pain. Ask your doctor, nurse practitioner or nurse for help if you are not sleeping well.

Q: How is cancer pain treated?

A: There are many ways of treating both acute and chronic cancer pain. Treatment depends on the cause of the pain, but relief is still available even if the cause is unknown.

Cancer pain is often treated in a variety of ways, such as:

- surgery, radiotherapy and chemotherapy (see pages 18–19)
- medicines and other treatments specifically for pain (see pages 28–42)
- a range of non-medicine methods, such as physiotherapy and complementary therapies (see pages 43–45).

Many people find a combination of treatments helps, but everyone is different, so it might take time to find the right pain relief for you. It may be a few weeks before you feel the benefits of some treatments, so in the meantime you will usually be given strong pain medicine.

Different things might work at different times, so it is important to try a variety of pain relief methods and persist in finding the best options for you.

Sometimes it's not possible to completely control all pain. You may still feel some discomfort. However, your health professionals can help make you as comfortable as possible.

The World Health Organization estimates that the right medicine, in the right dose, given at the right time, can relieve 80–90% of cancer pain.³

Q: When can I use pain relief?

A: You can use different types of pain relief whenever you feel any level of pain. If you have pain, it's better to get help and relief as soon as possible. This results in better pain control and less pain overall.

If pain lasts longer than a few days without much relief, see your doctor for advice. It's important not to let the pain get out of control before doing something about it.

Your doctor will talk to you about how much pain relief to take (the dose) and how often (the frequency).

Many people believe that they should delay using pain-killers for as long as possible, and that they should only get help when pain becomes unbearable. If you do this, it can mean you are in pain when you don't need to be. It can also make the pain more difficult to control. There is no need to save pain-killers until your pain is severe. Severe pain can cause anxiety and difficulty sleeping. These things can make the pain harder to control. The aim is for pain control to be constant. See page 20 for more information on *Using pain medicines*.



Try various pain relief methods more than once. If the pain doesn't improve the first time, try it a few more times before you give up. If you're taking medicine that doesn't seem to work or has stopped working, talk to your doctor – don't change the dose yourself.



Pam's story

I had found two lumps but, after a mammogram and ultrasound, the doctor said they looked like hormonal cysts. I decided to have surgery to correct my inverted nipple, and they found that my two hormonal cysts were in fact cancer. I then had my breast removed along with 14 lymph nodes with one infected.

After the mastectomy, I was in a lot of pain as the wound had been stitched up tight and firm. I took strong Panadol every four hours for two months.

A few years later, a mammogram picked up a tiny spot. I was told it was precancer, so I had the other breast removed. After the surgery I was in a lot of pain and resumed taking strong Panadol every four hours. Exercising my arm also helped. I would stretch my arm regularly, pointing my fingers to the stars, and gradually it became easier to move my arm. I also attended a breast cancer support group, and this

was a good way to share the emotional pain with people who had been through the same experience. Losing a breast is like losing your womanhood; I felt disfigured and needed time to heal emotionally.

To help with the pain of the implant, I was given Panadeine Forte®, but this made me feel not connected to the world. I was then given tramadol, but this made me feel dizzy. As these didn't agree with me I took strong Panadol for a while.

After the surgery and the implant, I developed lymphoedema. The swelling was painful but I saw a physiotherapist and he massaged my arm. I did this every week for a couple of months and this really helped.

The combination of Panadol, massage and being with my breast group has helped me cope with pain during my breast cancer diagnosis.

Q: Is palliative care the same as pain management?

- A:** To 'palliate' means to relieve. Pain management is only one aspect of palliative care. The palliative care team includes doctors, nurses, social workers, physiotherapists, occupational therapists and pastoral care workers. They work together to:
- maintain your quality of life by easing symptoms of cancer
 - ease your physical, practical, emotional and spiritual needs
 - help you feel in control of your situation and make decisions about your treatment and ongoing care.

Your hospital doctor or nurse can put you in touch with a palliative care team for treatment in hospital or at home. Referral to palliative care is possible throughout the course of cancer treatment, not just at end of life.

For more information, call Cancer Council 13 11 20 for a free copy of the *Understanding Palliative Care* booklet, or visit your local Cancer Council website to download a copy.

Q: Who helps manage my pain?

- A:** Different health professionals work together to help manage your pain. This is called a multidisciplinary team (MDT). The MDT may include some of the professionals listed on the opposite page. If your pain is not well controlled, you may want to ask your GP or palliative care physician for a referral to a pain medicine specialist.

Health professional	Role
general practitioner (GP)	takes care of your general health and coordinates specialist treatment
medical oncologist	prescribes and coordinates the course of chemotherapy (anti-cancer medicine)
radiation oncologist	prescribes and coordinates the course of radiotherapy to treat painful areas
surgeon	performs surgery to remove tumours or unblock affected organs
palliative care team	assesses physical, practical, emotional and spiritual needs, and coordinates care
pain medicine specialist	specialises in treating all types of pain, particularly severe or difficult pain
nurses and nurse practitioners	administer medicines and provide support during all stages of your treatment
pharmacist	dispenses medicines and can give advice about drugs, dose and side effects
physiotherapist and occupational therapist	help you with physical and practical problems
psychologist	assesses emotional factors that affect your pain and provides psychological methods of pain management
counsellor, social worker and pastoral care worker	help you with emotional and spiritual issues and can advise on support services



Key points

- Pain experienced during treatment can usually be controlled and often decreases after treatment ends. People with advanced cancer are slightly more likely to have pain.
- There are many types of pain, which are felt in different areas of the body and have different sensations.
- Acute pain can be mild or severe but usually resolves within a few days or weeks. Chronic pain is often constant and can vary in intensity, and usually lasts for more than three months.
- Cancer pain has many causes, including the after-effects of surgery, a tumour pressing on a nerve or organ, side effects of chemotherapy or radiotherapy, or bone pain from the spread of cancer.
- Pain can be treated using conventional treatments and medicines. Other ways of controlling pain without drugs include complementary therapies.
- Use pain relief as prescribed when you experience pain. It is better not to wait until the pain is severe before taking pain relief medicine.
- A palliative care team works to improve a person's quality of life by easing cancer symptoms. Pain relief is an important part of palliative care.
- A multidisciplinary team (MDT) works together to help you manage cancer pain. The MDT will be made up of various health professionals, including nurses, specialists and allied health practitioners.
- If your pain is not well controlled, ask your GP or palliative care physician if a referral to a pain medicine specialist would be helpful.



Describing pain

Describing your pain will help your health care team understand what you are feeling, work out the cause of the pain, and plan the most appropriate way to treat it.

Questions your doctor may ask

Answering these questions may help you describe your pain.

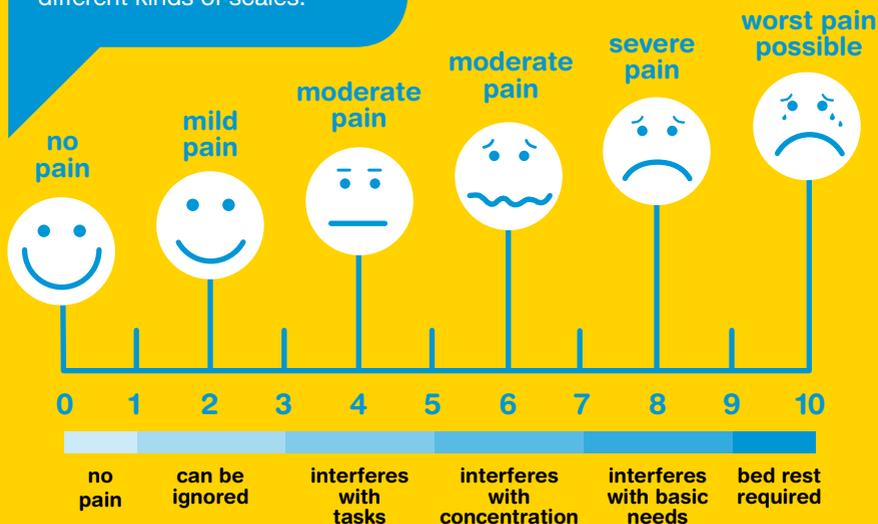
- In which parts of your body do you feel pain or discomfort?
- How bad is the pain? (See next page.)
- How does it compare to pain you have felt in the past?
- What does it feel like? For example, is it dull, throbbing, steady, constant, shooting, stabbing or burning? Are there any 'pins and needles' or tingling? Are there areas where it feels numb?
- Does your pain spread from one area to another (radiate)?
- When did the pain or discomfort begin? (Try timing the pain.)
- Is your pain constant? If not, how often does it occur? How long does the pain last each time it occurs?
- Which of your daily activities does it prevent you from doing? (Examples include: getting up, dressing, bending down, walking, sitting for long periods, exercising, carrying things, driving.)
- What activities do you think you could do or would like to do if the pain wasn't there?
- How does the pain make you feel emotionally?
- What relieves your pain? What makes it worse?
- What pain relief have you tried? What helped or didn't help?
- Did you have any side effects from the medicine?
- What have you done in the past to relieve other types of pain?
- Is there anything you are worried about with respect to the pain?

Tools to describe pain

You can use a variety of tools to describe your pain. This will help your health care team find the best pain control methods for you.

Use a pain scale

Some people rate the level of pain on a scale. There are different kinds of scales:



word scale – this rates the pain from none or mild through to moderate or severe

facial scale – this is the use of facial expressions to show how the pain makes you feel

number scale – this is from 1–10; the higher the number, the worse the pain

activity tolerance scale – this includes statements about how the pain affects what you can do



Keep a pain diary

A written record of your pain (how it feels at different times of the day, what you have tried for relief and how it has worked) can help you and those caring for you to understand more about your pain and how it can be managed.

Where to find a pain diary

Download a pain diary from nps.org.au/health-professionals/for-your-patients/treatment-plans/pain-diary. Some people use a mobile device, such as a smartphone or tablet, or download an app to keep track.

Make a note of triggers

Write down what seems to cause your pain. This is called a trigger, and it may be a specific event or situation. Knowing what triggers your pain might help you to prevent or relieve it.

Keep a health professionals contact list

Make a list of the health professionals in your team and their contact details. Keep this list handy in case you (or your carer) need to get in touch.



Talk to your doctors about what should prompt you to call. For example, you may be instructed to call if you need to take four or more doses of breakthrough pain relief, or if you are feeling very nauseated or sedated.



Cancer treatments for pain relief

Cancer treatment can help reduce pain by shrinking a tumour and reducing pressure on nerves or surrounding tissues. Cancer treatment aimed at relieving pain, rather than curing the disease, is called palliation or palliative treatment.

Depending on the cancer you have, and the location and nature of your pain, the treatments below may be used specifically for pain management.

Surgery

Some people may have an operation to remove part, or all, of a tumour. This can help relieve or improve pain caused by tumours pressing on nerves or organs.

Examples include unblocking the bile duct to relieve jaundice, which occurs in pancreatic cancer, or removing a bowel obstruction, which can occur with ovarian or bowel cancer.

Radiotherapy

This treatment uses high-energy x-rays or gamma rays (radiation) to kill or damage cancer cells. This will cause tumours to shrink and stop causing discomfort.

For example, radiotherapy can relieve bone pain caused by the spread of cancer, and headaches caused by cancer that has increased pressure in the brain.

Usually only one or two sessions of radiotherapy are needed. It can take 7–10 days to reduce your pain. You will need to keep taking your other pain medicines during this time. The dose of radiotherapy used to treat pain is low, and the treatment has very few side effects other than tiredness for a while.

Chemotherapy

This treatment uses anti-cancer (cytotoxic) drugs to kill cancer cells or slow their growth. In some cases, chemotherapy can shrink tumours that are causing pain, such as a tumour on the spine that cannot be operated on.

Hormone therapy

Some cancers grow in response to chemical messengers (hormones) in the body. Taking drugs that stop the body's production of these hormones can often slow the growth of these cancers. The drugs may also shrink tumours that are causing discomfort, reduce inflammation, and relieve symptoms of advanced cancer, such as bone pain. Corticosteroids are a type of hormone that lessens swelling around a brain tumour.

Call Cancer Council **13 11 20** or visit your local Cancer Council website for more information, including free booklets about surgery, radiotherapy and chemotherapy.





Using pain medicines

Medicines that relieve pain are called analgesics. They do not affect the cause of the pain, but they can reduce pain effectively. The medicine that is best for you depends on the type of pain you have and how severe it is.

Levels of pain control

There are different types and strengths of pain medicines suitable for different types of pain.

Mild



- Suitable for pain less than 3 on the pain scale (see page 16).
- Examples include paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs).
- See pages 28–29 for more information.

Mild to moderate



- Used for pain that is 3–6 on the pain scale.
- Examples include weak opioids, e.g. codeine.
- See page 30 for more information.

Severe



- Prescribed when pain is described as being higher than 6 on the pain scale.
- Examples include strong opioids, e.g. morphine, fentanyl.
- See pages 30–38 for more information.

How to use medicines

Take your medicines regularly

Taking your medicines as prescribed is the best way to control the pain. Some people call this ‘staying on top of the pain’. Doing this may mean you can use lower doses of pain relief than if you were to wait until the pain gets worse.

If you think your pain medicine isn’t working, it’s important to let your doctor know as they may need to adjust the dose or prescribe a different medicine.

Give your medicines time to work

Pain medicines may take different amounts of time to work. This will depend on whether the active ingredient is released slowly or immediately.

Slow release medicines – release the active ingredient continuously to provide pain control for 12–24 hours. They are designed for chronic pain and need to be taken as prescribed. This helps keep the amount of medicine in the blood high enough to be constant and effective.

Immediate release medicines – release the active ingredient quickly, usually in less than 30 minutes. They are designed for occasional, temporary pain because they work fast but don’t last.

How quickly different medicines relieve pain also varies greatly from person to person. It depends on how much medicine you take (the dose) and how often you take it (the frequency).

Understand the different types of pain relief

Pain relief comes in many forms, so you may be taking substances that you didn't realise were a medicine. Complementary therapies can also help to relieve pain.

Prescription medicines – These are medicines that your doctor must authorise you to take and only a pharmacist can give you (dispense). Most prescription medicines have two names:

- the generic name identifies the chemical compounds in the drug that make it work
- the brand name is the manufacturer's name for the medicine.

A medicine may have more than one brand name if it's produced by different companies. For a list of generic and brand names of strong medicines, see page 31.

Non-prescription medicines – These are available without a prescription, often from pharmacies and supermarkets, and include over-the-counter medicines such as pain-killers and cold medicines. Vitamin supplements and herbal remedies are also considered non-prescription medicines.

Complementary therapies – These are therapies that can be used with conventional medical treatments to improve your quality of life and wellbeing. Complementary therapies include relaxation, talking therapies, meditation, visualisation, acupuncture, aromatherapy, reflexology, music therapy, art therapy and massage. For more information, see pages 43–45 or read Cancer Council's booklet *Understanding Complementary Therapies*.



To manage your pain effectively, you may be given a combination of prescription and non-prescription medicines. You may also want to try complementary therapies to improve your quality of life.

Keep track of medicines

The National Prescribing Service (known as NPS MedicineWise) provides a medicines list to help you record information about what you need to take, when to take it, how much to take and why. The list is available in different formats from nps.org.au.

- **Paper** – Print the *Medicines List* to keep in your wallet or handbag.
- **Online** – Create, edit and save the *Medicines eList* as a PDF.
- **Smartphone app** – Download the *MedicineList+* app, then scan the barcode on the medicine packaging to add the medicine to the app and set up alarms for taking the medicine.

Discuss your use of pain medicines with family and friends

Family members and friends sometimes have opinions about the pain relief you're having. Your family members may feel anxious about you taking strong pain medicines. This may be because they are worried that you will become addicted.

Let your family know how the experience of pain affects you emotionally, and that keeping the pain under control allows you to remain comfortable and enjoy your time with them. You may want to ask your treatment team if they can explain to your family and carer why a particular medicine has been recommended for you.

Ways of taking medicines

Pain medicines are taken in several ways, depending on the type of medicine and the form that it is available in.

tablet or capsule	This is the most common form of pain medicine.
liquid	This may be an option if you have trouble swallowing tablets or for convenience.
lozenge	This is sucked on the inside of your cheeks and gums until it dissolves.
injection	A needle is inserted either into a vein (intravenously), into a muscle (intramuscularly) or under the skin (subcutaneously).
skin patch	This is stuck on your skin and gradually releases medicine into the body. The patch only needs to be changed every few days.
subcutaneous infusion	Medicine is slowly injected under the skin using a small plastic tube and a small portable pump called a syringe driver. This can take many hours or days.
intravenous infusion	Medicine is slowly injected into a vein using a small plastic tube and pump over many hours or days. The pump has a button that you press to release a set dose of medicine. This is called patient-controlled analgesia (PCA). It is used in hospitals under the supervision of a pain specialist.
intrathecal injection or infusion	Liquid medicine that is delivered into the fluid surrounding the spinal cord. It is commonly used to treat the most severe cancer pain.
suppository	A pellet is placed in the rectum, which dissolves and is absorbed by the body. This may be suitable for someone who has nausea or trouble swallowing.

Using medicines safely

Let your doctor, nurse or pharmacist know if you're taking any other medicines at the same time as your pain relief. This includes all prescription and non-prescription medicines, vitamins, herbs and other supplements. Different medicines may react with each other, stop a medicine from working properly in the body, or cause dangerous side effects. Some effects to keep in mind include:

- Many pills for colds and flu, and other over-the-counter medicines, can be taken with analgesics without any harmful effects. However, some over-the-counter medicines, such as paracetamol and anti-inflammatories, contain pain-killers, so a lower dose of pain medicine may be needed.
- Medicines for colds, menstrual (period) pain, headaches and joint or muscle aches often contain a mixture of drugs, including aspirin. People receiving chemotherapy should avoid aspirin because it increases the risk of internal bleeding. Any minor cuts are likely to bleed a lot and take longer to stop bleeding (clot).
- Over-the-counter medicines for allergies may cause drowsiness, as can some pain medicines. Taking them together can make it dangerous to drive or to operate machinery.

The Therapeutic Goods Administration (TGA) collects information about medicines and medical devices that haven't worked well. You can search the Database of Adverse Event Notifications (DAEN) at [tga.gov.au/database-adverse-event-notifications-daen](https://www.tga.gov.au/database-adverse-event-notifications-daen).



Tips for using medicines safely

- Ask your doctor, nurse or pharmacist for written information about your pain medicines: what they are for, when and how to take them, possible side effects and how to manage them, and any possible interactions with other medicines, vitamins or herbal remedies.
- Follow directions and ask questions if you need more information.
- Keep medicines in their original packaging so you and other people always know what they're for.
- Store medicines in a safe place that is out of reach of children.
- Remind yourself when to take your medicines by writing a note, setting an alarm or programming a reminder on your phone. This is safer than leaving your pills out.
- Let your health care team know of any side effects.
- Regularly check the expiry dates of medicines. If they are near or past their expiry, see your doctor for a new prescription.
- Take medicines that have expired or are no longer needed to the pharmacy to dispose of them safely.
- Check with your health care team whether it is safe to take any complementary therapies, such as nutritional supplements, together with your pain medicine.
- Find out more about your medicines by calling the National Prescribing Service (known as NPS MedicineWise) Medicines Line on **1300 MEDICINE (1300 633 424)**.
- Call the Adverse Medicine Events Line on **1300 134 237**, and tell your health care team immediately if you suspect you've had a reaction to any kind of medicine. If you need urgent assistance, call **000**.

Travelling with medicines

It's possible to take prescription medicines overseas for your own personal use, but it's best to follow a few guidelines.

- Ask your doctor if you need to change your medicine schedule to account for time differences.
- Make sure you have enough medicines to cover the whole time you're away, and pack a few extra doses in case you are delayed for any reason.
- Check with the embassies of the countries you're visiting to make sure your medicine is legal there.
- Carry a letter from your doctor or pharmacist outlining what the medicine is, and how much you'll be taking, and stating that the medicine is for your personal use.
- Keep medicines in their original packaging so they can be easily identified, and make sure the name on the medicines matches the name on the passport.
- Ask your doctor if there are limits on the amount of medicines you can take overseas – check online for different countries.
- Have any medicines you need ready for inspection at the airport. Liquid medicines are exempt from liquid restrictions, as are any icepacks or gel-filled heat packs that are needed to control the temperature of the medicines onboard the flight.



Treating mild pain

Medicines used to control mild pain include paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs). These types of drugs are excellent at relieving certain types of pain, such as bone pain, muscle pain, and pain in the skin or the lining of the mouth.

They can also be used with stronger pain medicines to help relieve moderate to severe pain.

Paracetamol

Paracetamol is a common drug that comes in many different formulations and is known by various brand names such as Panadol and Panamax. It's recommended that an adult have no more than 4 g of paracetamol a day (usually 8 tablets) unless approved by their doctor. The dose limit for children depends on their age and weight, so check with the doctor, nurse or pharmacist.

Some combination pain relievers, such as Panadeine Forte®, contain paracetamol and count towards your total intake. If taken within the recommended dose, paracetamol is unlikely to cause side effects. In some cases, taking paracetamol together with other pain medicines, such as oxycodone, helps them work better.

“ I could not believe how much better I felt after taking some pain relief. Everything seemed less stressful and I did not feel so angry and upset all the time. I had resisted taking anything for so long. I thought I should be able to handle the pain. I now wish I had taken something sooner. ” *Bill*

Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs, such as ibuprofen, naproxen, celecoxib, diclofenac and aspirin, vary in dose, frequency of dose and side effects.

You can have these medicines as a tablet or injection. Less commonly, NSAIDs are given as a suppository – a capsule inserted into the rectum.

Some NSAIDs are available over-the-counter from pharmacies without a prescription.

Side effects of NSAIDs

In some people, NSAIDs can cause indigestion or stomach ulcers, increase the risk of bleeding in the stomach or intestines, and reduce kidney function.

Some studies show that NSAIDs can lead to heart (cardiac) problems, especially with long-term use or in people who already have cardiac problems.

Talk to your doctor or nurse before taking NSAIDs, especially if you have had stomach ulcers, heart disease, kidney disease or gut reflux, are having chemotherapy or are taking other medicines (such as anticoagulants/blood thinners like warfarin) that also increase your risk of bleeding. It's generally recommended that you take ibuprofen with food to lower the risk of indigestion. You may be given other medicine that is less likely to cause indigestion and bleeding, such as celecoxib (another type of NSAID) or paracetamol.



Treating moderate to severe pain

Opioids are commonly used for pain that is hard to ignore or feels very severe. Moderate pain may be a pain score of 4–6 (out of 10), and moderate to severe pain may be a score of 6–10.

Opioids

There are many different types of opioids, and these need to be prescribed by a doctor.

Codeine is often used for moderate pain. Codeine is broken down in the body into morphine. However, one in 10 people find they don't get any pain relief as they cannot convert codeine. If taking Panadeine® or Panadeine Forte® does not offer more relief than paracetamol, let your doctor know as you may need other opioids.

Strong opioids, such as morphine, oxycodone, hydromorphone, methadone and fentanyl, are often effective for moderate to severe pain, and can be used safely if taken as prescribed.

Commonly used opioids are listed in the table opposite. They either release the morphine slowly and control your pain for long periods, or release the morphine quickly to control pain for short periods.

Working out the dose

As people respond differently to opioids, the dose is worked out for each person based on their pain level. It's common to start at a low dose and build up gradually until the pain is well controlled. Sometimes this can be done more quickly in hospital or under strict medical supervision.

Opioids commonly used for moderate to severe pain

	Generic name	Brand name
Slow release	morphine	<ul style="list-style-type: none"> MS Contin® Kapanol® MS Mono®
	oxycodone	<ul style="list-style-type: none"> OxyContin® Targin®
	hydromorphone	<ul style="list-style-type: none"> Jurnista®
	tramadol	<ul style="list-style-type: none"> Tramal/Tramal® SR Zydol/Zydol™ SR
	fentanyl	<ul style="list-style-type: none"> Durogesic®
Immediate release	morphine	<ul style="list-style-type: none"> Ordine® Anamorph® Sevredol®
	oxycodone	<ul style="list-style-type: none"> OxyNorm® Endone® Proladone®
	hydromorphone	<ul style="list-style-type: none"> Dilaudid®
	fentanyl	<ul style="list-style-type: none"> Actiq®

Side effects of opioids

Opioids can affect people in different ways. It can take a few days to adjust to taking strong pain medicines. You may have some of the following side effects:

Constipation – Most people regularly taking opioid medicines experience trouble passing stools (constipation). Your treatment team will suggest or prescribe a suitable laxative to take at the same time as the pain-killers. You may also be given a stool softener. Other ways to help manage constipation include drinking 6–8 glasses of water a day, eating a high-fibre diet and getting some exercise, but these may be difficult if you're not feeling well.

Drowsiness – Feeling sleepy is typical, but this usually lasts for only a few days until the pain relief dose is stable. Tell your doctor or nurse if it lasts longer as you may have to change medicines. Alcohol is likely to increase drowsiness and is best avoided. See page 37 for concerns about driving.

Tiredness – Your body may feel physically tired, so you may need to ask family or friends to help you with household tasks or your other responsibilities. Rest is important, but it's also beneficial to do some light exercise or activity, such as stretches or going for a short stroll. This helps you maintain a level of independence and can give you some energy.

Feeling sick – This usually passes when you get used to the dose, or can be relieved with other medicines. Sometimes a change in the type of opioid is necessary.

Dry mouth – Opioids can reduce the amount of saliva in your mouth, which can cause tooth decay or other problems. Chewing gum or drinking plenty of liquids can help. Visit your dentist regularly to check your teeth and gums.

Itchy skin – If you have itchy skin, sometimes it may feel so irritating that it is painful. A moisturiser may help, or ask your doctor if there is an anti-itch medicine available or if you can try a different opioid for your pain.

Poor appetite – You may not feel like eating. Small, frequent meals or snacks and supplement drinks may help. If the loss in appetite is ongoing, see a dietitian for further suggestions.

Confusion or hallucinations – This is rare. It is important to tell your doctor immediately if this occurs.

Physical dependence – If you stop taking opioids suddenly, you will usually have withdrawal symptoms or a withdrawal response. This may include agitation, nausea, abdominal cramping, diarrhoea, heart palpitations and sweating. To manage the chance of side effects, your doctor will decrease your dose gradually to allow your body to adjust to the change in medicine. Don't reduce your dose or stop taking opioids without talking to your doctor first.

Talk to your health care team often about any side effects you're having. If needed, they can change your medicines or the doses.



Common questions about opioids

Most people have questions about taking opioid medicines. Some common questions that may come up are answered on the following pages. Your doctor, nurse practitioner or nurse can also discuss any concerns you have.

If you are caring for someone with cancer pain, you may have some other specific questions about opioids. For answers to carers' common questions, see pages 49–50.

Q: Will I become addicted to opioids?

A: No – when people take morphine or other opioids only to relieve pain, they are unlikely to become addicted to the medicines. However, after some time, the body gets used to opioids and if they are stopped suddenly, people may have withdrawal symptoms (see previous page). This means you have developed a tolerance, but it is not a sign of addiction.

Health professionals will closely monitor your use to maintain effective pain relief and avoid potential side effects. They will adjust the dose if necessary. However, a person who has already had a drug addiction problem may be at risk of addiction if opioids are used for cancer pain relief.



Taking opioids for pain relief is different to an addiction. Someone with a drug addiction problem takes drugs to satisfy physical or emotional needs, despite the drugs causing harm.

Q: Will I need to have injections?

A: Not necessarily. Strong pain relievers are usually given by mouth in either liquid or tablet form. If you're vomiting, opioids can be given via the rectum as a suppository, by a small injection under the skin (subcutaneously), using a skin patch or in lozenge form. See page 24 for a list of the different ways medicines are taken.

Opioids can be injected into a vein for short-term pain relief, such as after surgery. This is called intravenous opioid treatment and is given in hospital.

Q: If I start opioids too soon, will they be less effective later?

A: Some people try to avoid taking pain medicine thinking it is better to hold out for as long as possible so it works better later. However, this usually makes the situation worse because the pain perception of the brain and nervous system changes and pain becomes entrenched, needing more opioids. It is better to take medicine as prescribed rather than just at the time you feel the pain.

Q: If I'm given opioids, does that mean my cancer is advanced?

A: People with cancer at any stage can develop severe pain that needs to be managed with strong pain medicine, such as morphine. If you have a strong pain-killer, this doesn't mean you will always need to take it. If your pain improves, you may be able to take a milder pain-relieving drug.

Q: What if I get breakthrough pain?

A: While breakthrough pain is relatively common among people diagnosed with cancer, this sudden flare-up of pain can be distressing.

You might get breakthrough pain even though you're taking regular doses of medicine. This breakthrough pain may last only a few seconds, several minutes or hours. It can occur if you've been more active than usual or you've strained yourself. Sometimes there seems to be no reason for the extra pain.

You need to talk to your health care team who will advise you on how to cope with breakthrough pain. They will usually suggest you take your pain medicine as well as another drug to help with the breakthrough pain. An extra, or top-up, dose of a short-acting opioid (immediate release opioid) will be prescribed to treat the breakthrough pain. The dose works fairly quickly, in about 30–40 minutes.

It is helpful to keep a record of how many extra doses you need so your doctor can monitor your overall pain management. If you find your pain increases with some activities, taking an extra dose of medicine beforehand may help.

“ I have an intrathecal pump, which is filled every 10 days by a community nurse. I also take breakthrough medication, but some days I don't need any. You can never tell. The pain is mysterious. ” *Kate*

Q: Will the opioids still work if my body gets used to them?

A: People who have used opioids for a long time will sometimes become tolerant to the original dose. This means their doctor will need to increase the dose to achieve the same pain relief. Your dose of opioids may also be increased if your pain gets worse. There is no benefit in saving the pain control until the pain is severe.

Q: Can I drive while using opioids?

A: Doctors have a duty to advise patients not to drive if they are a risk to themselves or others. During the first days of treatment, you may be less alert, so driving is not recommended. Once the dose is stabilised, you may want to consider driving. Seek your doctor's advice and keep the following in mind:

- Don't drive if you're tired, you've been drinking alcohol, you are taking other medicine that makes you drowsy, or road conditions are bad.
- If you have a car accident while under the influence of a drug, your insurance company may not pay out a claim.
- Special rules and restrictions about driving apply to people with brain tumours, including secondary brain cancer, or people who have had seizures. For more information, talk to your doctor or download a copy of *Brain Tumours and Driving: A guide for patients and carers* from the Neurological Society of Australasia website, nsa.org.au/documents/item/47.

Q: Can I stop my medicine at any time?

A: You should only reduce your dose or stop taking opioids in consultation with your health care team. If your pain gets better, you may end up needing less or no pain medicine. Morphine and other opioids will need to be decreased gradually to avoid side effects that may occur if you were to stop taking them suddenly. Withdrawal side effects can include flu-like symptoms or nausea.

Other medicines

You may be prescribed other medicines to help relieve your pain. These are known as adjuvant drugs or adjuvant analgesics because they are prescribed with opioids. While they are not designed to control pain, they may be used for this purpose, and they often work well for nerve pain. Adjuvant drugs can be added during any stage of diagnosis and treatment.

The most common types of adjuvant drugs prescribed are antidepressants and anticonvulsants. See the table on the opposite page for a full list. These medicines are usually given as a tablet or an injection into a vein.

Some adjuvant drugs take a few days to work, so opioids are used to control the pain in the meantime. If you are taking an adjuvant drug, it may be possible for your doctor to lower the dose of the opioids. This may mean that you experience fewer side effects without losing control of the pain. Ask your doctor if the adjuvant drugs are likely to cause side effects.

Drug type (class)	Generic names	Type of pain
antidepressant	<ul style="list-style-type: none"> • amitriptyline • doxepin • nortriptyline • duloxetine 	burning nerve pain, peripheral neuropathy pain, electric shocks
anticonvulsant	<ul style="list-style-type: none"> • carbamazepine • valproate • gabapentin • pregabalin 	burning or shock-like nerve pain
anti-anxiety	<ul style="list-style-type: none"> • lorazepam • diazepam • clonazepam 	muscle spasms with severe pain
steroid	<ul style="list-style-type: none"> • prednisone • dexamethasone 	headaches caused by cancer in the brain, or pain from nerves or the liver
bisphosphonates	<ul style="list-style-type: none"> • pamidronate • clodronate • zoledronate 	bone pain (may also help prevent bone damage from cancer)
GABA (gamma-aminobutyric acid)	<ul style="list-style-type: none"> • baclofen 	muscle spasm, especially with spinal cord injury
human monoclonal antibodies	<ul style="list-style-type: none"> • denosumab 	bone pain (may also help prevent bone damage from cancer)
local anaesthetic*	<ul style="list-style-type: none"> • lignocaine 	severe nerve pain

**requires careful monitoring*



Key points

- Surgery, radiotherapy, chemotherapy and hormone therapy are used to relieve pain, usually by removing or shrinking the tumour, or by stopping its growth. For other types of pain, or while these treatments are taking effect, medicines are usually given.
- Take precautions when managing or storing your medicines to avoid potentially dangerous mix-ups.
- Pain relief can be mild, such as paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs), or strong, such as opioids.
- Opioids are generally used for pain that is hard to ignore or feels very severe. As a general guide, moderate pain may be a pain score of 4–6 (out of 10), and moderate to severe pain may be a score of 6–10.
- Medicines can be given in the form of a tablet, liquid, lozenge, skin patch, injection or suppository.
- Medicines may cause different side effects. Tell your doctor or nurse about the side effects you experience so they can help you manage them.
- Other medicines, such as antidepressants or steroids, may be given with opioids to make them work more effectively. These are called adjuvant drugs or adjuvant analgesics.
- Most people (and their families) have questions about taking pain medicines. Talk to your health care team about any concerns you have, such as addiction, driving or breakthrough pain.



When pain won't go away

Sometimes pain can be difficult to relieve completely with medicines. In these situations, your doctor may suggest you see a pain medicine specialist in a multidisciplinary pain clinic. They may recommend the following therapies.

Epidural or spinal medicines

Sometimes to control pain, morphine is used in such high doses that severe side effects can occur. However, delivering the morphine directly onto the nerves in the spine via a tube (catheter) causes fewer side effects. Other drugs can also be added to improve pain control. Spinal medicine can be given in a number of ways:

- **Tunnelled spinal catheter** – A small tube put in the space around the spinal cord and then tunnelled out to the body's surface through the skin. The tube is attached to an external syringe pump, which delivers the medicine (e.g. anaesthetic and/or opioid). Medicine may be delivered in a single dose, as a continuous infusion, or using a combination of these methods.
- **Port-a-cath spinal system** – The tunnelled catheter is attached to the skin of the chest or abdomen through an opening (port), which allows needles and bags of pain relief to be inserted. Usually a nurse needs to replace the bags every 1–2 days.
- **Tunnelled spinal catheter and pump** – The catheter is connected to a pump that is implanted in the fatty tissue of the abdominal area. The pump is refilled every three months with a needle through the skin into the pump's port.

Nerve block

Injecting a local anaesthetic into or around a nerve will stop that nerve from sending (transmitting) pain messages. This is called a nerve block, and the effect is temporary. There are different types of nerve blocks. Sometimes nerves to part of the bowel or pancreas can be blocked to provide pain relief, especially in pancreatic cancer. This is called a coeliac plexus block.

Other pain relief methods

Your specialist may suggest one or more of the following options:

- **intensive cognitive behaviour therapy (CBT)** – a talking therapy that guides people to change the way they cope with the pain and to resume normal activity as much as possible
- **desensitisation** – a psychological technique that involves focusing on the pain and relaxing at the same time; it is used for neuropathic pain (e.g. numbness or tingling)
- **specialised physiotherapy** – helps reprogram the brain (e.g. dealing with phantom limb pain after an amputation)
- **radiofrequency ablation (RFA)** – uses heat to destroy the nerves causing pain
- **neuromodulation treatments** – uses electrical pulses to change nerve activity; the pulses cause the body to release a substance that stops feelings of pain from nerve damage (e.g. after surgery, chemotherapy or radiotherapy, and for non-cancer causes)
- **surgery to the brain or spinal cord** – in rare cases, you may have neurosurgery to relieve pain.



Other ways to control pain

For many people, some types of pain can be relieved through allied health services or complementary therapists.

Allied health care

Various allied health professionals support the work of doctors and nurses. Practitioners are usually part of your hospital MDT, or your GP can refer you to private practitioners as part of a chronic disease management plan. See page 13 for a list of allied health care professionals and a description of their role.

Complementary therapies

Complementary therapies may help you cope better with pain and other side effects caused by cancer and its treatment. These therapies may increase your sense of control, decrease stress and anxiety, and improve your mood and quality of life. For a list of therapies used to reduce pain, see pages 44–45.

Let your doctor know about any complementary therapies you are using or thinking about trying. This is because some therapies may cause reactions or unwanted side effects depending on your conventional treatment and the pain medicines you are taking. You should also tell the complementary therapist about your diagnosis, as some therapies, such as massage and exercise, may need to be modified to accommodate the changes in your body.

For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Complementary Therapies*.

Complementary therapies used to reduce pain

relaxation	Helps release muscle tension. It can help you sleep, give you more energy, reduce your anxiety, and make other pain relief methods – such as medicine or a cold pack – work more effectively.
meditation	Focuses on breathing techniques and quietening the mind. There are different types. Mindful meditation encourages people to be more aware of their body, thoughts and surroundings. Visualisation uses your imagination to create pleasant thoughts to take the mind off the pain and give a more hopeful outlook.
massage	A relaxing therapy that may increase your sense of wellbeing. It helps relieve muscle spasms and contractions, and joint stiffness. Avoid massaging the area with cancer.
aromatherapy	The use of aromatic essential oils extracted from plants for healing relaxation. Mainly used during massage, but can also be used in baths, inhalations or vaporisers (oil burners).
imagery	Can be used to distract your mind from pain or worries, or make you feel more in control of what is happening to your body. It involves using your imagination to think of shapes, colours, sounds – anything that helps you feel like you are in a particular place.

hypnotherapy	This deep relaxation technique is used to help people become more aware of their inner thoughts. It has been clinically tested with good results for helping people cope with pain.
art therapy, music therapy and journal writing	These techniques give you the opportunity to express your feelings in different creative ways. The techniques also provide some distraction from the pain. You can be creative at home, or some hospitals and support groups offer professionally run programs.
TENS (transcutaneous electrical nerve stimulation)	A battery-powered machine that delivers a mild electric current to the skin. This produces a pleasant sensation and relieves some pain. Many physiotherapists offer this treatment.
cognitive behaviour therapy (CBT)	A type of talk therapy psychologists use to help people identify unhelpful thoughts and behaviours, and change how they respond to negative situations or emotions. It can help control anxiety and reactions to stress.
heat and cold	Heat may relieve sore muscles, while cold may numb the pain.
distraction	A simple technique of focusing on something other than the pain.



Making decisions

Sometimes it is difficult to decide on the type of treatment for pain relating to cancer, but once you do, it will improve quality of life for both you and your family members.

You may feel that there is a lot of information to think about and you may be unsure what the best option is for pain management, but there is always time to consider different treatments. Even if you don't want to take up an option immediately, you may be able to later on.

Understanding what causes pain, the suggested treatments and their side effects will help you make your own decisions. You have the right to accept or refuse any treatment offered.

Discuss your level of pain with your doctor and find out what kind of impact the treatments could have on your pain. If you are offered a choice of treatments, consider how severe your pain is compared with the side effects of the medicine or treatment. If you have a partner, you may want to discuss the treatment options together. You can also talk to family and friends.

“ If a patient has severe pain, they often need strong pain relief, such as opioids, to get on top of the pain quickly. Cancer treatment tackles the cause of the pain, but can take time to give complete relief. Cognitive behavioural therapy and other types of analgesics can be used with opioids too. ” *Palliative care specialist*

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

Before an appointment, it may help to write down your questions – see some suggested questions on page 52. Bringing your pain diary and your answers to the questions on page 15 will also help your health care team understand how you're feeling. If your doctors use medical terms you don't understand, it's okay to ask for a simpler explanation. You can also check a word's meaning in the glossary (see pages 53–55).

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of managing pain to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments for pain and led to better outcomes for people diagnosed with cancer. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research* or visit australiancancertrials.gov.au.



Seeking support

Coping with cancer and cancer pain isn't something you need to do alone. Many services are available that support people with cancer.

Financial support – Assistance, through benefits or pensions, can help pay for the cost of prescription medicines and for travel to medical appointments. Cancer Council provides emergency financial assistance to help cover the cost of bills but doesn't cover medicines. This is a one-off payment.

Emotional support – Several services can put you in touch with people who have been through a similar cancer experience and can understand the feelings and challenges that cancer brings up. Call Cancer Council 13 11 20 for more information about cancer support groups and Cancer Connect.

Practical support – If you are in a lot of pain, you may need help around the home, in the garden or with children. It may be hard to tell people what to do, so you might prefer to ask a relative or close friend to coordinate offers of help. Your local council may also have volunteers or community services available. Cancer Council also offers a practical support program that offers similar short-term help.

You may find that while some people you know are supportive, others may not even know what to say to you. You may think that people don't understand the pain you're in and the other emotions you're feeling. Cancer Council's booklet about emotions and cancer might be helpful. Call 13 11 20 for a free copy or visit your local Cancer Council website to download a pdf or digital copy.



Caring for someone in pain

Caring for someone who is in pain can be very difficult and stressful. It's natural to feel upset and helpless at times – it can be distressing to watch someone you love suffer.

This chapter answers some common questions carers might have. If you have other concerns, or would like a free copy of *Caring for Someone with Cancer*, call Cancer Council 13 11 20. You can also contact Carers Australia on 1800 242 636 for support.

Questions you may like to ask

Q: What if the person with cancer asks for more pain medicine?

A: Only the person with cancer can feel how much pain they are in. If you have been using a pain scale together, this can help you both communicate about the need for extra doses. The person with cancer may be experiencing breakthrough pain and may need a top-up dose. If this occurs regularly, they should see their doctor again for advice on managing it.

If you're still worried the person with cancer is taking or wanting to take too much medicine, talk with their doctor about the dose they can safely have and other ways to help manage the pain.

Q: Should I keep opioids locked up?

A: As with all medicines, it is necessary to keep opioids away from children, perhaps in a high cupboard. If a member of your household or a visitor has a drug-dependence problem, it is safest to keep the opioids in a secure place.

Q: Can someone taking opioids sign legal documents?

A: When someone signs a legal document, such as a will, they must have capacity. This means they're aware of what they are signing and fully understand the consequences of doing so.

If a person taking opioids becomes drowsy in the first few days of treatment, it makes sense to delay important decisions until the dose is stabilised and the side effects reduce. Ask your GP or specialist to assess whether the person with cancer is fit to sign a legal document or talk to a lawyer. If you don't do this, documents can be contested later.

Q: When should I call the medical team?

A: Call a doctor or nurse for advice if the person with cancer:

- becomes suddenly drowsy or confused
- hasn't had a bowel motion for four days or more
- is vomiting and cannot take the pain relief
- has severe pain despite top-up doses
- is having difficulty taking the medicine or getting the prescriptions filled
- experiences other symptoms that the treatment team has mentioned, such as hallucinations with particular drugs.

Q: What if they lose consciousness?

A: If the person with cancer becomes unconscious unexpectedly, call the doctor, nurse or 000 immediately. Do not give opioids to an unconscious or very drowsy person.



Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

Australian

- Cancer Council Australia.....**cancer.org.au**
- Cancer Australia..... **canceraustralia.gov.au**
- Cancer Pain Management in Adults..... **wiki.cancer.org.au/australia/Guidelines:Cancer_pain_management**
- Carers Australia.....**carersaustralia.com.au**
- CareSearch: palliative care knowledge network..... **caresearch.com.au**
- Chronic Pain Australia..... **chronicpinaustralia.org.au**
- healthdirect Australia..... **healthdirect.gov.au**
- NPS MedicineWise..... **nps.org.au**
- Pain Australia..... **painaustralia.org.au**
- Palliative Care Australia..... **palliativecare.org.au**

International

- American Cancer Society..... **cancer.org**
- Macmillan Cancer Support..... **macmillan.org.uk**
- The Johns Hopkins Comprehensive Cancer Center – Center for Cancer Pain Research..... **www.cancerpain.jhmi.edu**
- Cancer-Pain.org..... **cancer-pain.org**
- International Association for the Study of Pain..... **iasp-pain.org**



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your pain and its treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What is causing my pain?
- Is the pain likely to get better or worse?
- What treatments do you recommend and why?
- How long will they take to work?
- How often should I take my medicine?
- Should I take extra doses if I still get pain?
- Are there other options if the medicine doesn't work?
- What are the possible side effects of the medicine?
- How can the side effects be managed?
- Who will manage my prescriptions?
- Will the different medicines I'm taking interfere with each other?
- Will I be able to drive when I'm taking this medicine?
- Are there any precautions I need to take, such as not drinking alcohol?
- Will I get addicted to my pain medicine?
- How much will my medicine cost? Can I reduce the cost of it?
- Can you tell me about non-medicine treatments?
- Are there any complementary therapies that might help?
- Will I keep seeing you about my pain relief, or will I see my GP or palliative care team?
- Who can I contact in an emergency?
- Who can I contact if I have questions about my pain levels or my medicines when I am at home?



Glossary

acute pain

Pain that starts suddenly and may be mild or severe. It lasts for a short time, perhaps only days or weeks.

adjuvant analgesic

Pain relief that is given with or shortly after the primary treatment. Also known as adjuvant drugs.

advanced cancer

Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

analgesic

A medicine used to relieve pain.

brand name

The name given to a medicine by the manufacturer.

breakthrough pain

A brief and often severe pain that occurs even though a person is taking pain medicine regularly.

chemotherapy

The use of anti-cancer drugs to treat cancer or reduce pain by killing cancer cells or slowing their growth.

chronic pain

Pain that can range from mild to severe and lasts a long time, usually more than three months.

coeliac plexus block

Pain medicine that is injected into the nerves at the back of the abdomen to block pain.

cognitive behaviour therapy (CBT)

A common type of counselling that

aims to change a person's perception of pain and how they respond to it.

complementary therapies

Treatments used in conjunction with conventional treatment, which improve general health, wellbeing and quality of life, and help people cope with side effects of conventional treatment.

dependence

When stopping the drug causes physical withdrawal symptoms.

dose

The amount of medicine taken.

epidural

An injection of anaesthetic drugs into the spinal column.

frequency

How often medicine is taken.

generic name

The name given to a type of medicine based on its key (active) ingredient, for example, paracetamol.

hormone therapy

A treatment that blocks the body's natural hormones, which sometimes help cancer cells grow. It is used when the cancer is growing in response to hormones.

immediate release medicine

A medicine that releases quickly and lasts only 30 minutes.

intramuscular injection

An injection into a muscle.

intrathecal injection

An injection into the fluid-filled space that surrounds the spine.

intravenous (IV) injection

An injection into a vein using a needle.

local anaesthetic

A medicine that blocks the feeling of pain in a specific location in the body for a short time.

multidisciplinary team (MDT)

A team of health care professionals who collaborate to discuss a patient's physical and emotional needs and decide on treatment.

nerve block

Pain medicine that is injected directly into or around a nerve or into the spine to block pain.

neuropathic pain

Pain caused by pressure on nerves or the spinal cord, or by damage to nerves. Also called nerve pain.

non-prescription medicine

Available without a prescription, often from pharmacies and supermarkets, and includes over-the-counter medicines such as pain-killers and cold medicines, vitamin supplements and herbal remedies.

non-steroidal anti-inflammatory drug (NSAID)

A type of mild pain relief.

nurse practitioner

A nurse who is qualified to treat certain medical conditions without the direct supervision of a doctor.

opioids

The strongest pain relievers available. These include morphine, fentanyl, codeine, oxycodone, hydromorphone and methadone.

pain diary

A record of when pain is greatest during the day and the medicine used to relieve the pain.

pain medicine specialist

A medical specialist who treats difficult pain problems.

pain scale

A scale that helps the patient to show how mild or severe their pain is based on a range of numbers, descriptions or facial expressions.

palliative care

The holistic care of people who have a life-limiting illness, their families and carers. It aims to improve quality of life by addressing physical, practical, emotional and spiritual needs.

patient-controlled analgesic (PCA) system

An intravenous system that allows a person to administer a dose of pain relief by pressing a button.

phantom pain

Pain felt in a limb or body part even though it has been surgically removed.

prescription medicine

Medicine that can only be given (dispensed) by a pharmacist after receiving authority from a doctor.

radiotherapy

The use of radiation, usually x-rays

or gamma rays, to kill or injure cancer cells so they cannot grow and multiply.

rectum

The last 15–20 cm of the large bowel, which stores faeces until a bowel movement occurs.

referred pain

Pain that is felt away from the area that is actually causing the pain.

side effect

Unintended effect of a drug or treatment.

slow release medicine

A medicine that releases slowly and lasts 8–12 hours.

subcutaneous injection

An injection under the skin.

suppository

Medicine placed in the rectum (the last part of the large bowel).

syringe driver

A battery-operated pump that gives a continuous dose of a drug.

TENS (transcutaneous electrical nerve stimulation)

A technique that involves applying a mild electric current to the skin where the pain occurs.

tolerance

When the body no longer responds to a drug, so a higher dose is needed to get the same level of pain control.

withdrawal symptoms

A range of symptoms that occur when a drug is stopped suddenly.

References

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3. World Health Organization. *Cancer Pain Ladder for Adults*: www.who.int/cancer/palliative/painladder/en/ Accessed 26 September 2015.

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For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary



How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

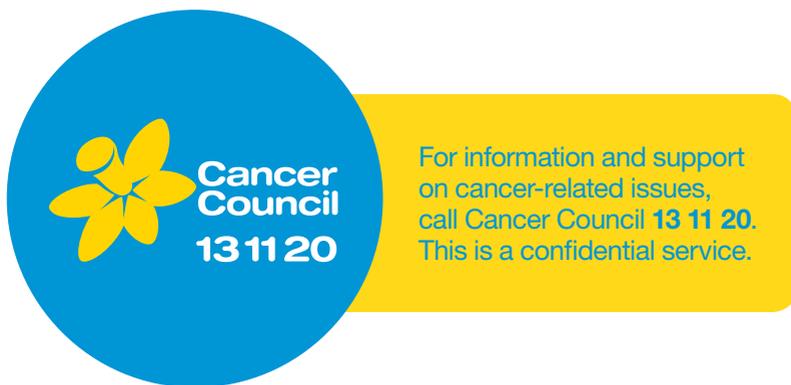
Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.



If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.
www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

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nt.cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*