



# Understanding Palliative Care

A guide for people with cancer,  
their families and friends

A large yellow shape, resembling a stylized sun or a large drop, occupies the lower half of the page. A purple circle is positioned on the right side of this shape. A thin orange line starts from the bottom of the purple circle and extends downwards and to the left, ending in a small orange telephone handset icon.

Treatment

For information & support, call

**13 11 20**

## Understanding Palliative Care

A guide for people with cancer, their families and friends

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*Understanding Palliative Care* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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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](http://cancer.org.au) or call your local Cancer Council.



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# Introduction

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 enhance your quality of life and help you maintain your independence for as long as possible. Palliative care 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. This booklet offers general information about palliative care. Talk to your general practitioner (GP) or palliative care team about the best approach for your situation.

You may find reading about palliative care distressing – read what seems useful now and leave the rest until you're ready.

## How this booklet was developed

This information was developed with help from Palliative Care Australia, a range of health professionals, and people affected by cancer who have used palliative care services.

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



**Cancer  
Council  
13 11 20**

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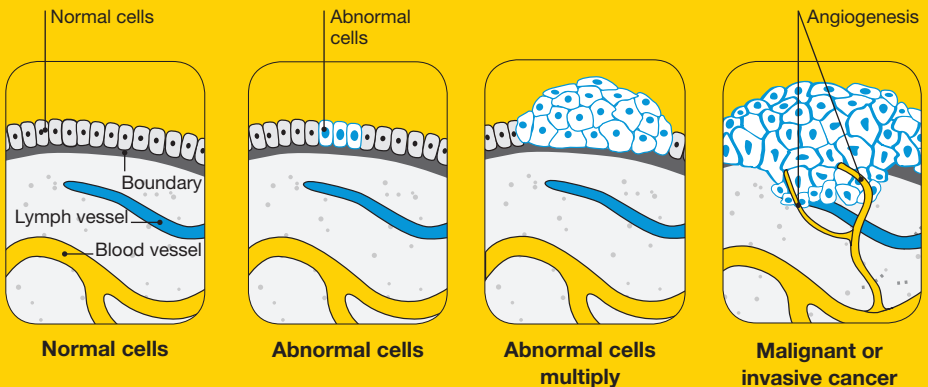
# What is advanced cancer?

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.

Primary cancer refers to the first mass of cancer cells (tumour) in an organ or tissue. The tumour has not spread from its original site, such as the bowel. This is also called cancer in situ, carcinoma in situ or localised cancer.

## How cancer starts



If cancer cells from the primary site move through the body's bloodstream or lymph vessels to a new site, they can multiply and form other malignant tumours (metastases). This is known as secondary or metastatic cancer. Secondary cancer keeps the name of the original, primary cancer. For example, bowel cancer that has spread to the liver is still called metastatic bowel cancer, even when the person has symptoms caused by cancer in the liver.

Although medical treatments may not be able to cure advanced cancer, some treatments may still 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. A range of other palliative care services (see page 7) can enhance quality of life at any stage of advanced cancer.

## How cancer spreads

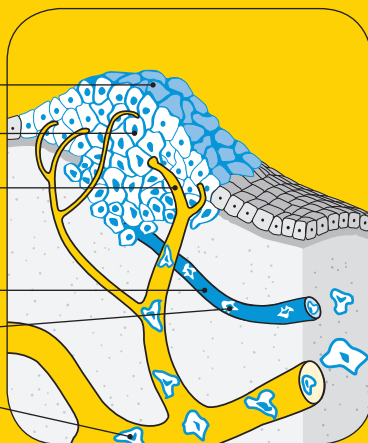
Primary cancer

Local invasion

Angiogenesis –  
tumours grow their  
own blood vessels

Lymph vessel

Metastasis –  
cells invade other  
parts of the body via  
blood vessels and  
lymph vessels





# The role of palliative care

Palliative care helps people with advanced cancer to live as fully and as comfortably as possible. The role of palliative care is to:

- identify and help you manage your physical, practical, emotional, spiritual and social needs
- help you achieve the best quality of life that you can for as long as possible
- help you feel in control of your situation and make decisions about your treatment and ongoing care
- provide support to families and carers.

This type of care can improve quality of life from the time of diagnosis, and can be given alongside other cancer treatments.

Palliative care involves a range of services offered by medical, nursing and allied health professionals, as well as volunteers and carers. This is called a multidisciplinary team (MDT) approach (see pages 19–23). Your care may be coordinated by your general practitioner (GP) or community nurse, or by the specialist palliative care team in your area. It may be provided in or out of the home.

## Palliative care providers

Where possible, you and your family can choose where you want to receive palliative care. This may be:

- at home (with support from community palliative care services and your GP)
- at a specialist palliative care unit (sometimes called a hospice)
- in a hospital
- in a residential aged care facility.



Specialist palliative care services see people with the most complex needs, but can also provide advice to other health care professionals. These services can be accessed through:

- many public and private hospitals (either as an inpatient or through an outpatient clinic)
- palliative care units (hospices)
- community-based specialist services.

If you think you need specialist palliative care, talk to your GP or oncologist about a referral to the service in your area.

## Palliative care services

Services will be tailored to your individual needs, but may include:

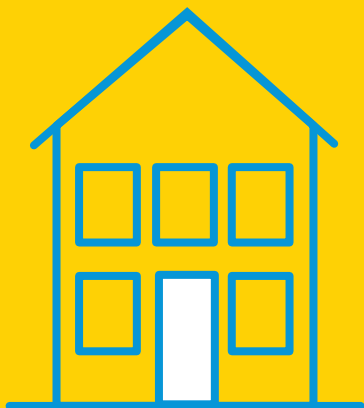
- relief of pain and other symptoms (e.g. nausea, vomiting)
- equipment to aid care at home, such as wheelchairs or special beds
- assistance for families to talk about sensitive or complex issues
- links to other services such as home help and financial support
- support for people to meet cultural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

Services offered in each state and territory vary. To find out what is available in your area, speak to your health care providers, contact your local palliative care organisation (see page 44), use the directory of services at [palliativecare.org.au](http://palliativecare.org.au) or call Cancer Council **13 11 20**.



## What is palliative care?

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.



### Care settings

The palliative care team will help you determine 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).

### Person with cancer

You will work with the palliative care team to communicate your care needs and decisions about treatment and ongoing care.



### 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.



### Care providers

Your care may be led by a specialist palliative care team or by your GP and a community nurse. 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

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 and organise equipment and services to make it easier for carers to look after you.

### Advance care planning

The team will encourage and support you to make decisions about your goals and preferences for future care and treatment (see pages 25–26).



### 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.



### 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 end-of-life care?**

**A:** Palliative care aims to provide quality care and quality of life for someone living with a life-limiting illness. It is about living for as long as possible in a way that is meaningful to you, within the constraints of your illness. It's not simply about dying.

While some people may use palliative care services for only a few weeks or months, the number of people receiving palliative care for several years is increasing.

Because improved treatments can help stop or slow the spread of cancer and relieve side effects, cancer may be considered a chronic (long-lasting) disease. You can have palliative care while you are still having active treatment for the cancer. You do not need to wait until you have stopped active treatment or until the end of life.

This type of care can improve quality of life from the time of diagnosis. One reason that some people don't access palliative care services early – or at all – is because they have the fear or misconception that it will mean they have given up hope or are going to die soon. This is certainly not the case for everyone referred to palliative care, nor does it mean that your doctor has given up hope.

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: Is palliative care the same as euthanasia?

**A:** Palliative care and euthanasia are not the same thing. Euthanasia is the act of deliberately ending the life of a person with an incurable condition or illness. Physician-assisted suicide is when a person ends their own life with the help of a doctor.

In early 2017 both euthanasia and physician-assisted suicide were illegal for all parties involved in every state and territory in Australia. Although the laws are under review in some places (visit [end-of-life.qut.edu.au](http://end-of-life.qut.edu.au) for updates), euthanasia and physician-assisted suicide are not part of palliative care practice.

The coordinated medical and support services of palliative care can help a person maintain comfort and quality of life throughout the advanced stages of their illness. Palliative care does not attempt to hasten death.

If you urgently need somebody to talk to because you are thinking about ending your life, call Lifeline on **13 11 14** for free, confidential telephone counselling at any time.



## **Q: Does it shorten or lengthen life?**

**A:** Palliative care does not try to end life sooner, nor does it try to prolong life. Instead, the palliative care team provides services to enhance your quality of life. This may include managing pain and other symptoms. Some studies show that controlling symptoms, such as pain, can lead to people feeling better and living longer.

## **Q: When can I start palliative care?**

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

Sorting out care earlier rather than later will reduce stress on you and your family. It will allow 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; they can be supported by palliative care services as needed throughout this time. For others, the cancer advances rapidly 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 continually assess your changing needs and adjust your care.


## 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 and support from a specialist palliative care service. It is likely that your GP or community nurse will continue to coordinate your care, and you may not need to see the specialist yourself.

Specialist palliative care services (see page 7) may coordinate the care of people with complex health needs, who will often see the palliative care specialist regularly as an outpatient. Sometimes people need to stay in hospital for short periods while the specialist adjusts their medicines or gets their pain under control, for instance.

The palliative care specialists will continue to consult your other doctors about your care and treatment. If your condition stabilises or improves, you may not need to see the palliative care specialists for periods of time or you may be discharged from palliative care.

It is important for your key family members or carers to be involved in any discussions about your treatment plan, especially if they are providing most of your day-to-day care.

“Working in palliative care allows us, as nurses, to provide patients with the most compassionate care possible at a time when they may be quite vulnerable.”  *Carla*

## **Q: Where will I receive palliative care?**

**A:** You can have palliative care in different settings 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 or in a residential aged care facility, or in a hospital or palliative care unit (hospice). People receiving palliative care often move between these settings 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.



## 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 radiotherapy 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 28–34).

### 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 can have palliative care for several months or years, sometimes alongside active treatment for the cancer. During this time, you can continue to enjoy many aspects of your life.

Some people with advanced cancer take pleasure in completing projects, spending time with friends, or exploring new hobbies. Others find that recording their feelings through a creative activity, such as writing or art, helps them to make sense of their situation.

As the disease progresses, your 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.

## 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 gain 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 therapist. You can also call Cancer Council **13 11 20** and ask for a free copy of the *Sexuality, Intimacy and Cancer* booklet, or download it from your local Cancer Council website.

## Q: Will I lose my independence?

**A:** Your palliative care team will give you options to help you remain independent for as long as possible. For example, they may identify modifications or services to help you stay at home (such as installing a ramp so you don't have to use steps), or offer 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: Do I have to pay for palliative care?

**A:** The federal, state and territory governments fund core palliative care services so that they are free in the public health system, whether you receive care at home or in a public setting. However, sometimes you may need to contribute to the costs of care.

Your state or territory palliative care organisation will be able to provide you with more specific information, but 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
- accessing 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.

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



## 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.
  - 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 advanced cancer brings.
  - Adjustments around the house can make things easier and safer for you, your family and carers. The team can help you identify 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.



# 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 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, where the doctors, nurses and allied health professionals are specifically trained to look after people with complex health care issues.

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 death and bereavement, or certain family customs, talk to your palliative care team so they can incorporate these into your palliative care plan where possible.

“ I enjoy helping people out, whether it's stringing up Christmas lights or helping record someone's life story. It's incredibly rewarding and a pleasure to help. ” Cheryl

## Members of the palliative care team

General practitioner (GP) or family doctor	Nurse	Palliative care specialist or physician
<ul style="list-style-type: none"> <li>• continues to see you for day-to-day health care issues if you are being cared for at home (and may make home visits)</li> <li>• liaises with your nurse and/or palliative care specialist about the coordination of your ongoing care</li> <li>• refers you to a palliative care specialist</li> <li>• can organise your admission to hospital or a palliative care unit (hospice) if your circumstances change</li> <li>• offers support to you, your family and carers</li> <li>• can provide referrals for counselling, including bereavement counselling if necessary</li> </ul>	<ul style="list-style-type: none"> <li>• may be a community nurse, a specialist palliative care nurse or a palliative care nurse practitioner</li> <li>• may work for a hospital, community nursing service, residential aged care facility or specialist palliative care service</li> <li>• if you are being cared for at home, will visit you in your home and may provide after hours telephone support</li> <li>• coordinates other health professionals and works out what care you need, including home nursing or personal care assistance</li> <li>• makes sure you have access to medicines and other treatments for pain and symptom relief, and talks to you about how to take your medicines</li> <li>• can suggest practical strategies to help you manage your condition (e.g. how to manage fatigue or loss of appetite)</li> </ul>	<ul style="list-style-type: none"> <li>• prescribes or recommends treatment for pain, nausea, constipation, anxiety, depression, shortness of breath or any other symptoms you may have</li> <li>• 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</li> <li>• communicates with and advises the cancer specialist and your GP so your treatment is well coordinated</li> <li>• may refer you and your family to a grief counsellor, psychologist or other support person</li> <li>• assists with decision-making about care and treatment choices</li> </ul>

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

## Members of the palliative care team (continued)

### Social worker

- assesses what sort of support you, your family and carers need, and identifies ways you can receive this support
- may provide counselling and emotional support to you, your family and carers, including working through feelings of loss and grief
- assists with communication within the family (including any relationship issues) and with other health care professionals, including any changes to your care goals
- discusses ways of coping and how to emotionally support your children, grandchildren or other dependents
- can help you work out ways to record your memories
- provides information and referrals for legal matters, financial support, home respite care, meal services, parking schemes, personal alarms, laundry services and aged care services
- may help people with limited support from family or friends to arrange temporary or permanent care for dependents or pets

### Occupational therapist or physiotherapist

- helps 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, 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
- teaches carers and family the best ways to move you or help you sit and stand
- 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 physical therapy to help clear congestion from your lungs
- may work with a massage therapist to relieve stiff and sore muscles or swelling, or a podiatrist to treat any foot conditions





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



# Looking ahead

## Prognosis

A prognosis is the expected outcome of someone's disease. Some people want to know whether and when they will die from cancer; others don't wish to know. If you are referred to palliative care, it does usually mean that at some stage you may die from the cancer.

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 different kinds of care. If you ask for an estimate of the time you have left to live, your doctor will probably talk about your remaining life span in terms of days to weeks, weeks to months, or months to many months. The actual time could be shorter or longer.

Some families and carers want to know the prognosis even when you don't. Let the 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 over any fears, worries, guilt or other emotions you are experiencing may help you come to terms with your situation.

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. You can also call 13 11 20 and ask for the *Emotions and Cancer* and *Facing End of Life* booklets, or download them from your local Cancer Council website.

## 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.

It's very useful for you and your family to think about these issues before they are raised by a health professional. What matters to you most? Might 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 can change over time.

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](https://dyingtotalk.org.au/discussion-starter).



## Advance care directive

You can write down your treatment wishes in what is known as an advance care directive, commonly called a “living will”. Depending on where you live, it may be known by a similar term such as advanced personal plan or advance health directive. This provides a record of your preferences for doctors, family and carers to consider if you become unable to communicate or make decisions. You can choose to revise or cancel your advance care directive.

Ask your doctor or hospital to place your directive on your medical record. You can also save it online at [myhealthrecord.gov.au](http://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.



Each state or territory has different laws about advance care planning. For more information about completing an advance care plan, call Cancer Council **13 11 20** or the Advance Care Planning Advisory Service on **1300 208 582**, or visit [advancecareplanning.org.au](http://advancecareplanning.org.au) or [palliativecare.org.au/advance-care-planning](http://palliativecare.org.au/advance-care-planning).



## 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, succour and friendship. Cancer Council helped me find 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 an important part of palliative care. It aims to manage the physical and emotional symptoms of cancer without trying to cure the disease. Some examples of palliative medical treatment are:

- radiotherapy to reduce pain if cancer has spread to the bones
- 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.

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.

## Common treatments

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.

For some people, treatment will cause significant side effects, such as nausea or fatigue. It's important to discuss any side effects with your palliative care team so they can be managed appropriately.

## Common treatments for cancer

<b>Surgery</b>	Surgery can remove tumours from affected areas, such as the bowel or lymph nodes; relieve discomfort caused by tumours that obstruct organs or cause bleeding; and improve outcomes from chemotherapy and radiotherapy by reducing the size of a tumour.
<b>Chemotherapy</b>	Chemotherapy uses drugs known as cytotoxics to kill or slow the growth of cancer cells. It can shrink 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.
<b>Radiotherapy</b>	Also known as radiation therapy, radiotherapy uses radiation, such as x-rays, to kill or injure cancer cells. Radiotherapy can shrink tumours or stop them spreading further. It can also relieve some symptoms, such as pain from secondary cancer in the bones.
<b>Hormone therapy</b>	Cancer that grows in response to hormones can often be slowed by taking drugs to suppress the body's production of the hormone.
<b>Immunotherapy</b>	Immunotherapy uses drugs to alter the immune system's response to the cancer. Some types work by permitting the immune system to bypass "checkpoints" set up by the cancer to block it. These drugs are approved to treat only some types of cancer.
<b>Targeted therapy</b>	Targeted therapy attacks specific particles (molecules) within cells that allow cancers to grow and spread, while minimising harm to healthy cells. Not all cancers respond to targeted therapy and it is sometimes available only on clinical trials.

## 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.

### Pain

Whether you have pain will depend on the location of the cancer and its size. Palliative care services are specifically trained in pain management. If you do experience pain, they will help you control it as much as possible.

Some people worry about becoming addicted to pain medicine, but this is unlikely when medicines are taken to relieve pain. Any side effects, such as constipation or drowsiness, can usually be managed. Correctly used doses of opioid medicine, such as morphine, will not shorten life or interfere with your breathing – people often survive for longer 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.



For more information on medical treatment for advanced cancer and managing pain, call **13 11 20** and ask for free copies of *Living with Advanced Cancer* and *Overcoming Cancer Pain*, or download them from your local Cancer Council website.



## Options for relieving pain

Some of the ways to relieve pain are:

- pain medicines – e.g. non-steroidal anti-inflammatory drugs and paracetamol for mild pain; codeine for moderate pain; or opioids such as 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
- a nerve block or an infusion of drugs into the spine (intrathecal infusion) for pain that is difficult to manage
- complementary therapies, such as massage or acupuncture
- chemotherapy, radiotherapy or surgery.

## Nausea and vomiting

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. Anti-nausea medicines (sometimes called anti-emetics) can be taken as tablets or, if swallowing is difficult, as wafers that dissolve on the tongue, as injections under the skin or as suppositories, which are inserted into the bottom and absorbed through the lining of the rectum. Finding the right anti-emetic can take time – if you still have nausea or vomiting after using the prescribed medicine, let your palliative care team know so that another type can be tried.

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.

## Loss of appetite

Many people with advanced cancer do not feel like eating. This may be because of the cancer, as a side effect of treatment, or because of anxiety or depression. Food and drinks can help improve your quality of life by maintaining your strength and bodily functions. Don't 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 for your appetite to lessen as the disease progresses – talk to your palliative care team if you are concerned.

## 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 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 or other opioid medicine), surgery or oxygen therapy. You can also try simple practical measures, such as sitting near an open window, having a fan in the room, adjusting your position in bed or doing relaxation exercises.



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 access these at [palliativecare.org.au](https://palliativecare.org.au).



## 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 the medicines.
- Use medicine packs made up by the pharmacist to assist with taking the right drug at the right time safely.
- Keep a medicines list to record each medicine, the dose, and when it should be taken. You can download a medicines list as a form or smartphone app at [nps.org.au](https://nps.org.au).

## Fatigue

Fatigue can be a major problem for people living with advanced cancer. This can be caused by the cancer itself, depression or anxiety, poor sleep, an infection, anaemia, cancer treatment, weight loss or medicines.

Fatigue can be difficult to treat, which can cause you a lot of distress. 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 some 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 cope.

## Complementary therapies

You may wonder whether there are any other therapies you could try. Complementary therapies, including meditation, yoga, massage or acupuncture, may improve the side effects of treatment, decrease stress and anxiety, and enhance your quality of life. These therapies are used alongside conventional medical treatments.

Alternative therapies are used instead of conventional medical treatments. They are often promoted as cancer cures but they are not scientifically tested or proven to be effective. They can be harmful and very expensive. If you have questions about a particular alternative therapy, call Cancer Council 13 11 20, talk to your doctor, or visit [iheard.com.au](http://iheard.com.au).

Let your doctor know about any therapies you plan to use – they may interact badly with your medical treatment. To find out more, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.

## Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments 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. For more information, see Cancer Council's *Understanding Clinical Trials and Research* booklet or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



# Caring for someone with advanced cancer

You may be reading this booklet because you are caring for someone with advanced cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

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

For more information about caring for someone with a life-limiting illness, visit Palliative Care Australia at [palliativecare.org.au](http://palliativecare.org.au). You can also download a copy of the *Caring for Someone with Cancer* booklet from your local Cancer Council website.



There are a range of support services to help you manage throughout the illness and in bereavement. Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role.

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit [carersaustralia.com.au](http://carersaustralia.com.au) for more information and resources.

## Respite (short-term) care

Caring can be a very difficult role and can challenge your own 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 access 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.

You may be able to access respite care through the Commonwealth Home Support Programme. Start by contacting My Aged Care (visit [myagedcare.gov.au](http://myagedcare.gov.au) or call 1800 200 422) or speak to your doctor or the palliative care team. It's best to make contact early on so you can find out what services are available and how you can access them. You can also contact a Commonwealth Respite and Carelink Centre for information on local carer support services and respite options. Call 1800 052 222 during business hours or call 1800 059 059 for emergency respite support outside business hours.

Some respite care services are subsidised by the government (you may have to contribute to the cost of the care); others are funded privately (you meet the cost yourself). The fees will depend on the care provider, how long the care is for, and the type of care required.

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. See [carergateway.gov.au](http://carergateway.gov.au).



## 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. Carers can also be prone to depression and anxiety. If you feel you are getting depressed or overly anxious, talk to your GP or another health professional.

**Grief counselling and information** – You and your family may be eligible for grief and bereavement counselling provided through the palliative care team. For more information about understanding grief, visit Palliative Care Australia at [palliativecare.org.au](http://palliativecare.org.au), or download a copy of the *Understanding Grief* booklet from your local Cancer Council website.

**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](http://carersaustralia.com.au) or call 1800 242 636.

**Young Carers Respite and Information Services Program** – Visit [youngcarers.net.au](http://youngcarers.net.au) or call 1800 242 636 for age-appropriate information. You can also call 1800 052 222 to find out about respite, practical help and social activities 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*





# Palliative care for young people

As with palliative care for adults, palliative care for children and teenagers focuses on enhancing quality of life by addressing physical, practical, emotional and spiritual needs, and supporting the family. The 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 combined with treatment that aims to actively treat 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 health care team.

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

## Tailored support

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 next 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, and resources on palliative care and end-of-life issues. Visit [canteen.org.au](http://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 journey, including palliative care and bereavement. Visit [campquality.org.au](http://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](http://redkite.org.au) or call 1800 733 548.

**Kids with Cancer Foundation Australia** – provides financial assistance to families of children with cancer, and helps fund projects in public hospitals and oncology units. Visit [kidswithcancer.org.au](http://kidswithcancer.org.au) or call 1800 255 522.

**Youth Cancer Services** – provide hospital-based cancer treatment and support services for young people aged 15–25. For more information and to find the service closest to you, visit [youthcancer.com.au](http://youthcancer.com.au).

**Palliative Care Australia** – provides a detailed resource, *Journeys*, 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/teenagers-and-children](http://palliativecare.org.au/teenagers-and-children).



# 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 or losing interest in things you used to enjoy. If you think you may be depressed, it is important to talk to your doctor, as counselling and medicines can help. The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to [beyondblue.org.au](http://beyondblue.org.au) or call 1300 22 4636 to order a fact sheet.

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 lonely, rejected, isolated or upset. At some point, you may need to leave work, hand in your driver's licence or give up other activities that are important to you. These changes can cause further sadness or stress.

It will probably help to talk about the different feelings you have. Your partner, family members and close friends can be a good source of 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 45
- 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, and 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. Investigate your options ahead of time so you know what assistance is available.

These extra costs can cause you and your family a lot of stress:

- 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 for this assistance.
- 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.
- See Cancer Council's booklet *Cancer and Your Finances* for more detailed information.

## Government assistance

<b>Sickness Allowance</b>	For people who have a job and temporarily cannot work because of an illness. It is income and assets tested.
<b>Disability Support Pension</b>	For people who are unable to work for two years or more because of a physical, intellectual or psychiatric impairment. It is income and assets tested.
<b>Carer Allowance</b>	For carers who provide a significant amount of assistance, either in their own home or in the home of the person they are caring for. It is not income and assets tested, so you may be eligible even if you are working or receiving another type of pension. However, both the carer and care recipient have to meet other eligibility requirements.
<b>Carer Payment</b>	For carers who provide constant care in the home of the person they are caring for. It is income and assets tested.

For more information, call the Department of Human Services (Centrelink) on **132 717**, visit **humanservices.gov.au** or speak 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](http://ilcaustralia.org.au)).

**Home help and transport** – Contact your local council, your palliative care team or Cancer Council 13 11 20 to find out if you can get help with housework, meals or transport.

## Other key services

**My Aged Care** – An Australian Government site with information about care options, available services including the Commonwealth Home Support Programme, respite care, assessment and eligibility. Visit [myagedcare.gov.au](http://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](http://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](http://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](http://palliativecare.org.au/directory-of-services).



# Cancer Council services

Cancer Council offers a range of services to support people affected by cancer, their families and friends.

**Cancer Council 13 11 20** – This is many people's first point of contact if they have a cancer-related question. Trained professionals will answer any questions you have about your situation. For more information, see the inside back cover.

**Practical help** – Your local Cancer Council can help you access services or offer advice to manage the practical impact of an advanced cancer diagnosis. This may include access to transport, accommodation and home help or legal and financial support. Call 13 11 20 to find out what services are available in your state or territory.

**Telephone support groups** – You might find it helpful to share your experiences with other people affected by cancer. For some people, this means joining a support group. Others prefer to talk to a trained volunteer who has had a similar cancer experience.

Although face-to-face support groups for people receiving palliative care are rare, Cancer Council runs a telephone support group for people with advanced cancer and another one for their carers. Call 13 11 20 for more information.

**Online discussion forums** – Visit the Cancer Council Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC) to connect at any time with other people affected by cancer or write a blog about your palliative care experience.

**Printed, online and audiovisual resources** – Cancer Council produces a wide variety of free information about cancer-related topics. This includes easy-to-read booklets and fact sheets on more than 20 types of cancer, treatment options, and emotional and practical issues.

Cancer Council publications are developed in consultation with health professionals and consumers. Content is reviewed regularly, according to best practice guidelines for health information.

### Related publications

You might also find the following free Cancer Council publications and audiovisual resources useful:

- *Cancer and Your Finances*
- *Cancer Care and Your Rights*
- *Caring for Someone with Cancer*
- *Emotions and Cancer*
- *Facing End of Life*
- *Living with Advanced Cancer*
- *Nutrition and Cancer*
- *Overcoming Cancer Pain*
- *Sexuality, Intimacy and Cancer*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Complementary Therapies*
- *Understanding Grief*
- *Talking to Kids About Cancer*
- *Relaxation/meditation CDs\**

Call **13 11 20** for copies, or download them from your local Cancer Council website.

*\* May not be available in all states and territories.*





# Useful websites

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

## Australian

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Cancer Council Australia.....	<b>cancer.org.au</b>
Cancer Australia .....	<b>canceraustralia.gov.au</b>
Advance Care Planning Australia .....	<b>advancecareplanning.org.au</b>
Australian Centre for Grief and Bereavement.....	<b>www.grief.org.au</b>
beyondblue .....	<b>beyondblue.org.au</b>
Carers Australia .....	<b>carersaustralia.com.au</b>
Carer Gateway.....	<b>carergateway.gov.au</b>
CareSearch.....	<b>caresearch.com.au</b>
Department of Health .....	<b>health.gov.au</b>
Department of Human Services .....	<b>humanservices.gov.au</b>
ehospice .....	<b>ehospice.com</b>
GriefLine .....	<b>griefline.org.au</b>
My Aged Care.....	<b>myagedcare.gov.au</b>
National Centre for Childhood Grief.....	<b>childhoodgrief.org.au</b>
National Palliative Care Service Directory .....	<b>palliativecare.org.au/directory-of-services</b>
PalAssist: 24-hour helpline (Qld only).....	<b>palassist.org.au</b>
Palliative Care Australia.....	<b>palliativecare.org.au</b>
The Palliative Care Bridge .....	<b>palliativecarebridge.com.au</b>
Young Carers.....	<b>youngcarers.net.au</b>

## International

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American Cancer Society.....	<b>cancer.org</b>
Macmillan Cancer Support (UK).....	<b>macmillan.org.uk</b>
National Cancer Institute (US).....	<b>cancer.gov</b>



## Question checklist

This question checklist may be a good starting point for you as you think about the questions you want to ask your doctor. If your doctor gives you answers that you don't understand, it is okay to ask for clarification.

- 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?
- Who will be a part of my palliative care team?
- Who will coordinate my care?
- Do I have to pay for any palliative care services?
- Where will I receive palliative care?
- If I'm at home, what kind of help will be available?
- Can my family or carers access respite care or other assistance?
- Can I call the palliative care team at any time?
- Will the palliative care team talk to my GP and other specialists about my care?
- How long will I need palliative care for? What is my prognosis?
- What if my condition unexpectedly improves?
- What financial and practical assistance is available?
- Can you help me talk to my family about what is happening?
- Are there any complementary therapies that might help?
- How can I get a second opinion about my need for palliative care?



For more suggestions, visit Palliative Care Australia at [palliativecare.org.au/resources/asking-questions](https://palliativecare.org.au/resources/asking-questions).



# Glossary

## **advance care planning**

When an individual 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 called an advance care directive, advanced personal plan or advance health directive.

## **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 who provides physical and/or emotional support to someone who is living with a disability or disease such as cancer.

## **chemotherapy**

The use of drugs to treat cancer by killing or slowing the growth of cancer cells. 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 therapies**

Supportive treatments that are used in conjunction with conventional or palliative treatment. They improve general health, wellbeing and quality of life, and help people cope with cancer symptoms and treatment side effects.

## **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. Distress may range from feelings of vulnerability and sadness to stronger feelings of depression, anxiety, panic and isolation.

## **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.

## **hospice**

See palliative care unit.

## **immunotherapy**

The prevention or treatment of disease using substances that stimulate your immune system to attack certain cells.

**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**

When cells are cancerous, which means they can spread (metastasise) and may 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 care needs. The team meets regularly to review cases and decide on treatments.

**oncologist**

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

**opioids**

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

**outpatient**

A person who visits a hospital for medical treatment and 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, practical, emotional, 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 nurse who has had additional training and is able to prescribe some medicines and order some tests.

**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. Also known as a hospice.

**palliative treatment**

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

**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 and financial needs are met within the limitations of your illness.

**radiotherapy**

The use of radiation, such as x-rays, gamma rays, electron beams or protons, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

**recurrence/relapse**

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

**remission**

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

**respite (short-term) care**

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

**secondary cancer**

See metastasis.

**specialist palliative care team**

A multidisciplinary team of health professionals who offer a range of services to improve a patient's quality of life. A palliative care nurse usually coordinates the team.

**substitute decision-maker**

A person who makes decisions on your behalf if you become incapable of making them yourself. The documents for appointing this person may be called an enduring power of attorney, an enduring guardian or a power of guardianship.

**supportive care**

See palliative care.

**targeted therapy**

Treatment that attacks 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 called a life-limiting illness.

**Can't find a word here?**

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)



# How you can help

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

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

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

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

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

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

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



# Cancer Council

## 13 11 20

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

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

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

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

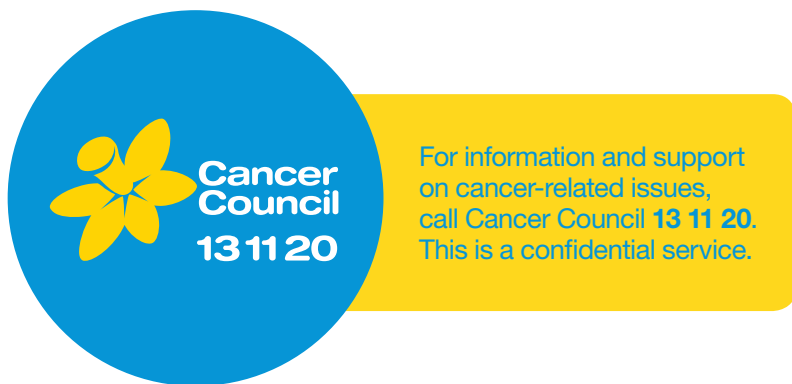
Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



Produced in collaboration with:



## 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**  
cancertas.org.au

**Cancer Council Victoria**  
cancervic.org.au

**Cancer Council WA**  
cancerwa.asn.au

**Cancer Council Australia**  
cancer.org.au

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*