Cancer Council

Overcoming Cancer Pain

A guide for people with cancer, their families and friends

Practical and support information

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13 11 20

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This booklet is funded through the generosity of the people of Australia.

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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About this booklet

This booklet has been prepared to help you understand more about cancer pain. People with cancer don't always have pain. However, some people may have pain – this can be caused by the cancer, its treatment, or other conditions unrelated to the cancer.

We cannot give advice about the best pain relief for you. You need to discuss this with your health professionals. However, we hope this booklet will help you understand what pain is and the different treatments used to manage it.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 54). You may also like to pass this booklet to family and friends for their information.

How this booklet was developed

This information was prepared by specialists working in pain management, oncology and palliative care. It reflects clinical practice guidelines[1] 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. You can also visit your local Cancer Council website (see back cover).

Cancer Council
13 11 20

Contents

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 people feel pain is influenced by emotional, environmental, behavioural 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 way you experience pain. Health professionals assess all these factors to help treat pain.

If left untreated, pain can lead to anxiety or depression, and prevent you from doing the things you want to do. 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 *Describing pain* on pages 13–15 for different ways to let health professionals know how you're feeling.

Q: Does everyone have cancer pain?

A: Cancer pain is a broad term for the different kinds of pain people may experience when they have cancer. Not everyone with cancer will have pain. Those who do experience pain may not be in pain all the time – it may come and go.

During treatment, about six out of ten people (55%) say they experience pain. People with advanced cancer are slightly more likely to experience pain (66%). After treatment, about one in three people (39%) say they experience pain.[2]

Q: What causes cancer pain?

A: People with cancer may have pain caused by the cancer itself or by cancer treatment. They may also have pain from other causes, such as arthritis. 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 surgery, radiation therapy, chemotherapy, targeted therapy or immunotherapy
- 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. This is a common concern when pain levels change.

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 how long the pain lasts.

Acute pain – Pain that starts suddenly and lasts a short time, possibly for a few 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 regular pain 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 illnesses. See page 35 for more information.

Nerve (neuropathic) pain – 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 as "pins and needles". Nerve damage to the hands and feet is called peripheral neuropathy.

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

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

Visceral pain – Pain caused by damage to or pressure on internal organs. This type of pain can be difficult to pinpoint. It may cause some people to feel sick in the stomach (nauseous).

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

Localised pain – Pain that 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. Phantom pain can be difficult to control with medicines, and other strategies often 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 physical cause of the pain itself, your emotions, thoughts, 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.

Fatigue

Extreme tiredness can make it harder for you to cope with pain. Lack of sleep can increase your pain. Ask your health care team for help if you are not sleeping well.

Environment

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

Emotions

You may worry or feel easily discouraged when in pain. Some people feel hopeless, helpless, embarrassed, angry, inadequate, irritable, anxious, frightened or frantic. You may notice your behaviour changes. Some people become more withdrawn and isolated.

Thoughts

How you think about pain can influence how you experience the pain, e.g. whether you see it as overwhelming or manageable.

Q: How is cancer pain treated?

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

- surgery, radiation therapy and drug therapies (see pages 17–18)
- medicines specifically for pain (see pages 19–37)
- interventions such as nerve blocks or spinal procedures such as epidurals (see pages 39–40)
- other treatments, such as physiotherapy, psychological interventions and complementary therapies (see pages 41–43)
- self-management strategies, such as pain management plans and goal setting (see pages 44 and 47).

Many people need a combination of treatments to achieve good pain control. It might take time to find the right pain relief for you, and you may need to continue taking pain medicines while waiting for some treatments to take effect.

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. 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]

Sometimes pain cannot be completely controlled. You may still feel some discomfort. However, your health professionals can help make you as comfortable as possible. If your pain persists, you can seek a second opinion or ask for a referral to a specialist pain management clinic.

Q: When can I use pain medicines?

A: You can use different types of pain medicines whenever you feel any level of pain. If you have pain, it's better to get 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 medicine to take (the dose) and how often (the frequency). The aim is for pain to be continuously controlled.

Many people believe that they should delay using pain medicines 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.

There is no need to save pain medicines until your pain is severe. Severe pain can cause anxiety and difficulty sleeping. These things can make the pain harder to control. See *Using pain medicines* on pages 19–26 for more information.

✓ If the pain doesn't improve the first time you use a new pain relief method, 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.

Q: Is palliative care the same as pain management?

A: To “palliate” means to relieve. Palliative care aims to relieve symptoms of cancer without trying to cure the disease. Pain management is only one aspect of palliative care. The palliative care team may include doctors, nurses, physiotherapists, social workers, occupational therapists, psychologists and spiritual care practitioners. They work together to:

- maintain your quality of life by relieving physical symptoms
- support your practical, emotional, spiritual and social needs
- provide support to families and carers
- help you feel in control of your situation and make decisions about your treatment and ongoing care.

Your cancer specialist or nurse can put you in touch with a palliative care team for treatment in hospital or at home. This type of care can improve quality of life from the time of diagnosis, and can be given alongside other cancer treatments.
› See our *Understanding Palliative Care* booklet.

Q: Who helps manage my pain?

A: Different health professionals work together to help manage your pain. Some of these professionals are listed on the next page. They will often discuss treatment options at a multidisciplinary team (MDT) meeting. If your pain is not well controlled, you may want to ask your GP or palliative care specialist for a referral to a pain medicine specialist who is experienced in cancer pain and part of a multidisciplinary pain clinic.

Health professionals you may see

general practitioner (GP)	assists with treatment decisions; provides ongoing care in partnership with specialists
surgeon*	surgically removes tumours from the body
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
medical oncologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
palliative care specialist*	treats pain and other symptoms to maximise wellbeing and improve quality of life
pain medicine specialist*	treats all types of pain, particularly acute pain during active treatment, ongoing pain after treatment, or pain that is difficult to control
nurse	administers drugs and provides care, information and support
nurse practitioner	works in an advanced nursing role; may prescribe some medicines and tests
pharmacist	dispenses medicines and gives advice about dosage and side effects
physiotherapist	helps with restoring movement and mobility, and preventing further injury
psychologist	helps you identify the thoughts, emotions and behaviours that affect your pain; provides psychological methods of pain management
counsellor, social worker	help you with emotional, practical or financial issues

** Specialist doctor*

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

Thinking about 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?
- Is your pain constant? If not, how often does it occur? How long does the pain last each time it occurs? (Try timing the pain.)
- Do you have any flare-ups of pain?
- 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 improves?
- How does the pain make you feel emotionally?
- What relieves your pain? What makes it worse?
- What pain relief methods have you tried? What helped or didn't help?
- Did you have any side effects from pain medicines?
- 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

Using a pain scale or keeping a pain diary can help you describe your pain and how it is affecting you. 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 rates the pain from none or mild through to moderate or severe	**Number scale** rates the pain from 1–10; the higher the number, the worse the pain	**Activity tolerance scale** rates how much the pain affects what you can do, e.g. walking or carrying things
no pain	0, 1	no pain
mild pain	2	can be ignored
moderate pain	3, 4	interferes with tasks
moderate pain	5, 6	interferes with concentration
severe pain	7, 8	interferes with basic needs
worst pain possible	9, 10	bed rest required

Make a note of triggers

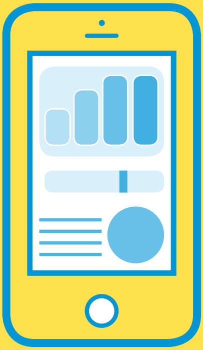
Write down what seems to cause your pain. This is called a trigger, and it may be a specific activity or situation. Knowing what triggers your pain might help you to prevent or relieve it.

Keep a 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.

When to seek help

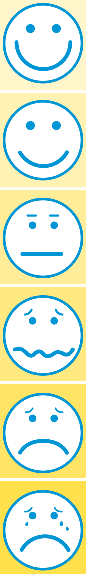
Talk to your doctors about what should prompt you to call and who to call, particularly if it's after hours. For example, you may be instructed to call if you need to take four or more doses of breakthrough pain relief, or if you are feeling very sick or sleepy.



Keep a pain diary

A written record of your pain can help you and those caring for you understand more about your pain and how it can be managed. Note down how the pain feels at different times of the day, what you have tried for relief and how it has worked. Some people track their pain using an app on a mobile device, such as a smartphone or tablet.

Facial scale uses facial expressions to show how the pain makes you feel



Key points about pain

Types of pain

- Pain may be caused by the cancer itself or as a side effect of treatment.
- 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 usually lasts for more than three months.

Who helps manage pain

- A multidisciplinary team (MDT) of health professionals work together to help you manage cancer pain.
- A palliative care team works to improve a person’s quality of life by easing cancer symptoms, including pain.
- Pain teams in hospitals work along with the palliative care and oncology teams to help manage acute pain.
- A pain medicine specialist can help if your pain is not well controlled or your pain persists after active treatment is finished.

Tools to describe pain

- Explaining how the pain feels can help your doctor work out the cause of the pain.
- A pain scale can help you describe how bad the pain is to your health care team.
- A pain diary can help you keep track of your pain, how long it lasts, and any triggers.

Cancer treatments for pain relief

Cancer treatments such as surgery, chemotherapy or radiation therapy can reduce pain by helping to remove its cause. Cancer treatment aimed at relieving pain, rather than curing the disease, is called palliation or palliative treatment.

Depending on the cancer, and the location and nature of the 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 from the body. This may be a major, invasive operation or a relatively minor procedure. Surgery can help relieve or improve pain caused by tumours pressing on nerves or obstructing organs.

Examples include unblocking the bile duct to relieve jaundice, which can occur with pancreatic cancer, or removing a bowel obstruction, which can occur with ovarian or bowel cancer.
› See our *Understanding Surgery* booklet.

Radiation therapy

Also known as radiotherapy, this treatment uses a controlled dose of radiation, usually in the form of x-ray beams, to kill or damage cancer cells so they cannot grow, multiply or spread. This will cause tumours to shrink and stop causing discomfort. For example, radiation therapy can relieve pain if cancer has spread to the bones, or headaches if cancer has increased the pressure in the brain.

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

› See our *Understanding Radiation Therapy* booklet.

Drug therapies

Drug therapies may be used for an extended period of time to control the cancer's growth and stop it spreading. The drugs reach cancer cells throughout the body. This is called systemic treatment, and includes:

- **chemotherapy –** the use of drugs to kill or slow the growth of cancer cells
- **hormone therapy –** the use of synthetic hormones to stop the body's natural hormones from helping some cancers to grow
- **targeted therapy –** the use of drugs to attack specific molecules within cells that make cancer grow and spread
- **immunotherapy –** treatment that triggers the body's own immune system to fight cancer.

In some cases, drug therapies can shrink tumours that are causing pain, such as a tumour on the spine that cannot be operated on. By shrinking a cancer that is causing pain and other symptoms, drug therapies can improve quality of life.

In other cases, drug therapies can reduce inflammation and relieve symptoms of advanced cancer, such as bone pain. They can also be used as maintenance treatment to try to prevent the cancer coming back.

› See our *Understanding Chemotherapy* booklet, and *Understanding Targeted Therapy* and *Understanding Immunotherapy* fact sheets.

Using pain medicines

Medicines that relieve pain are called analgesics (also known as pain medicines, painkillers and pain relievers). These drugs 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. Your medical team will also balance the expected pain relief against possible side effects and their impact on your quality of life.

Levels of pain control

There are different types and strengths of pain medicines suitable for different levels of pain (see page 14 for pain scales).

Mild

- Suitable for pain less than 3 on the pain scale.
- Examples include paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs).
- See pages 27–28 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 29 for more information.

Severe

- Prescribed when pain is higher than 6 on the pain scale.
- Examples include strong opioids, e.g. morphine, fentanyl.
- See pages 29–37 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 – they may need to adjust the dose or prescribe a different medicine.

Give your medicines time to work

Different pain medicines take different amounts of time to work. How long each one takes depends 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 used for constant 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. Also known as sustained release medicines.

Immediate release medicines – release the active ingredient quickly, usually in less than 30 minutes. They are used 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

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.

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 30.

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

Allied health services – These offer therapies, such as physiotherapy techniques, exercises and psychological therapies, to help people manage their pain (see pages 41–42).

Complementary therapies – These are therapies that can be used alongside conventional medical treatments to improve your quality of life and wellbeing (see pages 42–43).

Keep track of medicines

There are different ways to help ensure you take the correct dose of medicine at the right time.

Medicine packs – You can ask your pharmacist to organise your tablets and capsules into a blister pack (e.g. Webster-pak) that sets out all the doses that need to be taken throughout the week, along with a description of each drug.

Medicines list – This records what you need to take, when to take it, how much to take and what each medicine is for. You can:

- create your own list on paper or on a computer
- order a printed NPS MedicineWise list to keep in your wallet or handbag at nps.org.au/order
- download the MedicineWise app from the App Store or Google Play onto your smartphone. You can scan the barcode on packaging to add a medicine to the app and set up alarms for taking the medicine.

Discuss your pain medicines with family and friends

Family members, carers and friends sometimes have opinions about the pain relief you're having. Your family members may feel anxious about your use of strong pain medicines. This may be because they are worried that you will become addicted (see page 33).

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 carers 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. It is usually swallowed with water.
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, into a muscle or under the skin.
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 portable pump. This can be given over many hours or days.
intravenous infusion	Medicine is slowly injected into a vein over many hours or days using a small plastic tube and pump. You press a button on the pump 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 is delivered into the fluid surrounding the spinal cord. This is commonly used to treat the most severe cancer pain.
suppository	A pellet is put into the bottom (rectum). The pellet breaks down and the medicine is absorbed by the body. This may be suitable if you have nausea or trouble swallowing.

Using medicines safely

All medicines may have side effects, particularly if they are not taken as directed. 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. Some medicines may react with each other, causing them to stop working properly or creating harmful 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 pain medicines without any harmful effects. However, if they contain paracetamol or anti-inflammatories this counts towards your total daily intake (see page 28), and you may need to take a lower dose of standalone pain medicine.

- 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. Aspirin may also cause minor cuts 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 and 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.

Tips for using pain medicines safely

- Ask your doctor 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 possible interactions with other medicines, vitamins or herbal and natural remedies.
- Follow the directions and only take the recommended dose. This will reduce the risk of misuse or accidental overdose.
- Keep medicines in their original packaging so you and other people always know what they're for. Or ask your pharmacist to put your tablets and capsules into a labelled blister pack (see page 22).
- Store medicines in a safe place that is out of reach of children.
- Take precautions when managing or storing your medicines to avoid potentially dangerous mix-ups.
- Remind yourself when to take your medicines by writing a note, or setting an alarm or reminder on your phone.
- Talk to your GP about having a pharmacist carry out a home medicines review. This can help ensure you take all your medicines safely.
- Check the expiry dates of medicines. If they are near or past their expiry, see your doctor for a new prescription.
- Take expired medicines or any that are no longer needed to the pharmacy for safe disposal.
- Check with your health care team whether it's safe to take complementary therapies, such as nutritional supplements, with your pain medicine.
- Find out more about your medicines by calling the NPS MedicineWise Medicines Line on **1300 633 424**.
- Let your health care team know of any side effects. Call the Adverse Medicine Events Line on **1300 134 237** if you suspect you've had a reaction to any kind of medicine. If you need urgent assistance, call **000** or go to a hospital emergency department**.**

Travelling with medicines

It's possible to take prescription medicines overseas for your own personal use, but it's best to follow the Australian government's recommendations. As these may change from time to time, check the current recommendations and restrictions before you travel at homeaffairs.gov.au/travelsecure.

A reasonable amount of medicine and medical equipment is allowed under powder, liquid, aerosol and gel restrictions in carry-on baggage. Have any medicines you need during the flight ready for screening at the airport. Pack the rest of your medicines in your checked baggage.

To help you prepare for travelling with medicines:

- ask your doctor if you need to change your medicine schedule to allow for time differences and if there are limits on the amount of medicines you can take overseas
- check with the embassies of the countries you're visiting and with the travel advice at smarttraveller.gov.au to make sure your medicine is legal there
- 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
- carry a letter from your doctor outlining each medicine, how much you'll be taking, and any equipment such as hypodermic needles or gel packs, 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
- call the Travelling with PBS Medicines Enquiry Line on 1800 500 147 for more information.

Treating mild pain

Medicines used to control mild pain include paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs). They are often available over the counter from pharmacies without a prescription. 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 in 24 hours (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 stronger pain medicines contain paracetamol in combination with another drug, and count towards your total intake. If taken within the recommended dose, paracetamol is unlikely to cause side effects. In some cases, your doctor will recommend you take paracetamol with other pain medicines, such as oxycodone, to help 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 now wish I had taken something sooner.” *Bill*

Non-steroidal anti-inflammatory drugs

Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen, naproxen, celecoxib, diclofenac and aspirin, vary in dose, frequency of dose and side effects. They are known by various brand names, such as Advil and Nurofen. You can have these medicines as a tablet or sometimes as an injection. Less commonly, NSAIDs are given as a suppository – a capsule inserted into the bottom (rectum).

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. If you are taking NSAIDs in high doses or for a long time, it's generally recommended you take them 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 paracetamol.

Listen to a discussion about "Managing Cancer Pain" at **cancercouncil.com.au/podcasts**. This podcast episode includes some practical pain relief strategies.

Treating moderate to severe pain

Opioids are commonly used when pain is hard to ignore or feels very severe. These drugs need to be prescribed by a doctor. Opioids are not effective for all types of pain. For instance, moderate to severe nerve pain is treated with other types of medicine (see pages 37–38).

Opioids

Opioids are medicines obtained from the opium poppy or created in a laboratory. They work on opioid receptors in the brain and spinal cord to reduce pain. There are many different types of opioids.

Codeine is often used for short periods to manage moderate pain. It is not recommended for long-term or palliative use because it causes constipation (see page 31). In most cases, codeine is broken down in the body into morphine. However, one in ten people find they don't get any pain relief as they cannot convert codeine into morphine.

Codeine is often available in combination with other pain medicines, such as paracetamol (e.g. Panadeine Forte) or ibuprofen (e.g Nurofen Plus). If taking one of these stronger combination pain medicines does not offer more relief, let your doctor know as you may need other opioids or a different type of analgesic.

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 on page 30. They either release the opioid slowly to control your pain for long periods, or release it 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 (long-acting)	fentanyl	Durogesic
	hydromorphone	Jurnista
	morphine	MS Contin Kapanol MS Mono
	oxycodone	OxyContin Targin
	tramadol	Tramal SR Durotram XR Zydol SR
	tapentadol	Palexia SR
Immediate release (short-acting)	morphine	Anamorph Ordine Sevredol
	oxycodone	Endone OxyNorm Proladone
	hydromorphone	Dilaudid
	fentanyl	Actiq
	tramadol	Tramal

Side effects of opioids

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

Breathing problems – Opioids can cause breathing problems. To help your body adapt to the effects of opioids on breathing, you will usually start on a low dose and gradually increase the amount. Your doctor may advise you not to drink alcohol or take sleeping tablets while you are on opioids.

Constipation – Most people who regularly take opioid medicines experience difficulty passing bowel motions (constipation). Your treatment team will suggest or prescribe a suitable laxative to take at the same time as the pain medicines. 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 things may be difficult if you're not feeling well.

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.

Drowsiness – Feeling sleepy is typical, but this usually lasts for only a few days until the pain medicine 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. Your doctor may advise you not to drive – see page 36 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, such as stretches or a short walk. This helps you maintain a level of independence and can give you some energy.

Feeling sick (nausea) – 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.

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 of 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 lower 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.

Your health care team will closely monitor your use of opioids to maintain effective pain relief and avoid potential side effects. Let them know about any side effects you have. They will change the medicine if necessary.

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 common questions from carers, see pages 51–52.

Will I become addicted to opioids?

When people take morphine or other opioids only to relieve acute pain or for palliative care, they are unlikely to become addicted to the medicines. You may experience withdrawal symptoms (see opposite page) when you stop taking a drug, but this is not addiction. For this reason, your doctor will reduce your dose gradually. Talk to your doctor if you are concerned about drug dependence.

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. A small number of people who take opioids long-term for pain relief are at risk of becoming addicted. The risk is higher for people who have misused medicines in the past.

Will I need to have injections?

Not necessarily. Strong pain relievers are usually given by mouth in either liquid or tablet form. If you're vomiting, opioids can be given as a suppository inserted into the bottom, by a small injection under the skin (subcutaneously), through a skin patch or in lozenge form. See page 23 for a list of the different ways medicines are taken.

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

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

Some people try to avoid taking pain medicine until the pain is severe, thinking it is better to hold out for as long as possible so the medicine works better later. However, this may change the way the central nervous system processes the pain, causing people to experience pain long after the cause of the pain is gone. It is better to take medicine as prescribed rather than just at the time you feel the pain.

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

People with cancer at any stage can develop severe pain that needs to be managed with strong pain medicine, such as morphine. Just because you have to use an opioid, it doesn't mean you will always need to take it.

If your pain improves, you may be able to take a milder painkiller or you may be able to stop taking pain medicines.

What if I get breakthrough pain?

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 have been more active than usual or have strained yourself. Other causes of breakthrough pain include anxiety or illnesses such as a cold or urinary tract infection. 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) may 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 found the decision to take morphine really difficult. Having made it, I have been taking the slow release tablets for 18 months with no appreciable side effects. Without the morphine the pain would be too debilitating for me to continue doing all the things I do now.” *Pete*

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

People who have used opioids for a long time will sometimes become tolerant to the original dose. This means that the body stops responding to the drug, and their doctor will need to increase the dose to achieve the same level of pain control. Your dose of opioids may also be increased if your pain gets worse. There is no benefit in saving pain medicines until the pain is severe.

Can I drive while using opioids?

Doctors have a duty to advise patients not to drive if they are a risk to themselves or others. While taking opioids, particularly during the first days of treatment, you may be less alert, so driving is not recommended. Once the dose is stabilised, you may think that it is safe for you to drive, however, using breakthrough pain medicine can affect your driving ability.

Before you start driving again, seek your doctor's advice and keep the following in mind:

- Don't drive if you're tired, you've been drinking alcohol, you're taking other medicine that makes you sleepy, or road conditions are bad.
- It is against the law to drive if your ability to drive safely is influenced by a drug. Also, 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 the publication, *Assessing Fitness to Drive for commercial and private vehicle drivers*, from austroads.com.au.

Can I stop my medicine at any time?

You should only reduce your dose or stop taking opioids in consultation with your health care team. If your pain improves, 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. See page 32 for information about withdrawal side effects.

Other medicines

You may be prescribed other medicines to help relieve your pain, e.g. antidepressants and anticonvulsants. While they are not designed to control pain, they may be used for this purpose, and they often work well for nerve pain. See the table on the next page for a full list.

These medicines are usually given as a tablet you swallow. They can be used on their own or with opioids at any stage of diagnosis and treatment. When prescribed with opioids, these drugs are known as adjuvant drugs or adjuvant analgesics.

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.

Your doctor will talk to you about any potential side effects before you start taking a new drug. See also *Tips for using pain medicines safely*, page 25.

Other drugs used to treat pain

Drug type (class)	Generic names	Type of pain
antidepressant	• amitriptyline • doxepin • duloxetine • nortriptyline • venlafaxine	burning nerve pain, peripheral neuropathy pain, electric shocks
anticonvulsant	• gabapentin • pregabalin	burning or shock-like nerve pain
anti-anxiety	• diazepam • clonazepam • lorazepam	muscle spasms with severe pain
steroid	• dexamethasone • prednisone	headaches caused by cancer in the brain, or pain from nerves or the liver
bisphosphonates	• clodronate • pamidronate • zoledronic acid	bone pain (may also help prevent bone damage from cancer)
GABA (gamma-aminobutyric acid) agonist	• baclofen	muscle spasm, especially with spinal cord injury
monoclonal antibodies	• denosumab	bone pain (may also help prevent bone damage from cancer)
local anaesthetic*	• lidocaine	severe nerve pain

** Requires careful monitoring*

Other ways to control pain

Sometimes cancer-related pain can be difficult to relieve completely with medicines, or you may need to stop taking a pain medicine because of its side effects. It is important to let your health care team know if you have pain. Uncontrolled pain may lead to depression, relationship difficulties and inability to return to work.

Your doctor may suggest you see a pain management specialist in a multidisciplinary pain clinic. The specialist can recommend a range of pain-relieving therapies and help you create a pain management plan to restore your ability to function.

Medical treatments

These techniques can be temporary or longer lasting and range from simple options such as nerve blocks to more complex procedures such as implanted pumps. They are not suitable for everyone, but can be particularly useful for treating nerve pain or pain that is difficult to control. Your pain specialist will talk to you about the risks and benefits of each procedure they recommend.

Nerve block – A nerve block uses an injection of local anaesthetic to numb the nerve sending the pain signals. Sometimes an x-ray or ultrasound machine is used to help guide the needle. In most cases, the effect lasts for a few hours but it sometimes lasts for days. A nerve block is generally used to provide short-term pain relief or to help diagnose which nerve is sending the pain signals.

Radiofrequency ablation (RFA) – This procedure can be used after a nerve block to provide longer-lasting pain relief. A pulsed RFA aims to re-educate the pain nerve to lessen the pain signal. It may take up to two months to take effect. A thermal RFA uses heat to damage the nerve.

Epidural – An injection of local anaesthetic and sometimes other pain medicines near the nerves in the back. An epidural is given in hospital and the pain relief can last for up to two weeks. An epidural can also be used to see if a spinal procedure (see below) is likely to help.

Spinal catheter with port or pump – If longer-term pain control is needed, a small tube (epidural catheter) may be placed a little deeper in the back. This is connected to an opening (port), which allows pain medicine to be dripped in continuously. If pain is likely to last longer than six months, the catheter is attached to a pump implanted under the skin of the abdomen (known as an intrathecal pump). This pump is refilled about every three months with pain medicine. The pump can be adjusted to provide a suitable amount of relief for your pain.

Spinal cord stimulator – This is a long-lasting procedure to treat nerve pain problems. An electrical device is placed into the spine. It causes tingling against the nerves in the back or neck, which reduces the amount of pain felt. The procedure is done in two phases, with an initial trial phase to assess the benefit. If pain relief is above 60%, the device is permanently implanted.

> “I have an intrathecal pump, which is filled 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*

Allied health services

Allied health professionals, such as physiotherapists, psychologists and exercise physiologists, support the work of doctors and nurses. Practitioners are usually part of your hospital multidisciplinary team (MDT), or your GP can refer you to private practitioners. They can teach you techniques for managing your physical activity, thoughts and emotions to help improve your pain management.

Exercise techniques – A physiotherapist or exercise physiologist can develop a program to improve muscle strength and increase the ability to function, which may help relieve pain.

Specialised physiotherapy – This can help reprogram the brain (e.g. to manage phantom limb pain after an amputation).

Transcutaneous electrical nerve stimulation (TENS) – TENS delivers electrical pulses to the skin to change nerve activity and relieve pain. Many physiotherapists offer this treatment.

Talk therapies – Psychological therapies such as cognitive behaviour therapy, acceptance and commitment therapy, and mindfulness-based cognitive therapy can help people understand how their thoughts and emotions can influence how they respond to pain. This can help them build new coping skills and resume normal activity as much as possible.

Desensitisation – This psychological technique involves focusing on the pain and relaxing at the same time; it is used for neuropathic pain (e.g. numbness or tingling).

Hypnotherapy – This psychological technique helps people relax and become more aware of their inner thoughts. It has been clinically tested with good results for helping people cope with pain.

Distraction techniques – These help people temporarily focus on something other than the pain, e.g. by counting, drawing, reading.

Complementary therapies

Complementary therapies may help you cope better with pain and other side effects caused by cancer and its treatment. These therapies are used alongside conventional treatments. They may increase your sense of control, decrease anxiety, and improve your quality of life.

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

› See our *Understanding Complementary Therapies* booklet.

Alternative therapies are used instead of conventional medical treatments. They are unlikely to be scientifically tested and may prevent successful treatment of cancer-related pain. Cancer Council does not recommend the use of alternative therapies for cancer-related pain.

Complementary therapies used to manage pain

acupuncture	Uses fine, sterile needles placed under the skin into energy channels (called meridians) to stimulate energy flow.
aromatherapy	Uses 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).
creative therapies (art therapy, music therapy, journal writing)	Help you express your feelings in creative ways. The techniques also provide some distraction from the pain. You can be creative at home, or attend a program at some hospitals and support groups.
heat and cold	Uses heat to relieve sore muscles, and cold to numb the pain.
massage	Releases both muscular and emotional tension, and may increase your sense of wellbeing. It helps relieve muscle spasms and contractions, and joint stiffness. Avoid massaging the area with cancer.
mindfulness meditation	Focuses on breathing techniques and quietening the mind. It encourages people to be more aware of their body, thoughts and surroundings. It can help you change the way you think about experiences.
relaxation	Helps release muscle tension, and reduce anxiety and depression. 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.

Ways to manage ongoing pain after treatment

Improvements in diagnosing and treating cancer have led to an increase in the number of people surviving cancer. After treatment for cancer, some people will have ongoing pain. This is known as chronic pain and it can be treated in a variety of ways:

- Discuss your pain with your doctor so you can develop a pain management control plan.
- A multidisciplinary pain clinic can help minimise pain, restore function and return you to your normal activities.
- Mild painkillers (see pages 27–28) may be used. Opioids such as codeine and morphine have been shown not to work very well to control chronic pain.
- Being actively involved in managing your pain has been shown to help reduce pain. Learning how pain works can help you think about the pain differently and increase your confidence to do daily activities.
- Psychological therapies can change how you respond to pain (see pages 41–42).
- Some complementary therapies may help, especially those that require your active participation (see pages 42–43).
- If pain is interfering with daily activities, set yourself some achievable goals. Gradually increase your activity – e.g. if it hurts to walk, start with walking to the front gate, then to the corner, and then to the bus stop up the road.
- Movement is very important: daily stretching and walking can help you deal with the pain. It is important to pace activities throughout the day, including rest and stretch breaks.
- Mindful movement combines relaxation, mindfulness and movement. It provides a way to change pathways in the body and brain that have become overactive due to pain.
- Relaxation techniques may improve the effectiveness of other pain relief methods and help you sleep. Call **13 11 20** for a free copy of our relaxation and meditation recordings, or find them on our website.

Key points about pain relief

How pain is relieved	• Surgery, radiation therapy and drug therapies are used to relieve pain, usually by removing or shrinking the tumour, or stopping its growth. • Pain medicines are commonly used. Pain relief can be mild, such as paracetamol, or strong, such as opioids. • Other medicines, such as antidepressants or steroids, may also be given to help treat pain.
Using pain medicines	• Pain medicines can be given in a variety of ways, e.g. tablets, liquids, skin patches. • You may have side effects from pain medicines, but these can often be managed. • Keep track of your medicines to ensure you use them safely.
Using opioids	• Opioids need to be prescribed by a doctor. They are commonly used to treat strong pain. • It can take a few days to adjust to taking opioids and you may have some side effects. Your doctor may give you medicines to help prevent these side effects.
Other ways to control pain	• Medicine may be delivered directly into the spine or a nerve to improve pain control. • Allied health professionals can teach you techniques for managing your physical activity, thoughts and emotions to help improve your pain management. • Complementary therapies can help you cope better with pain and other side effects.

Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have for cancer-related pain. You may feel that there is a lot of information to think about, and you may be unsure about the best form of pain management. Ask your treatment team to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding what causes the pain, the suggested treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Even if you don't want to take up an option immediately, you may be able to later on. Discuss your level of pain with your doctor and find out what kind of impact the treatments could have on the pain.

Record the details – When your doctor talks with you about your treatment options, you may not remember everything you are told. Taking notes or recording the discussion may help. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – Before an appointment, it may help to write down your questions – see page 53 for some suggestions. Bringing your pain diary and your answers to the questions on page 13 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 the glossary (see pages 54–55).

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. If you are offered a choice of treatments, consider how severe your pain is compared with the

side effects of the medicine or treatment. Consider the impact of the treatment on your quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.
› See our *Cancer Care and Your Rights* booklet.

Make a pain management plan – Once you know your treatment options, talk with your treatment team about making a pain management plan. This is a written document setting out your prescribed therapies, possible side effects, and ways to manage them. It should also include advice about when and who to call if you have problems. Make sure you have a copy of the plan to take home with you and to show to all your health care providers. You can download a pain management plan template and other self-management resources from wiki.cancer.org.au/australia/Guidelines:Cancer_pain_management.

Should I join a clinical trial?

Your doctor or nurse may suggest that 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit **australiancancertrials.gov.au**.
› See our *Understanding Clinical Trials and Research* booklet.

Seeking support

Cancer-related pain can affect every aspect of your life. It can cause stress and anxiety, create practical and financial issues, and prevent you from doing the things you want to do. There are many sources of support to help you, your family and carers cope with cancer-related pain, including:

- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20. The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

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.

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.

› See our *Emotions and Cancer* booklet.

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).

Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.

Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit **cancercouncil.com.au/OC**.

Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian	
Cancer Council Australia	**cancer.org.au**
Cancer Australia	**canceraustralia.gov.au**
Cancer Council Online Community	**cancercouncil.com.au/OC**
Carer Gateway	**carergateway.gov.au**
Carers Australia	**carersaustralia.com.au**
Department of Health	**health.gov.au**
Healthdirect Australia	**healthdirect.gov.au**
Australian Pain Management Association	**painmanagement.org.au**
Chronic Pain Australia	**chronicpainaustralia.org.au**
NPS MedicineWise	**nps.org.au**
Palliative Care Australia	**palliativecare.org.au**
Pain Australia	**painaustralia.org.au**
The Australian Pain Society	**apsoc.org.au**
The Thing About Cancer	**cancercouncil.com.au/podcasts**
International	
American Cancer Society	**cancer.org**
Cancer Research UK	**cancerresearchuk.org**
Macmillan Cancer Support (UK)	**macmillan.org.uk**
International Association for the Study of Pain	**iasp-pain.org**

Caring for someone in pain

You may be reading this booklet because you are caring for someone with cancer-related 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. To find out more about carers' services, call Cancer Council 13 11 20. You can also get support and advice from Carers Australia (call 1800 242 636 or visit carersaustralia.com.au) or find services through the Carer Gateway (call 1800 422 737 or visit carergateway.gov.au).
› See our *Caring for Someone with Cancer* booklet.

Questions you may like to ask

What if they ask for more pain medicine?

Only the person with cancer can know how much pain they feel. 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.

Should I keep opioids locked up?

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.

Can a person taking opioids sign legal documents?

When someone signs a legal document, such as a will, they must have capacity. This means they must be aware of what they are signing and fully understand the consequences of doing so. If they lack capacity, the documents can be contested later.

If a person's ability to reason is affected by taking opioids, it makes sense to delay important decisions until the impairment has passed. Ask your GP or specialist to assess whether the person with cancer is fit to sign a legal document or talk to a lawyer about this before the document is signed.

When should I call the medical team?

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

- becomes suddenly sleepy or confused
- hasn't had a bowel motion for three 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 prescriptions filled
- experiences other symptoms that the treatment team has mentioned, such as hallucinations with particular drugs.

What if they lose consciousness?

If the person with cancer becomes unconscious suddenly, call 000 immediately. Do not give opioids to an unconscious or very drowsy person.

Question checklist

Asking your doctor questions about your pain and its treatment will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What is causing my pain?
- Is the pain likely to get better or worse?

Treatment

- What treatments do you recommend? What is the aim of each treatment?
- 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?
- Can you tell me about non-medicine treatments?
- Are there any complementary therapies that might help?

Side effects

- What are the risks and possible side effects of each treatment?
- How can the side effects be managed?
- 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?

Practical concerns

- Who will manage my prescriptions?
- How much will my medicine cost? Can I reduce the cost of it?
- 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 when I am at home?
- How can I record my pain levels and any breakthrough pain?

Glossary

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

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

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.

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

complementary therapy
Any of a range of therapies used alongside conventional treatment to improve general health, wellbeing and quality of life.

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.

immediate release medicine
A medicine that releases quickly and lasts only 30 minutes.

intravenous (IV)
Injected into a vein.

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

multidisciplinary pain clinic
A clinic with a team of pain specialists and allied health professionals specialising in the treatment of chronic pain.

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. Includes some painkillers, cold medicines, vitamins and herbal remedies.

non-steroidal anti-inflammatory drug (NSAID)
A type of mild pain relief.

opioids
The strongest pain medicines available. They include codeine, morphine, fentanyl, oxycodone and methadone.

pain diary
A record of when pain is greatest 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 maintain quality of life by addressing physical, practical, emotional, spiritual and social needs.

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.

rectum
The last 15–20 cm of the large bowel, just above the anus.

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. Also known as sustained release medicine.

suppository
Medicine placed in the bottom (rectum).

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

Can’t find a word here?

For more cancer-related words, visit:

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

References

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2. MH van den Beuken-van Everdingen et al., “Update on prevalence of pain in patients with cancer: systematic review and meta-analysis”, *Journal of Pain and Symptom Management*, vol. 51, no. 6, 2016, pp. 1070–90.
3. World Health Organization, *Cancer Pain Ladder for Adults*. Available from: who.int/cancer/palliative/painladder/en [accessed 2 May 2018].

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 other Pink events, 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).

Interpreter

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, you can contact us through the National Relay Service. www.relayservice.gov.au

OVERCOMING CANCER PAIN

Cancer Council
13 11 20

For information and support
on cancer-related issues,
call Cancer Council **13 11 20.**
This is a confidential service.

Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

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

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