



Understanding Palliative Care

A guide for people with cancer,
their families and friends



Treatment

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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About this booklet

This booklet has been prepared to help you understand more about palliative care (sometimes called supportive care). Although palliative care is for anyone with a life-limiting illness, this booklet has been written specifically for people affected by advanced cancer.

The aim of palliative care is to improve your quality of life and help you stay independent for as long as possible. It may be beneficial for people at any stage of advanced cancer – it is not just for end of life.

Palliative care is managed in various ways throughout Australia and is tailored to each individual's needs. This booklet offers general information about palliative care. Talk to your health care team about the best approach for your situation (see page 48 for some questions).

If you find reading about palliative care distressing, read what seems useful now and leave the rest until you're ready. You may also like to pass this booklet to family and friends.

How this booklet was developed

This information was developed with help from Palliative Care Australia, health professionals, and people affected by cancer.

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**

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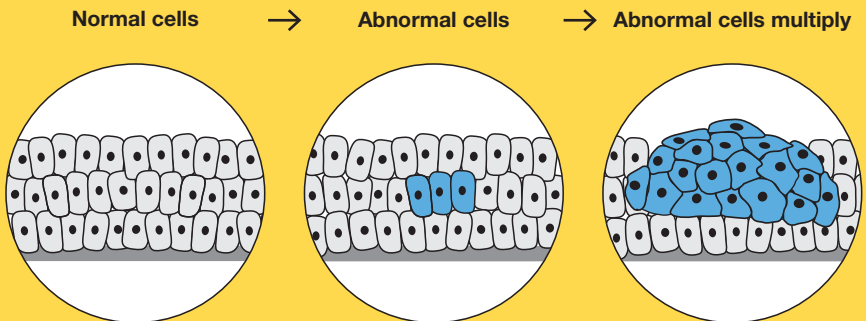
What is advanced cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. It occurs when abnormal cells divide and multiply in an uncontrolled way. There are many types of cancer and each type develops differently. Some grow slowly, some advance rapidly, and others behave unpredictably. Some types of cancer respond well to treatment, while other types are more difficult to treat.

Advanced cancer is a term used to describe cancer that is unlikely to be cured. It may be primary or secondary cancer.

The cancer that first develops in an organ or tissue is known as the primary cancer. It is considered locally advanced if the tumour is very large or the cancer has spread to nearby tissues. If cancer cells from the

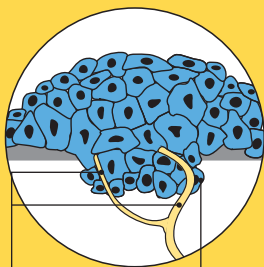
How cancer starts



primary site break away and travel through the bloodstream or lymph vessels to other parts of the body, they can grow and form another tumour at a new site. This is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, bowel cancer that has spread to the liver is still called metastatic bowel cancer, even though the main symptoms may be coming from the liver.

Although medical treatments may not be able to cure advanced cancer, they may be able to slow its growth or spread, sometimes for months or even years. Palliative care can also help manage cancer symptoms, which may include pain, and can reduce side effects from cancer treatments. Other palliative care services (see page 7) can improve quality of life at any stage of advanced cancer.

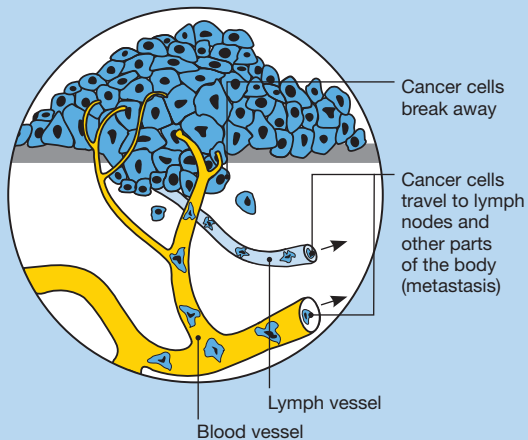
→ **Malignant cancer**



Grows own blood vessels (angiogenesis)

Invades surrounding tissue

How cancer spreads



Cancer cells break away

Cancer cells travel to lymph nodes and other parts of the body (metastasis)

Lymph vessel

Blood vessel



The role of palliative care

You may be reading this booklet because you or someone you know has advanced cancer. The cancer care team may have suggested palliative care, or you may be wondering if palliative care could help.

Palliative care is person-centred care that helps people with a progressive, life-limiting illness to live as fully and comfortably as possible. The main goal is to help you maintain your quality of life by identifying and addressing your physical, emotional, cultural, social and spiritual needs. This type of care can help from the time of diagnosis, and can be given alongside other cancer treatments. Palliative care also offers support to families and carers.

Palliative care providers

Palliative care is an approach to care that may be delivered by any of your care providers, from doctors, nurses and allied health professionals, to volunteers and carers. Together these people make up your palliative care team (see pages 19–23).

Specialist palliative care services see people with more complex needs, and also provide advice to other health care professionals. These specialist services can be accessed through many public and private hospitals, palliative care units, and community-based palliative care providers. Not everyone needs specialist palliative care.

Depending on what services are available in your area, you and your family can choose where you want to receive palliative care. This may be at your home or residential aged care facility, in a hospital or specialist palliative care unit (see page 16).



Person-centred care responds to your needs, preferences and values, as well as the needs of your family and carers. It means that your health care provider will respect your care goals, and involve you in decisions about your treatment and ongoing care.

Services provided

Palliative care involves a range of services that will be tailored to your individual needs. Services may include:

- relief of pain, breathlessness, nausea and other symptoms
- help organising equipment for home (e.g. wheelchairs, special beds)
- assistance for families and carers to talk about sensitive issues
- links to other services such as home help and financial support
- support for people to meet cultural obligations
- counselling, grief and bereavement support
- support for emotional, social and spiritual concerns
- referrals to respite care services.

The palliative care team will work with you and your family to identify your care needs and care wishes, and may record these in a care plan. This plan will outline your care goals and how they will be met, as well as how any symptoms will be managed, and who to contact for help.

A care plan is not a fixed document – it should be reviewed regularly as your care needs change. It is important for your key family members or carers to be involved in any discussions about your care plan, especially if they are providing most of your day-to-day care.

How palliative care works

Palliative care addresses the needs of people with a life-limiting illness in a holistic way. It provides individualised care to improve your quality of life and make the time you have as valuable as it can be for you and your family.



When to start

Palliative care is useful at all stages of advanced cancer and can be provided alongside active treatment for cancer. Starting palliative treatment from the time of diagnosis can help improve your quality of life.



Person with cancer

The palliative care team will work in partnership with you to assess your care needs and make decisions about treatment and ongoing care. Your care goals may change over time.

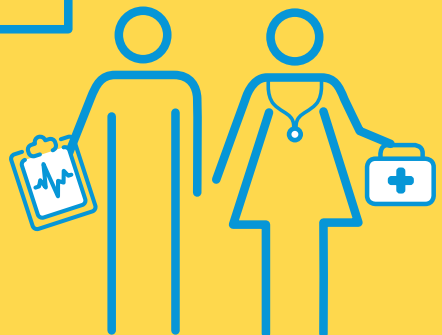
Care settings

The palliative care team will help you work out the best place for your care. This may be at home supported by community palliative care services, in hospital, at a residential aged care facility or in a palliative care unit (hospice).



Care providers

Your care may be led by your general practitioner (GP) or community nurse, or by specialist palliative care providers. They will be supported by a team of people with different skills to help you with a range of issues (see pages 19–23).



Family and carers

With your agreement, the palliative care team will involve your family and carers in decisions about care, and provide them with emotional support, including access to counselling and grief support.



Equipment

If you want to remain at home, team members can help identify equipment and services to help you with your daily activities and make it easier for carers to look after you.



Support services

Team members will help you work out how to live your days in the most satisfying way you can – this might mean enjoying time with family and friends, recording your memories or reflecting on your life. They can also refer you to organisations and services that can assist with financial, emotional and practical needs.

Advance care planning

The team will encourage and support you to think about, discuss and record your values, goals and preferences for future care and treatment (see pages 25–26).



Symptom relief

Palliative treatment can help you manage any symptoms, such as pain, shortness of breath or fatigue (see pages 28–34).





Key questions

Q: Does palliative care mean I will die soon?

A: Palliative care aims to maintain quality of life for people with a life-limiting illness. It is about living in a way that is meaningful to you, within the constraints of your illness. It's not simply about dying. One reason that some people don't access palliative care services early – or at all – is because they fear that it means they have given up hope or are going to die soon. This is certainly not the case for everyone referred to palliative care.

Depending on your needs, you may use palliative care services occasionally or you may use them continuously for a few weeks or months. The number of people receiving palliative care for several years is increasing. This is because improved cancer treatments can sometimes stop or slow the spread of advanced disease and relieve side effects for a number of years, and the cancer may be considered a chronic (long-lasting) disease. You can have palliative care while still having active treatment for the cancer. There is no need to wait until the end of life.

The reality is that some people do die from cancer. As people draw closer to death, the end-of-life aspect of palliative care becomes important.

“ There is still a life to be lived and pleasures to be found and disappointments to be had. Living with advanced cancer is a different life, not just a journey towards death. ” *Julie*

Q: How can palliative care help?

- A:** The palliative care team is there to help make life easier for you, your family and carers in a variety of ways, including:
- If you're living at home, the team can call or visit regularly. This can reduce feelings of isolation and fear, help your carers look after you, and keep you out of hospital (if that is your wish).
 - The team can help dispel any myths and misconceptions about advanced cancer you or your family and carers have.
 - Your care is usually coordinated by one person who communicates with the team on your behalf.
 - The team can help you to make treatment decisions and to prepare for the changes that lie ahead.
 - Adjustments around the house can make things easier and safer for you, your family and carers. The team can suggest suitable equipment and aids (e.g. a shower chair).
 - The team can assist you with planning for the future, such as thinking about the type of care you may need and where you would prefer to receive care.
 - Your palliative care service may offer a number you can call for advice in an emergency at any time of day or night.
 - The team can provide emotional support – a social worker, counsellor or psychologist can help you work out your goals and how to achieve them. These goals may be specific end-of-life wishes, but can also simply involve getting the most out of each day (e.g. enjoying time with friends and family).
 - The social worker or counsellor can help you and your family deal with loss or grief. Counselling can be worthwhile to help you deal with the changes advanced cancer brings.

Q: Can I still have cancer treatment?

A: You can still have active treatment to shrink or stop the cancer growing while receiving palliative care. The palliative care team will work with your cancer specialists to manage side effects from treatment and help maintain your quality of life. Cancer treatments such as surgery, chemotherapy, immunotherapy, targeted therapy and radiation therapy may also be used as part of palliative treatment. In this case, the aim is not to control the cancer but to relieve symptoms (see pages 28–35).

Q: Does palliative care shorten or lengthen life?

A: Palliative care sees death and dying as a normal part of life. It does not try to shorten life, nor does it try to make life longer. Instead, the palliative care team provides services to improve your quality of life. This may include managing pain and other symptoms. Some studies show that if symptoms, such as pain, are controlled, people will feel better and may live longer.

It is important to understand the difference between palliative care and euthanasia or voluntary assisted dying. Euthanasia is the act of deliberately ending the life of a person with an incurable condition or illness. Voluntary assisted dying is when a person ends their own life with the help of a doctor. Palliative care, however, does not attempt to hasten death.

At the time of publication (May 2019), euthanasia and voluntary assisted dying are illegal in Australia. Voluntary assisted

dying for people who meet strict criteria will become legal in Victoria from 19 June 2019 (for more information, visit health.vic.gov.au and search for “voluntary assisted dying”). Although the laws in some other states and territories are under review (visit end-of-life.qut.edu.au for updates), euthanasia and voluntary assisted dying are not part of palliative care.

The coordinated medical and support services of palliative care can help maintain comfort and quality of life throughout the advanced stages of illness. If you urgently need to talk to somebody because you are thinking about ending your life, call Lifeline on 13 11 14 for free, confidential telephone counselling.

Finding hope

Some people avoid palliative care because they hope that a cure will be found for their cancer. However, palliative care does not mean giving up hope. You may find that you focus your hopes on the things that are most important to you, e.g. feeling valued, having meaningful relationships or receiving effective pain relief.

People with advanced cancer may have palliative care for several months or years and continue to enjoy many aspects

of life in that time. Some take pleasure in completing projects, spending time with friends, or exploring new hobbies. Others make sense of their situation through a creative activity, such as writing, music or art.

As the disease progresses, goals may change. For example, you might hope to live as comfortably as you can for as long as possible or you may have some unfinished business to complete. Palliative care can help you achieve this.

Q: When can I start palliative care?

A: Once you know the cancer is advanced and likely to shorten your life, it is a good idea to start exploring the services that can be provided by palliative care. Talk to your cancer care team about a referral to palliative care. You can find out what the different team members do and which services might be relevant now or in the future.

Sorting out care sooner rather than later will reduce stress on you and your family. It will give you time to better understand and manage any physical symptoms (such as pain or nausea), and to consider your practical, emotional and spiritual needs.

Some people live comfortably for months or years after a diagnosis of advanced cancer, and can be supported by palliative care services as needed throughout this time. For others, the cancer advances quickly so that their care is focused on end-of-life needs soon after their referral to a palliative care service. Whatever stage you're at, your palliative care team will work with you to continually assess your changing needs and adjust your care.

“ I only found out about palliative care a few years ago. For me, this made such a positive difference – I now have equipment such as a walking frame, wheelchair, shower seat and toilet seat. My palliative care nurses visit me at home twice a week. ” Agnes

Q: Who will coordinate my care?

A: In most cases, a GP or community nurse will coordinate your palliative care. If your care needs increase beyond their area of expertise, they will seek advice from a specialist palliative care service, but you may not see the palliative care specialist yourself.

If you have more complex health needs, such as symptoms that are difficult to control, your care may be coordinated by a specialist palliative care service. You will usually see a palliative care specialist, or sometimes a nurse practitioner, as an outpatient. You may also need to stay in hospital for short periods to have your medicine adjusted or get your pain under control.

The specialist palliative care service will continue to consult your cancer care team about your treatment. If your condition stabilises or improves, you may not need to see the specialist palliative care service for periods of time or you may be discharged from palliative care.

Q: Will I lose my independence?

A: Your palliative care team will discuss ways you can remain independent for as long as possible. For example, they may suggest modifications or services to help you stay at home (such as installing a ramp so you don't have to use steps), or recommend equipment to help conserve your energy (such as a walking frame). For many people, maintaining control over day-to-day decisions is important – the team will respect your wishes if you don't want to take up their suggestions.

Q: Where will I receive palliative care?

A: You can have palliative care in different places depending on your situation, where you live, and whether you have family or friends who can help. In many cases, you and your family can choose where you want to receive palliative care. This may be at home, at a residential aged care facility or other out-of-home facility, or it may be in a hospital or specialist palliative care unit (hospice). People receiving palliative care often move between these places as their needs change.

An important role for the palliative care team is to assess the best place for your care. Many people prefer to receive care at home. The team will respect your wishes where possible. They will consider your home environment, your support networks, and what organisations and individuals are available in your area to help you, and then discuss the possibilities with you, your family and carers.

If you are cared for at home, you (and anyone who cares for you) can be supported by community-based palliative care services. You can decide at any stage to change your mind about staying at home and explore other options.

Depending on your situation, it may not always be possible to stay at home, even with home help. Hospitals and palliative care units are designed for short-term stays. If you cannot return home and require care for several months or more, the palliative care team will talk to you and your carers about options for your ongoing care, such as a residential aged care facility.


Q: Do I have to pay for palliative care?

A: The federal, state and territory governments fund a range of palliative care services that are free in the public health system, whether you receive care at home or as an inpatient.

However, sometimes you may need to contribute to the costs of care. Some examples of additional costs are:

- hiring specialised equipment for use at home
- paying for medicines
- paying for your own nursing staff if you choose to stay at home and require 24-hour assistance
- paying an excess if you have health insurance that covers palliative care and you go to a private hospital
- using respite services that charge a fee
- paying the fee of a private allied health professional, such as a psychologist, that isn't fully covered by Medicare
- paying for complementary therapies, such as massage therapy and acupuncture.

For more specific information, contact your state or territory palliative care organisation. For contact details, call Cancer Council 13 11 20 or visit palliativecare.org.au/members.



If you are admitted to a public hospital, palliative care unit or other facility as a private patient and you have private health insurance, contact your health fund to check what is covered. Talk to your social worker about what financial assistance is available for patients and carers from Centrelink and other organisations in your area.



Anna's story

My husband had been having treatment for lung cancer for around eight months when he got very ill, very quickly.

When the oncologist and nurses started talking about palliative care I was terrified...I wasn't ready for my husband to die.

It is so important that someone knowledgeable about palliative care explains what it is. Our cancer care team sat with us and talked about how palliative care could make my husband's life easier and more meaningful.

We received support in many different ways, from palliative chemotherapy in hospital, to help with modifying our home so that my husband could remain as independent as possible.

The palliative care team provided me with education on medicines, nutrition and so on, so that my husband improved and we did the one thing he wanted to do – go on a family holiday with our two boys. If I hadn't had this support, we wouldn't have got there.

Often it was the little practical suggestions that were the most helpful – such as getting extra prescriptions and a letter from my doctor to explain why I was travelling with so many strong medicines, or getting a foam wedge to help my husband sleep.

I found it so useful to have someone talk to me about what was going to happen, and to know that help was available when I needed it.

I hadn't realised that people could go in and out of palliative care as they needed it. We used palliative care services for around six months. Sometimes this was in hospital and sometimes it was at home with support from a community-based palliative care service, but there were times we didn't need it. It was only in the last days of care that we moved into the end-of-life stage.

Palliative care gave us time for my husband to talk to family and friends. I now think of palliative care as quality of life care for someone with a terminal illness.



The palliative care team

Your palliative care team will be made up of medical, nursing and allied health professionals who offer a range of services to assist you, your family and carers throughout your illness. Volunteers can also offer practical and emotional support, and may sometimes form an important part of your team.

Depending on your needs, your palliative care may be coordinated by your GP or a community nurse, or you may be referred to a specialist palliative care service. These services consist of a multidisciplinary team of doctors, nurses and allied health professionals specifically trained to look after people with complex health care issues. Your cancer care team will remain involved and will work with the palliative care providers at all stages of the illness.

You will have regular appointments or visits with the health professionals in your team so they can monitor your progress and adjust your care. The most common team members are listed in this chapter. You won't necessarily see all these people – some roles overlap and assistance varies across Australia. Your GP, nurse or palliative care specialist can help you work out which services will benefit you most.

If you have cultural or religious beliefs about dying, death and bereavement, or particular family customs, let your palliative care team know. They can then incorporate these into your care plan where possible.

●● We had a palliative care nurse visit every day. He was excellent and became like a friend. ●● *Linda*

Possible members of the palliative care team

General practitioner (GP) or family doctor	Nurse	Palliative care specialist or physician
<ul style="list-style-type: none"> • continues to see you for day-to-day health care issues if you are being cared for at home (and may be able to make home visits) • liaises with your nurse and/or palliative care specialist about the coordination of your ongoing care • can refer you to a palliative care specialist for help with more complex needs • can organise your admission to hospital or a palliative care unit (hospice) if your circumstances change • offers support to you, your family and carers • can provide referrals for counselling, including bereavement counselling for family and carers, if necessary 	<ul style="list-style-type: none"> • may be a community nurse, a specialist palliative care nurse or a palliative care nurse practitioner • may work for a hospital, community nursing service, residential aged care facility or specialist palliative care service • if you are being cared for at home, will visit you in your home and may provide after hours telephone support • coordinates other health professionals in the team and works out what care you need, including home nursing or personal care assistance • helps you manage pain and other symptoms with medicines and other treatments, and by suggesting practical strategies • a nurse practitioner can prescribe some medicines, order tests and make referrals to other health professionals 	<ul style="list-style-type: none"> • prescribes or recommends treatment for pain, nausea, constipation, anxiety, depression, breathlessness or any other symptoms you may have • usually provides care in a palliative care unit (hospice) or hospital (both for inpatients or people attending an outpatient clinic), but may also be able to visit you in your home or residential aged care facility • communicates with and advises the cancer specialist and your GP so your treatment is well coordinated • may refer you and your family to a grief counsellor, psychologist or other support person • assists with decision-making about care and treatment choices

Cancer specialist	Counsellor or psychologist	Spiritual care practitioner
<ul style="list-style-type: none"> • may be a medical oncologist, surgeon, radiation oncologist or haematologist • diagnoses the advanced cancer and may refer you to a specialist palliative care team • continues to oversee treatment aimed at managing symptoms of the cancer (such as surgery, chemotherapy, immunotherapy, targeted therapy or radiation therapy) • may manage some aspects of your palliative care 	<ul style="list-style-type: none"> • trained in listening and counselling • allows you to talk about any fears, worries or conflicting emotions • helps you identify and talk about feelings of loss or grief • assists you and your family to communicate and to explore relationship or emotional issues • might suggest strategies for lessening the distress, anxiety or sadness you and others are feeling • helps you to explore the issues you are facing so you can find more pleasure in your life • may teach meditation or relaxation exercises to help ease physical and emotional pain • provides bereavement care and support to your family and carers 	<ul style="list-style-type: none"> • may also be known as a spiritual adviser or pastoral carer • supports you and your family in talking about spiritual matters • reflects with you about your life and, if you choose, may help you search for its meaning • helps you to feel hopeful and develop ways to enjoy your life despite the illness • may organise special prayer services and religious rituals for you, if appropriate • connects you with other members of your faith • may discuss emotional issues, as many are trained counsellors

Possible members of the palliative care team (continued)

Social worker	Physiotherapist	Occupational therapist
<ul style="list-style-type: none"> • assesses what sort of support you, your family and carers need, and identifies ways you can receive this support • provides information and referrals for legal matters, financial support, home respite care, meal services, parking schemes, personal alarms, laundry services and aged care services • helps you communicate with your family and health professionals, including about changes to your care goals • discusses ways of coping and how to emotionally support your children, grandchildren or other dependents • may provide counselling and emotional support, including working through feelings of loss and grief • in some cases, may help arrange care for dependents or pets 	<ul style="list-style-type: none"> • helps to keep you moving and functioning as well as you can • assists with pain relief techniques, such as positioning your body in a better way, using hot and cold packs, and stimulating certain nerves in your body • shows you how to exercise to reduce pain and stiffness and increase mobility and energy • uses manual techniques to help clear congestion from your lungs and teaches you breathing exercises to better manage breathlessness • may work with a massage therapist to relieve stiff and sore muscles or swelling, or a podiatrist to treat any foot conditions 	<ul style="list-style-type: none"> • identifies ways to help you manage the physical aspects of your daily activities, such as walking, bathing, and getting into and out of bed and chairs safely • advises you on physical aids to improve your mobility and maintain your independence, such as a walking frame or a device to help you put on your socks • organises equipment hire or modifications to your house for a safer, more accessible environment (e.g. hand rails, shower chair) • teaches carers and family members the best ways to move you or help you sit and stand • assists you to prioritise your daily activities and conserve your energy so that you can achieve the things that are important to you

Pharmacist	Dietitian	Volunteer
<ul style="list-style-type: none"> • gives you access to prescription and over-the-counter medicines to take at home • can 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 • provides information about how to safely take medicines and possible side effects or interactions with other drugs • communicates with the prescribing doctor if necessary • helps you manage symptoms so you can achieve the best possible quality of life • assists you or your carer with keeping track of medicines, including the costs on the Pharmaceutical Benefits Scheme (PBS) 	<ul style="list-style-type: none"> • works out the best eating plan for you and your family • helps you choose suitable food and nutritional supplements • tries to resolve any digestive issues, such as poor appetite, nausea or constipation • may work with a speech pathologist, who can assess and help you deal with problems swallowing food and drinks 	<ul style="list-style-type: none"> • offers friendship, support and companionship • provides practical assistance, e.g. taking you shopping or to appointments, giving your carer a break, minding children, or doing basic jobs around the house • can be most helpful if you give them specific tasks so that they don't have to guess what you need • roles will vary, depending on the organisation they volunteer for • may be found through a palliative care service – these volunteers are screened, trained and supervised • can also be found through your state or territory palliative care organisation • can be a friend, family member or neighbour – although you may feel embarrassed about asking for help, you will probably find that many people want to do something for you



Looking ahead

Prognosis

Prognosis means the expected outcome of a disease. Some people with advanced cancer want to know whether and when they are likely to die; others don't wish to know. If you are referred to palliative care, it does usually mean that at some stage the cancer will shorten your life.

No-one can tell you exactly when you are going to die. Your doctors may be able to give a general indication of your life expectancy, based on an average patient, but everyone is unique and responds differently to treatment. If you ask for an estimate of the time you have left to live, your doctor will probably talk in terms of days to weeks, weeks to months, or months to many months. The actual time could be shorter or longer. Your team will work with you to ensure that you receive the best care to meet your changing needs.

Some families and carers want to know the prognosis even when you don't. Let the palliative care team know your preferences and whether they can talk to your family or carer when you're not there.

Dealing with death is difficult and confronting for most people and their families, whatever their cultural background or religious beliefs. Talking about any emotions you are experiencing may help you come to terms with your situation (see page 42).

Feeling low or depressed is common after a diagnosis of advanced cancer. Consider sharing your thoughts with family and friends or speaking confidentially to a trained counsellor, social worker, psychologist or spiritual adviser.

➤ See our *Emotions and Cancer* and *Facing End of Life* booklets.

Advance care planning

When faced with a life-limiting illness, some people think about what they'd like to achieve in the time they have left. Palliative care teams are experienced with helping patients and their families talk about their goals and preferences for care, and the amount of treatment they want for the cancer. This can involve difficult discussions about balancing the quality and length of life.

This process is called advance care planning. While it may be confronting, many people also find this process empowering. It can be started at any stage, whether you are feeling well or ill. It enables you to convey your preferences for your future health care if you become unable to communicate your wishes.

You and your family may find it very useful to start thinking about these issues before they are raised by a health professional. What matters to you most? Would you choose to have less time if it means feeling relatively well, or would you want as much time as possible even if treatment would lead to unpleasant side effects? Everyone has their own individual preferences and these will often change as your circumstances change.



Advance care planning doesn't mean you have given up or will die soon. Your needs might change over time and it is a good idea to regularly review your plan. Palliative Care Australia has developed a discussion starter that can help you reflect on your preferences for care and talk about them with your family, carers and close friends. See dyingtotalk.org.au/discussion-starter.

Advance care directive

You can write down your wishes for your future medical care in what is known as an advance care directive. Depending on where you live, it may be called an advanced personal plan or advance health directive, and it is sometimes known as a “living will”. This document provides a record of your values and treatment preferences for doctors, family, carers and substitute decision-makers to consider if you become unable to communicate or make decisions. You can revise or cancel your advance care directive at any time. Ask your doctor or hospital to place your directive on your medical record. You can also save it online at myhealthrecord.gov.au.

Substitute decision-maker

You can legally appoint someone to make decisions for you if at some point in the future you're not able to make them yourself. This can include decisions about your finances, property, medical care and lifestyle. A substitute decision-maker should be someone you trust and who understands your values and wishes for future care. Depending on where you live, the documents for appointing this person may be known as an enduring power of attorney, enduring power of guardianship, or appointment of enduring guardian or medical treatment decision-maker.



Each state or territory has different laws about advance care planning. For more information about completing, changing or cancelling an advance care plan, call the Advance Care Planning Advisory Service on **1300 208 582**, or visit advancecareplanning.org.au.



Pat's story

I was first diagnosed with bowel cancer two years ago. I had a year of intensive treatment and thought I was in remission, but then a PET scan revealed advanced cancer.

The oncologist recommended another seven months of chemotherapy treatment. The treatment is palliative – it is trying to stop the cancer spreading further.

My main worry was transport: “How will I get to hospital for all these appointments?” My husband is 89 and can drive only in the local area. Our children are all working and I wanted to lessen the impact on them.

The local community care service put me in touch with a volunteer palliative care group. The volunteers are marvellous. They drive me to all my appointments, but also offer mentoring, comfort and friendship. I also got some help with house cleaning, which has taken such a burden off me and my husband.

I've used many of the hospital services as well. My oncologist arranged a meeting with the counsellor. The social worker gave me practical advice, and the occupational therapist modified our home to suit my illness. My spiritual needs are met by the chaplain, and I know the palliative care coordinator will be there to help me.

With all these palliative care services, I feel like I have a window of time to get my house in order. I want my transition to be easy for my family.

I've taught my children how to live, and now I'm teaching them how to die. Strangely, it's an experience I wouldn't have missed – it's brought so many beautiful people into my life and renewed my faith that kindness and love are at the core of all humanity.

I'd like people with advanced cancer to know that there are a myriad of services. You only have to ask; you are not alone.



Palliative treatment

Medical treatment is a key part of palliative care. It aims to manage the physical and emotional symptoms of cancer without trying to cure the disease. There is no single program of palliative treatment. The treatment you are offered will be tailored to your individual needs and will depend on the type of cancer you have, how far it has spread, your symptoms, and the amount of support you have. Some examples of palliative medical treatment are:

- radiation therapy to reduce pain (e.g. if cancer has spread to the bones or a tumour is pressing on nerves or organs)
- chemotherapy or targeted therapy to stop the cancer growing into other organs
- surgery to reduce tumours causing pain or other symptoms
- medicines to control symptoms and relieve discomfort.

The table opposite describes cancer treatments that can be used palliatively. If you are having these treatments, you may experience side effects, such as nausea or fatigue. Let your palliative care team know about any side effects so they can be managed.

Making treatment decisions

You have the right to say no to any treatment offered, but your medical team need to be confident that you understand the nature of the treatment proposed and the possible consequences of not having it. You do not have to accept treatments on an all-or-nothing basis – you can refuse some and accept others. Treatments for advanced cancer can cause significant side effects, and some people choose not to have active treatment for the cancer but to focus on controlling their symptoms to reduce pain and discomfort.

➤ See our *Living with Advanced Cancer* booklet.

Types of palliative cancer treatments

surgery	<p>Surgery can be used to:</p> <ul style="list-style-type: none">• remove tumours from affected areas, such as the bowel or lymph nodes• relieve discomfort caused by tumours blocking organs or pressing on nerves• improve outcomes from chemotherapy and radiation therapy by reducing tumour size• insert a thin tube (stent) into a blocked organ to create a passage for substances to pass through.
drug therapies	<p>Drugs are delivered into the bloodstream so the treatment can travel throughout the body. This is called systemic treatment, and includes:</p> <ul style="list-style-type: none">• chemotherapy – the use of drugs to kill or slow the growth of cancer cells• hormone therapy – drugs that stop the body’s natural hormones from helping some cancers to grow• immunotherapy – treatment that triggers the body’s own immune system to fight cancer• targeted therapy – drugs that attack specific molecules within cells that help cancer grow. <p>Some drug therapies can shrink a cancer that is causing pain because of its size or location; slow the growth of the cancer; and help control symptoms, including pain and loss of appetite. Other drug therapies can reduce inflammation and relieve symptoms such as bone pain.</p>
radiation therapy	<p>The use of a controlled dose of radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Radiation therapy can shrink tumours or stop them spreading further. It can also relieve some symptoms, such as pain from secondary cancer in the bones.</p>

Managing symptoms

The relief of symptoms is one of the main aims of the palliative care team. While it may not be possible to completely eliminate all symptoms, there are many things that can be done to help make you as comfortable as possible. It may take time to find the most effective treatment – let your palliative care team know if a treatment is not working as they may be able to offer an alternative.

This section outlines some symptoms common to people with advanced cancer and offers suggestions on how to cope with them. For more information and support, call Cancer Council 13 11 20.

Pain

Whether you have pain will depend on the location of the cancer and its size. People experience pain in different ways and even people with the same type of cancer can experience different levels of pain. Palliative care services are specifically trained in pain management. If you do have pain, they will help you control it as much as possible.

Many people need a combination of treatments to achieve good pain control. Ways to relieve pain include:

- pain medicines, such as non-steroidal anti-inflammatory drugs and paracetamol for mild pain, and opioids including morphine, oxycodone and fentanyl for strong pain
- other types of medicine for nerve pain, such as antidepressants, anticonvulsants, or local anaesthetics
- anti-anxiety drugs for muscle spasms
- interventions such as nerve blocks or spinal procedures such as epidurals for pain that is difficult to manage

- other treatments, such as physiotherapy, complementary therapies (e.g. massage, acupuncture), and psychological interventions (e.g. relaxation, mindfulness, distraction techniques)
- surgery, drug therapies or radiation therapy (see page 29).

Some people worry about becoming addicted to pain medicine, but this is unlikely when it is used to relieve pain. Any side effects, such as constipation or drowsiness, can usually be managed. Correctly used opioid medicine, such as morphine, will not shorten life or interfere with your breathing – people may even live longer with better quality of life when their pain is treated. Talk to a specialist palliative care service if you are having trouble getting the correct dose for your level of pain, and ask your specialist palliative care team or your GP to regularly review your pain management plan.

➤ See our *Overcoming Cancer Pain* booklet.



Ways to manage medicines

Many people having palliative treatment take many different medicines throughout the day. There are some ways to help ensure you don't forget to take the correct dose of each medicine:

- Ask your palliative care team for a list of medicines and what each one is for.
- Use medicine packs made up by the pharmacist to help you take the correct dose of each drug at the right time.
- Keep a medicines list to record each medicine, the dose, and when it should be taken. Order a printed NPS MedicineWise list at nps.org.au/order or download the MedicineWise app from the App Store or Google Play.

Problems with eating and drinking

Many people with advanced cancer do not feel like eating. This may be because of the cancer or a side effect of treatment. It may also be caused by anxiety, fatigue or depression. However, food and drinks can help improve your quality of life by maintaining your strength and bodily functions.

It is important not to force yourself to eat – this may make you feel uncomfortable, and cause vomiting and stomach pain. Try having small meals or eating your favourite foods more frequently, and relax any dietary restrictions. It is common to feel less hungry as the disease progresses – talk to your palliative care team if you are concerned. They may suggest you drink nutritional supplements.

You may feel sick or have trouble keeping food down either because of the cancer or as a side effect of a medicine you're taking. You will probably be given anti-nausea medicine that you can take regularly to relieve symptoms. Finding the right one can take time – if you still have nausea or vomiting after using the prescribed medicine, let your palliative care team know so the dose can be adjusted or another medicine can be tried. Constipation (see opposite page) can also cause nausea and appetite issues.

An empty stomach can make your nausea worse – eat small meals and snacks regularly, and eat something soon after getting up in the morning. Avoid fried, greasy, spicy and strong-smelling foods. Try to drink water or other fluids, and consider eating foods with ginger, which can ease nausea.

► See our *Nutrition and Cancer* booklet.

Bowel changes

Many people having palliative care experience difficulty passing bowel motions (constipation), often as a side effect of opioids, cancer treatments or other medicines, or because of changes to their diet or physical activity levels. The usual suggestions for managing constipation, such as drinking lots of water, eating a high-fibre diet and exercising, are often not useful for people with advanced cancer who feel unwell. Your treatment team will advise the best way to manage this problem, and may prescribe laxatives and stool softeners.

Shortness of breath

People with advanced cancer often experience breathlessness (dyspnoea). This may be because of the cancer itself, an infection, a side effect of treatment, anxiety or an underlying disorder such as asthma or emphysema. Symptoms of breathlessness include difficulty catching your breath, noisy breathing or very fast, shallow breaths. Depending on the cause, breathlessness may be managed with medicine (such as low-dose morphine), surgery or oxygen therapy (if your oxygen levels are low). Simple practical measures can also be helpful. These include sitting near an open window, having a fan in the room or using a small handheld fan, adjusting your position in bed, doing breathing exercises, and practising relaxation techniques.



Palliative Care Australia provides resources on topics such as what questions to ask your palliative care team; facts about medicines used in palliative care; pain and pain management; and advance care planning. You can find these at palliativecare.org.au.

Fatigue

Fatigue is different from tiredness, as it doesn't always go away with rest or sleep. It can be caused by the cancer itself, cancer treatment, depression or anxiety, poor sleep, an infection, anaemia, weight loss or medicines. Ongoing fatigue can be distressing.

Your palliative care team may be able to adjust your medicines or treat the infection or anaemia that is causing the fatigue. Your team can also suggest practical measures. These could include occupational therapy, some gentle aerobic exercise guided by a physiotherapist, or additional equipment to help you conserve your energy. You may find that the fatigue increases as the disease progresses – counselling may help reduce your distress, and complementary therapies such as meditation and relaxation can also help you and your family cope.

Sexuality and palliative care

People with advanced cancer usually experience major physical and psychological changes.

These can have an enormous impact on how they feel sexually, but do not mean that intimacy needs to end.

We are all sexual beings, and intimacy can provide comfort and maintain connection. Even if sexual intercourse is no longer possible or desired, you may

enjoy physical closeness through cuddling, stroking or massage.

Talk with your partner about your feelings and concerns about the sexual changes in your relationship, and ways to maintain intimacy. If you have concerns about sexual intimacy, talk to your GP, nurse or psychologist.

› See our *Sexuality, Intimacy and Cancer* booklet.

Complementary and alternative therapies

You may wonder whether there are any other therapies you could try. It is important to understand the difference between complementary and alternative therapies.

Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as meditation, yoga, massage and acupuncture, may improve the side effects of treatment, decrease stress and anxiety, and enhance your quality of life. Let your doctors know about any complementary therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are therapies used instead of conventional medical treatments. While they may claim to cure cancer, they are not scientifically tested or proven to be effective. These therapies are often expensive and can be very harmful. Cancer Council does not recommend the use of alternative therapies for cancer.

› See our *Understanding Complementary Therapies* booklet.

Taking part in a clinical trial

Your doctor or nurse may suggest a clinical trial. Doctors run clinical trials to test new or modified treatments to see if they are better than current methods. Clinical trials may help improve palliative care and the management of common symptoms of advanced cancer. If you decide to take part in a trial, you can withdraw at any time.

› See our *Understanding Clinical Trials and Research* booklet or visit australiancancertrials.gov.au.



Palliative care for young people

As with palliative care for adults, palliative care for children and teenagers focuses on maintaining quality of life by addressing physical, emotional, cultural, spiritual and social needs, and supporting the family. The palliative care team must also consider how the young person's stage of development affects all these needs.

Because there may be uncertainty about the course of a child's illness, elements of palliative care are often introduced early and can be combined with active treatment for the cancer.

Palliative care for young people involves health professionals with specialised skills in paediatrics (the care of children), as well as palliative care experts. Most children's hospitals have some specialist paediatric palliative care services, which may provide care directly or advise the young person's cancer care team.

Depending on their circumstances, young people can receive palliative care at home, in hospital or in a paediatric palliative care unit (hospice).

Support for young people

There are a number of organisations that specifically support young people with cancer and their families by providing palliative care, financial assistance, counselling, resources and respite care. These are listed on the opposite page.

The hospital social worker can also provide support, and may know of other useful networks in your local community.

CanTeen – supports young people aged 12–25 affected by cancer and bereavement through an interactive online forum, counselling services, and resources on palliative care and end-of-life issues. Visit canteen.org.au or call 1800 835 932.

Camp Quality – offers support for children aged 0–13 living with cancer, and their families, through each stage of the cancer experience, including palliative care and bereavement. Visit campquality.org.au or call 1300 662 267.

Redkite – a charity that supports young people and their families through cancer by providing emotional guidance (including bereavement support), financial assistance and educational services. Visit redkite.org.au or call 1800 733 548.

Youth Cancer Services – provide hospital-based cancer treatment and support services for young people aged 15–25. For more information and to find the Youth Cancer Service closest to you, visit canteen.org.au/youth-cancer.

Palliative Care Australia – provides a detailed resource, *A Family Companion*, to help families and carers prepare for situations they may face during their child's illness. You can download this resource from palliativecare.org.au/children.



Caring for someone with advanced cancer

You may be reading this booklet because you are caring for someone with advanced cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

- See our *Caring for Someone with Cancer* booklet for suggestions on how you can look after yourself during this time.

Carers as part of the team

Family and carers play a key role in palliative care and are considered part of the team. As a carer, you can work with the palliative care team to ensure you understand, and are included in, decisions about the care and treatment of the person you care for.

You will need the written consent of the person you are caring for before the team can talk with you about their care when they are not present. This consent and your contact details should be formally recorded in the individual's case file.

The goal of palliative care is to improve quality of life not only for the person with cancer, but also for their family and carers. The palliative care team will assess your needs and identify services that can support you in your caring role. It is important that you know who to contact for help and support in an emergency or after hours.

Carers can sometimes feel they are at risk of losing their identity as partner, child, sibling or friend to their caring role. Accepting help from the palliative care team can mean you can spend more quality time with the person you're caring for.

Information for carers

- See our *Facing End of Life* booklet for ways you can provide practical and emotional support for a person nearing the end of their life.
- Palliative Care Australia provides fact sheets and videos for carers. Topics include the role of palliative care, managing symptoms, and caring for yourself. Visit palliativecare.org.au/im-a-carer.
- Use the Carer Gateway's "Find a service" search function to locate home help, transport and respite care, as well as counselling and support groups near you. Visit carergateway.gov.au.

Respite (short-term) care

Caring can be a very difficult role that can challenge your own physical and emotional wellbeing. Respite care is available to give you a break. It can sometimes be given in your home, or the person you are caring for may be admitted to a respite care centre, residential aged care facility or, in some cases, a hospital or palliative care unit (hospice).

Respite care can be for a couple of hours, overnight or for several days. You can use respite care for any reason, such as looking after your own health, visiting friends or other family members, or catching up on some much needed sleep at home.

Some carers avoid using respite care because they feel guilty or concerned about leaving the person they are caring for. However, it is important to look after your own health – by taking a break, you will probably find that you can continue your caring role more effectively.

It's a good idea to start looking into respite services before you actually need them. Talk to your doctor or the palliative care team about what services are available and how you can access them. Commonwealth Respite and Carelink Centres can also provide information on local carer support services, respite options and other support that may suit your needs. Call 1800 052 222 during business hours or call 1800 059 059 for emergency respite support outside business hours.

You may have to pay part or all of the cost of respite care. The fees will depend on the care provider, whether it is subsidised by the government, how long the care is for, and the type of care required.

Counselling and support

Carers often experience a range of conflicting emotions. Talking confidentially with a counsellor or social worker may help you work through your worries and concerns, learn communication strategies, and come to terms with changes in your life.

If the person you are caring for is nearing the end of life, the palliative care team will provide the support you need to help you understand what is happening and what happens next. This may include discussions about feelings of loss and grief, now and in the future.

It is not unusual for carers to experience depression and/or anxiety. If you feel you are getting depressed or overly anxious, talk to your GP or another health professional. For information about practical and financial support, see pages 43–46.

Grief counselling and information – You and your family may be eligible for grief and bereavement counselling provided through the palliative care team.

➤ See our *Understanding Grief* booklet or visit palliativecare.org.au.

Cancer Council telephone support group – Cancer Council offers a national telephone support group for carers. It runs twice a month. For more information about how you can speak with other people in a carer role, call 13 11 20.

Carers Australia programs – The National Carer Counselling Program provides short-term counselling. The Carers Associations in each state and territory also run local support groups. For more information, visit carersaustralia.com.au or call 1800 242 636.

Young Carers – Find age-appropriate information for young carers at youngcarersnetwork.com.au, or call 1800 242 636. You can also call your nearest Commonwealth Respite and Carelink Centre on 1800 052 222 to find out about respite services for carers under 25.

“ The social worker helped Brian and me talk about difficult and confronting issues, and she helped the children understand what was happening. The respite care was also a welcome relief and helped me remain strong. ” *Janine*



Seeking support

Emotional support

When you are referred to palliative care or while you are having palliative care, you may have a range of emotions. Many people feel shocked, fearful, sad, anxious or angry. Others feel relief or a sense of inner peace.

Some people have ongoing depression after receiving a diagnosis of advanced cancer. Signs of depression include trouble thinking clearly, losing interest in things you used to enjoy, or changes to sleep patterns and appetite. If you think you may be depressed, it is important to talk to your doctor, as counselling and medicines can help. For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

You may find that while some people you know are supportive, others may avoid you or not know what to say. This can be difficult, and you could feel rejected, isolated or upset. Advanced cancer can mean changes to your lifestyle – at some point, you may need to leave work, stop driving or give up other activities that are important to you. These changes can cause further sadness or stress.

It will probably help to talk to someone. Your partner, family and close friends can offer support, or you might prefer to talk to:

- members of your palliative care or treatment team
- a counsellor, social worker or psychologist
- your religious leader or spiritual adviser
- a telephone support group or peer support program – see page 46
- Cancer Council 13 11 20.

Financial support

For many people, an illness can be a financial strain. This may be caused by extra out-of-pocket costs or from loss of income. For example, if you need to stay at home more, household bills may increase, or you may buy more prepackaged meals to save your time and energy for other tasks. You may need to pay for child care, transport, medicines and equipment. If you live alone and have limited support from family or friends, you may need to pay for private services, such as nursing, cleaning or shopping. Research your options ahead of time so you know what assistance is available.

These extra costs can cause you and your family additional stress, but support may be available:

- Ask your social worker about any financial or practical assistance available to you or your carer, and apply for it as soon as possible. You may be eligible for assistance from the government, volunteer bodies, church groups or your local council.
 - Call the National Debt Helpline on 1800 007 007 for free, confidential and independent financial counselling.
 - Your local Cancer Council may be able to organise legal and financial advice. Contact Cancer Council 13 11 20 to find out what services are available in your area and whether you are eligible.
 - Talk to your superannuation fund about applying for an early release of your superannuation savings on the grounds of severe financial hardship or terminal illness.
 - Ask your utility company, loan provider or local council about how they might be able to help you manage payment of your bills or loans.
- See our *Cancer and Your Finances* booklet.

Centrelink benefits

The Department of Human Services (Centrelink) offers a range of payments that may be available to people with cancer and their carers. These include:

- Sickness Allowance
- Disability Support Pension
- Carer Allowance and Carer Payment
- Bereavement Payment and Bereavement Allowance.

You may also be eligible for the Pensioner Concession Card or the Health Care Card, which can reduce your expenses. Centrelink benefits may be income and asset tested or have other eligibility requirements. For more information, visit humanservices.gov.au or talk to your social worker.

Practical assistance

Equipment and aids – Talk to your palliative care team about equipment and aids that will help you remain independent. Independent Living Centres Australia offers advice on a range of products and services to help with aspects of day-to-day living, including mobility, sleeping, eating and transport (call 1300 885 886 or visit ilcaustralia.org.au). Depending on where you live and what your needs are, there may be funding available to help with these items.

Home help and transport – Contact your palliative care team, local council, My Aged Care (see opposite page) or Cancer Council 13 11 20 to ask about help with meals, housework or transport. The availability and cost of services vary across Australia.

Other key services

My Aged Care – An Australian Government site with information about aged care options, available services including the Commonwealth Home Support Programme, respite care, assessment and eligibility. Visit myagedcare.gov.au or call 1800 200 422.

Carer Gateway – An Australian Government service providing practical information and resources for carers, information about respite care, and links with local support services. Visit carergateway.gov.au or call 1800 422 737.

Commonwealth Respite and Carelink Centres – Provide free, confidential information about carer respite and other services. Call 1800 052 222 to talk to an adviser.

Palliative Care Australia – This national peak body and its state and territory member organisations work to raise awareness of palliative and end-of-life care, and to improve the understanding and availability of services across Australia. It also provides information for people living with a life-limiting illness and their families, carers and health professionals. Visit palliativecare.org.au to download resources and find links to state and territory organisations. You can also call the head office on 02 6232 0700.

To find other palliative care services and organisations in your area, search Palliative Care Australia's National Palliative Care Service Directory at palliativecare.org.au/directory-of-services.



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
Advance Care Planning Australia	advancecareplanning.org.au
My Aged Care	myagedcare.gov.au
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
CareSearch	www.caresearch.com.au
Department of Health	health.gov.au
Department of Human Services	humanservices.gov.au
National Palliative Care Service Directory	palliativecare.org.au/directory-of-services
NPS MedicineWise	nps.org.au
Palliative Care Aged Care Evidence	palliaged.com.au
Palliative Care Australia	palliativecare.org.au
The Palliative Care Bridge	palliativecarebridge.com.au
Young Carers Network	youngcarersnetwork.com.au

International

American Cancer Society	cancer.org
Macmillan Cancer Support (UK)	macmillan.org.uk
Cancer Research UK	cancerresearchuk.org



Question checklist

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

Palliative care

- Who will be a part of my palliative care team?
- Who will coordinate my care?
- Where will I receive palliative care?
- If I'm at home, what kind of help will be available?
- Can I call the palliative care team at any time? Who do I contact after hours?
- Will the palliative care team talk to my GP and cancer specialists about my care?
- How long will I need palliative care for? What is my prognosis?
- How can I get a second opinion about my need for palliative care?
- Do I need to see a specialist palliative care service?
- What if my condition unexpectedly improves?

Other treatment

- Are there other treatments available that might cure the cancer?
- Will I receive treatment for the cancer if I have palliative care?
- Are there any clinical trials I could join?
- If I don't have further treatment, what should I expect?
- Are there any complementary therapies that might help?

Support services

- Can my family or carers get respite care or other assistance?
- Do I have to pay for any palliative care services?
- What financial and practical assistance is available?
- Can you help me talk to my family about what is happening?



Palliative Care Australia provides many more suggested questions at palliativecare.org.au/asking-questions.



Glossary

advance care planning

When a person thinks about their future health care and discusses their wishes with their family, friends and health care team. The written record of these wishes may be known by different names, such as an advance care directive, advanced care plan or “living will”.

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).

allied health professional

A tertiary-trained professional who works with others in a health care team to support a person’s medical care. Examples include psychologists, social workers, occupational therapists, physiotherapists and dietitians.

carer

A person providing unpaid care to someone who needs this assistance because of a disease such as cancer, a disability, mental illness or ageing.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. Chemotherapy can also be used as a palliative treatment to reduce the size of the cancer and help lessen pain.

community nurse

A nurse who provides primary health care to people in their homes and communities, and may coordinate their palliative care. Community nurses usually work for local health services.

complementary therapy

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

depression

Very low mood and loss of interest in life, lasting for more than two weeks. It can cause physical and emotional changes.

distress

Emotional, mental, social or spiritual suffering.

dyspnoea

The medical term for difficulty breathing. Also called breathlessness.

end-of-life care

Health care provided in the final days and hours of life.

euthanasia

The act or practice of deliberately ending the life of a person suffering from a terminal illness or incurable condition. It is illegal in Australia.

immunotherapy

Treatment that uses the body’s own immune system to fight cancer.

inpatient

A person who stays in hospital while having treatment.

life-limiting illness

An illness that is unlikely to be cured and will cause death at some stage in the future. A person with a life-limiting illness may live for weeks, months or even years.

malignant

Cancerous. Malignant cells can spread (metastasis) and eventually cause death if they cannot be treated.

metastasis (plural: metastases)

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

multidisciplinary care

A system where all members of the treatment team collaborate to discuss a patient's physical and emotional needs.

oncologist

A doctor who specialises in the study and treatment of cancer.

opioids

The strongest pain medicines. They include morphine, oxycodone, fentanyl, hydromorphone and methadone.

outpatient

A person who visits hospital for medical care without being admitted.

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, emotional, cultural, spiritual and social needs. Also known as supportive care.

palliative care nurse

A nurse who has specialised in the field of palliative care. Provides support to the patient, family and carers, and may coordinate the palliative care team.

palliative care nurse practitioner

A palliative care nurse with additional qualifications who can provide complex

care management, including referral to other health professionals, prescribing some medicines and ordering tests.

palliative care plan

An outline of a person's care needs and goals, and how they will be met.

palliative care specialist (physician)

A doctor who has specialised in the field of palliative medicine, prescribes medical treatment for pain and other symptoms, and supports and advises other members of the palliative care team, the patient, family and carers.

palliative care unit

A place providing comprehensive care for people with a life-limiting illness. This may include inpatient medical care, respite care and end-of-life care for people who are unable to be cared for at home, or don't wish to die at home. It may also offer day care facilities and home visits. Sometimes called a hospice.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms. Treatment may include radiation therapy, chemotherapy or other therapies. It is an important part of palliative care.

practice nurse

A nurse who works with a GP, usually within the same practice location.

primary cancer

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

prognosis

The expected outcome of a person's disease.

quality of life

Your comfort and satisfaction, based on how well your physical, emotional, spiritual, sexual, social and financial needs are met within the limitations of your health and personal circumstances.

radiation therapy

The use of targeted radiation (usually x-ray beams) to kill or damage cancer cells so they cannot grow, multiply or spread. Also called radiotherapy.

recurrence

The return of a disease after a period of improvement (remission). Also called relapse.

remission

When the signs and symptoms of the cancer reduce or disappear. This may not mean that the cancer is cured.

respite care

Alternative care arrangements that allow the carer and person with cancer a short break from usual care arrangements. The care can be given in a range of settings.

secondary cancer

See metastasis.

specialist palliative care service

A multidisciplinary team of health professionals specialising in palliative care. Offers a range of services to improve the quality of life of people with a life-limiting illness.

substitute decision-maker

A person who makes decisions on your behalf if you become incapable of making them yourself. The documents to appoint this person may be called an enduring power of attorney, an enduring power of guardianship, or appointment of enduring guardian or medical treatment decision-maker.

supportive care

See palliative care.

targeted therapy

Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread.

terminal illness

An illness that is unlikely to be cured and will eventually result in a person's death. It may also be known as a life-limiting illness.

voluntary assisted dying

When a person in the late stages of advanced disease asks their doctors for help to end their life.

Can't find a word here?

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 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.

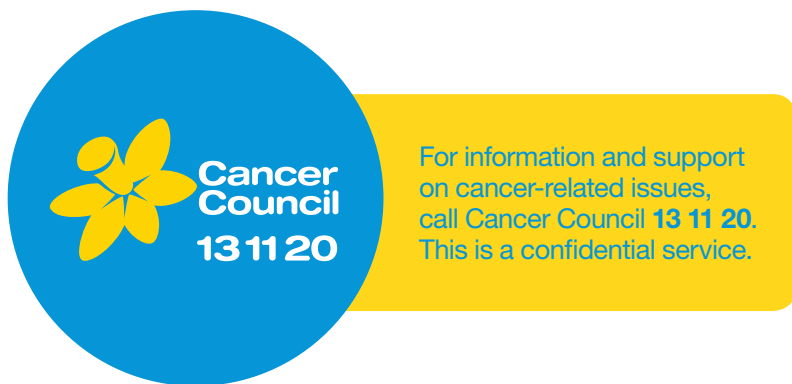
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



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



Produced in collaboration with:



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actcancer.org

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