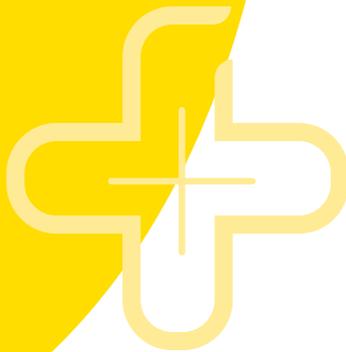


# Understanding Palliative Care

*A guide for people with cancer, their families and friends*



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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### 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.



*Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.*



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**Telephone** 02 8256 4100 **Email** [info@cancer.org.au](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

# 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 – not just at the end of life.

Palliative care is managed in various ways throughout Australia and is adapted 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. This information may answer some of your questions and help you think about what to ask your health care team (see page 48 for a question checklist).

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 for their information.

**How this booklet was developed** – This information was developed with help from Palliative Care Australia, health professionals and people affected by cancer. It is based on an Australian strategy.<sup>1</sup>



If you or your family have any questions or concerns, 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).

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## Key to icons

Icons are used throughout this booklet to indicate:



More information



Personal story



Tips

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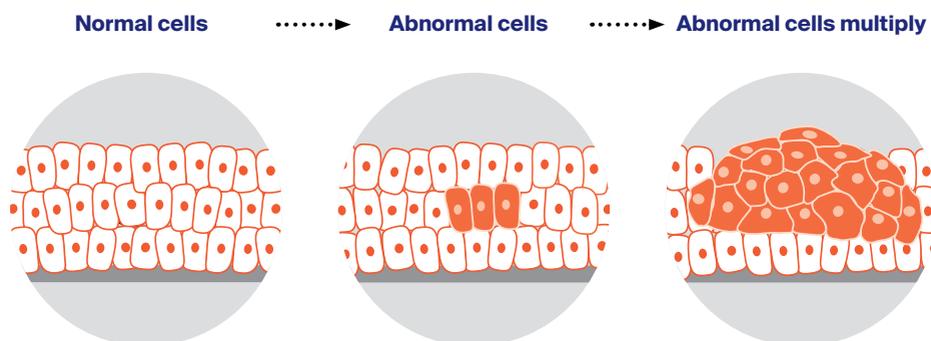
# What is advanced cancer?

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.

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 primary site break away and travel through the bloodstream or lymph

## How cancer starts

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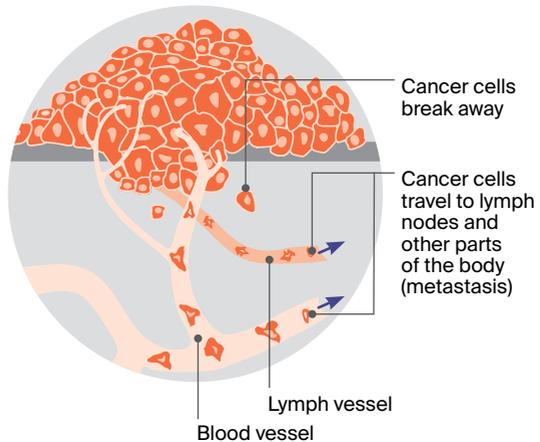
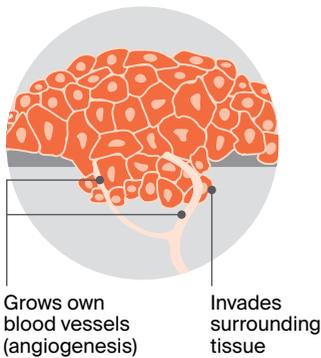
vessels to other parts of the body, they can grow and form another tumour at a new site. This is called advanced cancer, secondary cancer or metastasis.

The most common sites a cancer may spread to include the lungs, brain, liver and bones. 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, or relieve symptoms. Palliative care can also help manage symptoms and reduce side effects at any stage of advanced cancer. This can help maintain quality of life for months or even years.

## How cancer spreads

### .....▶ Malignant cancer





# What is palliative care?

You may be reading this booklet because you or someone you know has advanced cancer. The health 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 comfortably as possible. The main goal is to help you maintain your quality of life by dealing with 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 supports families and carers.

## Who provides care?

A palliative approach to care may be delivered by doctors, nurses, allied health professionals, volunteers and carers. Together these people make up your palliative care team (see pages 19–23). Your care may be coordinated by one member of the team who communicates with you.

People with more complex and ongoing needs may see a specialist palliative care service. This service is provided by a team with extra training and it can also provide advice to other health 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 where you live, you can have palliative care at home, in a community setting such as a residential aged care facility, in a hospital or a specialist palliative care unit (see page 15).



Person-centred care is care that treats you in the way you'd like to be treated and listens to your needs, preferences and values, as well as the needs of your family and carers. It means that your health care provider will involve you in planning your treatment and ongoing care.

## What care is available?

Palliative care offers a range of care and support options that can be tailored to meet your individual needs in five areas.

**Physical needs** – This may include: relief of symptoms such as pain, breathlessness and nausea; help with medicines; help with movement; suggesting changes around the house to make things easier and safer; and referrals to services to give your carer a break for a short period of time (respite care).

**Emotional needs** – This may include support for families and carers to: talk about the changes advanced cancer brings and other sensitive issues; plan for the future about what type of care you may need and where you would prefer to receive care; work through feelings and referral to counselling; and help you cope with loss or grief.

**Cultural needs** – This can include ensuring care is culturally sensitive and appropriate.

**Social needs** – This can: help you achieve your goals, such as how to get the most out of each day; assist with day-to-day needs; provide advice on financial issues; and help identify or set up a support network.

**Spiritual needs** – This involves support for your spiritual concerns, such as finding meaning, purpose and value in life.

## How palliative care works

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

### Person-centred care



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

### Where care is provided



The health professionals in the palliative care team will work with you and your carers to help plan 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).

### When to start



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

### Who provides care



Your palliative care team is made up of people with different skills to help you with a range of issues (see pages 19–23). Your care may be led by your general practitioner (GP), nurse practitioner or community nurse, or if your care needs are complex, by a specialist palliative care team.

## Support services



The palliative care team will help you work out how to live in the most fulfilling 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.

## Family and carers



With your agreement, the palliative care team will involve your family and carers in decisions about care. They will also provide them with emotional support and referrals to counselling, grief support, respite, and financial assistance.

## Symptom relief



Palliative treatment can help you manage symptoms related to the cancer or its treatment, such as pain, appetite loss, shortness of breath or fatigue (see pages 28–36).

## Advance care planning



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

## Equipment



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

# Key questions

## **Q: Does palliative care mean I will die soon?**

**A:** When most people hear the term palliative care, they fear that it means their treatment team has given up hope or they are going to die soon. This is certainly not the case for everyone referred to palliative care. This fear is one reason that some people don't access palliative care services early – or at all. 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 limits of your illness. It's not simply about dying.

Some people live comfortably for months or years after a diagnosis of advanced cancer, and can be supported by palliative care as needed. 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 adjust your care to meet your changing needs.

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

**A:** Depending on your needs, you may use palliative care from time to time or you may use it regularly for a few weeks or months. Some people receive palliative care for several years. This is because improved cancer treatments can sometimes stop or slow the spread of advanced disease and relieve symptoms for a number of years. The cancer may then be considered a chronic (long-lasting) disease. There is no need to wait until you need end-of-life care, as research shows having palliative care early on improves quality of life for people with cancer.

*“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 do I get palliative care?**

**A:** To access palliative care, you will need a referral from your GP, medical specialist or other health professional. Once you know the cancer is at an advanced stage, you can consider having palliative care.

Sorting out care sooner rather than later will reduce stress on you and your family. You can find out what the different team members do and how they can help now or in the future. It will give you time to better understand and manage any physical symptoms (such as pain or nausea), and to consider your emotional, cultural, social and spiritual needs.

## **Q: Can I still have cancer treatment?**

**A:** If you have palliative care, you can still have active treatment to shrink the cancer or stop it growing. The palliative care team will work with your cancer specialists to manage side effects from treatment and maintain your quality of life. Cancer treatments such as surgery, drug therapies and radiation therapy may also be used as part of palliative treatment. In this case, the aim is not to cure the cancer but to control the cancer or relieve symptoms (see pages 28–36). You may also want to consider joining a clinical trial (see page 32).

## Q: Does palliative care shorten or lengthen life?

**A:** Palliative care treats 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 throughout the advanced stages of illness. 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.

## Voluntary assisted dying

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It is important to understand the difference between palliative care and voluntary assisted dying.

Voluntary assisted dying is when a person with an incurable condition or illness chooses to end their life and uses medicines specially prescribed by a health practitioner. “Voluntary” means it is the choice of the person to end their life.<sup>2</sup>

Voluntary assisted dying is not part of palliative care.

At the time of publication (August 2021), voluntary assisted dying is illegal in most Australian states and territories. In Victoria and Western

Australia, voluntary assisted dying is legal only for people who meet all the strict conditions and follow certain steps. Visit [health.vic.gov.au](http://health.vic.gov.au) or [health.wa.gov.au](http://health.wa.gov.au) and search for “voluntary assisted dying” to find out more about the law in these states.

Voluntary assisted dying laws have been passed in Tasmania and South Australia, and voluntary assisted dying is likely to start in late 2022. The laws in some other states and territories are under review.

For more information and updates, visit [end-of-life.qut.edu.au/euthanasia](http://end-of-life.qut.edu.au/euthanasia).

## Finding hope

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Some people avoid palliative care because they hope that a cure will be found for their cancer. Having palliative care does not mean giving up hope. You may find that you focus 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 people take pleasure

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

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, such as planning a family trip. Palliative care can help you achieve these goals.

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## Q: Who will coordinate my care?

**A:** In most cases, a GP or community nurse will coordinate your palliative care. If your care becomes complex, 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 hard 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. Some specialist palliative care services can visit you at home. You may also need to stay in hospital or a palliative care unit (hospice) for short periods to have medicines adjusted or get 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:** This is a common concern for people. Depending on your condition, you may need a little help with a few things or more help with lots of daily tasks. This is likely to change over time.

Your palliative care team will discuss practical ways you can maintain a sense of independence for as long as possible. They may suggest modifications or services to help you stay at home (such as installing handrails or a ramp). They may also recommend or loan you 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. If you feel you are losing your independence, you might feel angry and fear what the future holds.

*“I see a palliative care person every eight weeks. Not for direct intervention but to discuss what particular things might be confronting me. It is a security to know that there is a team and individual nurses you can call upon if you need them.”* BRYCE

## Q: Where can I have palliative care?

A: You can have palliative care in different places, including:

- your own home
- at a residential aged care facility or other out-of-home facility
- in a hospital
- at a specialist palliative care unit (hospice).

An important role for the palliative care team is to work out the best place for your care. The team will consider your care needs, 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.

You and your family may be able to choose where you want to receive palliative care. You may be able to move between these places as your needs change.

Many people want to receive care at home because it is a familiar environment close to family and friends. If you are cared for at home, you (and anyone who cares for you) may be able to receive community-based palliative care services. This can include a range of services on an occasional or regular basis.

Depending on your situation, it may not be possible to stay at home, even with home help. Hospitals and palliative care units are designed for short-term stays, usually for people nearing end of life.

If you cannot return home and need care for several months or more, the palliative care team will talk to you and your carers about where you can receive 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, in a residential aged care facility, or in hospital (inpatient care).

Sometimes you may need to pay part of the cost of care. Examples of extra costs include:

- hiring specialised equipment for use at home
- paying for medicines
- paying for your own nursing staff if you choose to stay at home and need 24-hour assistance
- paying an excess if you have private health insurance that covers palliative care and you go to a private hospital
- using short-term care (respite services) that charge a fee
- paying the fee of a private allied health professional, such as a psychologist or physiotherapist (you may be eligible for a Medicare rebate for up to five visits per calendar year as part of a Chronic Disease Management Plan with your GP)
- 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](http://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, check what is covered with your health fund. Ask your social worker about what financial help is available for patients and carers from Centrelink and other organisations in your area.



## **Anna's story**

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*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 talked about how palliative care could make my husband's life easier and more meaningful. I found it so useful to know that help was available when I needed it.*

*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 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.*

## Key points about palliative care

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### What it is

- Palliative care is person-centred care that helps people with a progressive, life-limiting illness to live as comfortably as possible.
- It is useful at all stages of advanced cancer. It is not only about end-of-life care.
- It helps meet your physical, emotional, cultural, social and spiritual needs.
- Palliative care also supports families and carers.

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### How to get palliative care

- Ask for a referral from your GP, medical specialist or other health professional.
- Palliative care is best started early on to help you maintain the best quality of life, according to your wishes, for as long as possible.

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### Who provides care

- Care is provided by doctors, nurses, allied health professionals, volunteers and carers.
- Specialist care is available for people with more complex and ongoing needs.

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### Where do you have care

Care can be provided at your home, or in a residential aged care facility, hospital or specialist palliative care unit (hospice).

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### What it costs

Many federal, state and territory palliative care services are free. You may need to contribute to the costs of some services.



# 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. Spiritual care practitioners and volunteers can offer practical and emotional support. They may sometimes form an important part of your team.

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

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

If you are being treated at end of life and you have cultural or religious beliefs and practices about dying, death and bereavement, or particular family customs, let your palliative care team know. Aboriginal and Torres Strait Islander health workers work with other health professionals to provide care that is respectful to culture.

## Possible members of the palliative care team

### General practitioner (GP) or family doctor

- 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)
- talks with your nurse and/or palliative care specialist to coordinate 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 needed

### Nurse

- may be a community nurse or a specialist palliative care nurse
- 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 help with personal care
- helps you manage pain and other symptoms with medicines, treatments and practical strategies

### Palliative care specialist, physician or nurse practitioner

- oversees 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 and for people attending an outpatient clinic)
- may also be part of a community specialist palliative care service and visit you in your home or in a 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



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 cancer and may refer you to a specialist palliative care team</li><li>• oversees treatment (such as surgery, chemotherapy, immunotherapy, targeted therapy or radiation therapy) aimed at slowing cancer growth and/or managing symptoms of the cancer</li><li>• may manage some aspects of your palliative care</li></ul>	<ul style="list-style-type: none"><li>• trained in listening and offering guidance</li><li>• allows you to talk about any fears, worries or conflicting emotions</li><li>• helps you talk about feelings of loss or grief</li><li>• assists you and your family to talk together and to explore relationship or emotional issues</li><li>• might suggest strategies for 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 teach 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>• helps you reflect on your life and, if you choose, may help you in your search for meaning</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>

## Possible members of the palliative care team – continued

Social worker	Physiotherapist	Occupational therapist
<ul style="list-style-type: none"> <li>• assesses what support you, your family and carers need, and identifies ways you can receive this support</li> <li>• provides practical and emotional support to you, your family and carers</li> <li>• provides referrals and information to legal services, aged and disability services, and housing support</li> <li>• helps you communicate with your family and health professionals, including about changes to your care goals</li> <li>• discusses ways of coping and emotionally supporting your children, grandchildren or other dependants</li> <li>• may provide counselling and emotional support, including working through feelings of loss and grief</li> <li>• in some cases, may help arrange care for dependants or pets</li> </ul>	<ul style="list-style-type: none"> <li>• helps to keep you moving and functioning as well as you can</li> <li>• 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</li> <li>• shows you how to exercise to reduce pain and stiffness</li> <li>• uses a range of manual techniques to help manage lymphoedema, and clear congestion from your lungs, and teaches you breathing exercises to better manage breathlessness</li> <li>• may work with a massage therapist to relieve stiff and sore muscles or swelling, or a podiatrist to treat any foot conditions</li> </ul>	<ul style="list-style-type: none"> <li>• helps you manage the physical aspects of daily activities, such as walking, bathing, and getting into and out of bed and chairs</li> <li>• 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</li> <li>• organises equipment hire or modifications to your home to make it safer and more accessible (e.g. handrails, shower chair)</li> <li>• teaches carers and family members the best ways to move you or help you sit and stand</li> <li>• helps you prioritise your daily activities to conserve your energy for important tasks</li> </ul>

Pharmacist	Dietitian	Volunteer
<ul style="list-style-type: none"> <li>• supplies prescription and over-the-counter medicines</li> <li>• can put your tablets and capsules into a medicine organiser (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 manage symptoms 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</li> <li>• helps you choose suitable 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 problems swallowing food and drinks</li> </ul>	<ul style="list-style-type: none"> <li>• offers friendship, support and companionship</li> <li>• roles will vary, depending on the organisation they volunteer for</li> <li>• may provide 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>• may be found through a palliative care service – these volunteers are screened, trained and supervised</li> <li>• can also be found through your state or territory palliative care organisation</li> <li>• 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</li> </ul>



# Looking ahead

This chapter covers some of the practical and legal issues to consider when using palliative care.

## 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. It's a very personal decision.

If you want to know, you can ask your doctor. They won't be able to give you an exact answer, but can give a general indication of your life expectancy, based on an average patient. Your doctor will probably talk in terms of days to weeks, weeks to months, or months to many months. As everyone responds to treatment differently, the actual time could be shorter or longer.

Sometimes, families and carers want to know the prognosis even when you don't. You can ask the palliative care team to talk to your family or carer when you're not there.

Dealing with death is difficult and confronting for most people and their families. Talking about any emotions you are experiencing may help you come to terms with your situation (see pages 43–44).

Feeling low or depressed is common after a diagnosis of advanced cancer. Talking to your family and friends, your GP or a counsellor, social worker, psychologist or spiritual adviser may help.

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

## Advance care planning

When diagnosed with a life-limiting illness, some people think about what is important to them. 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. It can involve:

- completing advance care documents – see next page
- appointing a substitute decision-maker – see next page.

While it may be difficult to think about, some people find planning ahead helps them. Advance care planning can be started at any stage, whether you feel well or ill. It allows you to share your preferences for your future health care if you become unable to make decisions for yourself.

Making your wishes clear can help give you peace of mind. Think about 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? Where would you like to be cared for? Everyone has their own individual preferences, and these will often change as your circumstances change. You and your family may find it useful to start thinking about these issues before they are raised by a health professional.



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

## Making an advance care directive

You can write down your goals and instructions for your future medical care in a document known as an advance care directive. Depending on where you live, the advance care directive may have a different name such as an advance health directive or advanced care plan. This document provides a record of your values and treatment preferences. Doctors, family, carers and substitute decision-makers can consider this record if you become unable to communicate or make decisions.

You can update 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](http://myhealthrecord.gov.au).

## Appointing a substitute decision-maker

The ability to make a legally binding decision is called capacity. You can legally appoint someone to make medical decisions for you if in the future you lose capacity to make these decisions yourself.

A substitute decision-maker should be someone you trust. They should understand your values and preferences for future care and be able to make decisions you would have wanted. 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 medical treatment decision maker.

► See our *Cancer Care and Your Rights* booklet.



Each state and 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 [www.advancecareplanning.org.au](http://www.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 symptoms of cancer without trying to cure the disease. The treatment you are offered will depend on your individual needs, what type of cancer you have, how far it has spread, your symptoms, and the support you have. Some examples of palliative treatment include:

- 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. Let your palliative care team know about any side effects you may have so they can be managed.

## Making treatment decisions

You have the right to say no to any treatment recommended, but your medical team need to be confident that you understand what you've been offered and how not having the treatment may affect your prognosis. You do not have to accept treatments on an all-or-nothing basis – you can refuse some and accept others. Treatments 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. You may want to discuss your decision with the treatment team, GP, family and friends, or call Cancer Council 13 11 20.

► See our *Living with Advanced Cancer* booklet.

## Types of palliative cancer treatments

### surgery

Surgery can be used to:

- remove all or part of a tumour from affected areas, such as the bowel or lymph nodes
- relieve discomfort caused by tumours blocking organs or pressing on nerves
- reduce tumour size (debulking) to help improve outcomes from chemotherapy and radiation therapy
- insert a thin tube (stent) into a blocked organ to create a passage for substances to pass through.

### drug therapies

Drugs can travel throughout the body. This is called systemic treatment. Drug therapies include:

- **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 uses the body's own immune system to fight cancer
- **targeted therapy** – drugs that target specific features of cancer cells to stop the cancer growing.

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.

### radiation therapy

This uses 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 cancers in the bones. You can have radiation therapy in different ways and doses. It can be given in single or multiple visits.

## Managing symptoms

One of the main aims of having palliative treatment is the relief of symptoms. These symptoms can impact your quality of life and be distressing for your family. While it may not be possible to alleviate all symptoms, the suggestions in this chapter can 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. For more information and support, call Cancer Council 13 11 20.

### Pain

Whether you have pain will depend on where the cancer is and its size. Pain is different for everyone, 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 the distress it is causing 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 (such as morphine, oxycodone, hydromorphone and fentanyl) for strong pain
- other types of medicine for nerve pain, such as antidepressants, anticonvulsants and local anaesthetics
- anti-anxiety drugs for muscle spasms
- procedures such as implanted devices, nerve blocks and 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 and radiation therapy (see previous page).

Some people worry about becoming addicted to pain medicine but this is unlikely when medicines are taken palliatively. Your health care team will monitor you to avoid potential side effects. Any side effects, such as constipation or drowsiness, can usually be managed. Taking high-strength opioids (such as morphine) as prescribed 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 the dose you have been prescribed does not relieve your pain. Ask your specialist palliative care team or your GP to regularly review your pain management plan, especially if you have side effects from the pain medicine.

► See our *Understanding Cancer Pain* booklet.



## Ways to manage medicines

If you're taking several different medicines throughout the day, there are many ways to remember what you need to take and to help ensure you have the correct dose at the right time.

- Ask your palliative care team for a list of medicines and what each one is for.
- Ask your pharmacist to put your tablets and capsules into a medicine organiser (e.g. Webster-pak), which sets out all the doses you need to take throughout the week. This will help you take the correct dose of each drug at the right time.
- Keep a medicines list to record what you need to take, when to take it and how much to take.
- Download the MedicineWise app from the App Store or Google Play or order a printed NPS MedicineWise list at [nps.org.au/order](https://nps.org.au/order). You can also create your own list on paper or computer.

## Should I join a clinical trial?

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Your doctor or nurse may suggest that 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. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, clinical trials have improved palliative care and the management

of common symptoms of advanced cancer, and led to better outcomes.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

► See our *Understanding Clinical Trials and Research* booklet.

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## Problems with eating and drinking

Many people with advanced cancer do not feel like eating or drinking. This may be because of the cancer or a side effect of treatment. Loss of appetite may also be caused by anxiety, fatigue or depression. However, food and drinks help maintain your strength and bowel movements, which improves your quality of life.

**Loss of appetite** – You don't need to force yourself to eat. This may make you feel uncomfortable, and cause vomiting and stomach pain. Try having small meals, eating your favourite foods more frequently, and relaxing your usual 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.

**Nausea** – You may feel sick (nausea), have reflux 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 below) can also cause nausea and appetite issues.

Having an empty stomach can make your nausea worse – try to eat something soon after getting up in the morning and then eat small meals and snacks regularly throughout the day. 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.

**Difficulty swallowing** – If chewing and swallowing become difficult, you may need to change the consistency of your food by chopping, mincing or pureeing. A speech pathologist can check how you're swallowing.

▶ See our *Nutrition and Cancer* booklet.

## Bowel changes

Many people have difficulty passing bowel motions (constipation), often as a side effect of opioids, cancer treatments or other medicines, or because of changes to what they're eating or how much they're moving.

The usual suggestions for managing constipation, such as drinking lots of water, eating a high-fibre diet and exercising, may not be possible if you feel unwell. Your treatment team will discuss other ways of managing constipation, such as laxatives and stool softeners.



Palliative Care Australia has resources on 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](http://palliativecare.org.au).

## Shortness of breath

Breathlessness (dyspnoea) is an uncomfortable feeling of being short of breath. It may be caused by the cancer itself, an infection, a side effect of treatment, anxiety or an underlying disorder such as asthma or emphysema.

Depending on the cause, breathlessness may be managed with taking medicine (such as low-dose morphine), draining fluid from around the lungs, or having oxygen therapy (if your oxygen levels are low). Simple ways to improve breathlessness are to:

- sit near an open window
- use a handheld fan to direct a cool stream of air across your face
- sleep in a more upright position
- listen to a relaxation recording – look for our *Finding Calm During Cancer* podcast in Apple Podcasts or Google Play.

## Fatigue

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

Your palliative care team may be able to adjust your medicines or treat the cause of the fatigue. A physiotherapist, exercise physiologist or occupational therapist can explain how to modify your activities to help you conserve your energy.

You may find that the fatigue gets worse as the disease progresses – complementary therapies such as meditation and relaxation can reduce distress and help you and your family cope.

- ▶ See our *Fatigue and Cancer* fact sheet.

## Changes in mood

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

It is quite common for people diagnosed with advanced cancer to have continued feelings of depression. 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, because counselling or medicines – even for a short time – can help.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit [beyondblue.org.au](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline 13 11 14 or visit [lifeline.org.au](http://lifeline.org.au).

You may find that while some friends and family members are supportive, others may avoid you or not know what to say. This can be difficult, and you could feel 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.

## Sexuality and palliative care

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People with advanced cancer usually experience major physical and psychological changes. While these can have an effect on how you feel sexually, it doesn't mean that intimacy needs to end.

For many people, 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.

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## Complementary and alternative therapies

You may wonder whether you should try complementary and alternative therapies. It is important to understand how they are different.

Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as meditation, massage and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctors know about any 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. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

► See our *Understanding Complementary Therapies* booklet.



# Palliative care for young people

As with palliative care for adults, palliative care for babies, children and teenagers focuses on maintaining quality of life by dealing with their physical, emotional, cultural, social and spiritual needs, and supporting the family. The palliative care team will also consider the young person's stage of development, which will affect their understanding of illness and ability to participate in making decisions.

Palliative care for young people is provided by health professionals who specialise in paediatrics (the care of children), as well as palliative care experts. Most children's hospitals have specialist paediatric palliative care services who can provide care directly or advise the cancer care team. Family are considered part of the palliative care team.

Depending on the needs of the young person and their family, palliative care may be in the home, in hospital or, where available, in a children's 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 next page.

The hospital social worker can also provide support and may know of other useful networks in your local community. You can also call Cancer Council 13 11 20.

**CanTeen** – This service 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. Call 1800 835 932 or visit [canteen.org.au](http://canteen.org.au).

**Camp Quality** – This service offers support for children aged 0-15 living with cancer, and their families, through each stage of the cancer experience, including palliative care and bereavement. Call 1300 662 267 or visit [campquality.org.au](http://campquality.org.au).

**Redkite** – This charity supports young people and their families through cancer by providing emotional guidance (including bereavement support), financial assistance and educational services. Call 1800 733 548 or visit [redkite.org.au](http://redkite.org.au).

**Youth Cancer Services** – This service provides 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](http://canteen.org.au/youth-cancer).

**Palliative Care Australia** – This organisation provides detailed resources to help families and carers prepare for situations they may face during their child's illness. You can download these resources from [palliativecare.org.au/children](http://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.

## 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. The person you are caring for must give written consent before the palliative care 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 for both the person with cancer, and their family and carers. The palliative care team will help identify services that can offer emotional and practical support to you in your caring role. Ask your health care team who to contact 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. They may also feel overwhelmed as they juggle work, their family and the person they are caring for. Accepting help from the palliative care team can mean you can spend more quality time with the person you're caring for.



## Where carers can find support

As a carer you may need support at any stage of cancer, but your responsibilities usually increase if the disease progresses. You may need help managing symptoms, providing personal care, preparing food and organising finances.

- Read our *Caring for Someone with Cancer*, *Living with Advanced Cancer* and *Facing End of Life* booklets.
- Find fact sheets and videos for carers on the Palliative Care Australia website. Visit [palliativecare.org.au/im-a-carer](http://palliativecare.org.au/im-a-carer). Topics include what is palliative care, managing symptoms, and caring for yourself.
- Find information on home help, transport and respite care, as well as counselling and support groups near you, from Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).
- Listen to *The Thing About Advanced Cancer* podcast episodes for carers.
- Call Cancer Council 13 11 20 for more information.

## Respite (short-term) care

Caring can be demanding and can affect your own physical and emotional wellbeing. Respite care lets carers have a break.

Some carers don't arrange respite care because they feel guilty or concerned about leaving the person they are caring for. But by taking a break, you will probably find that you can continue your caring role with more energy and enthusiasm.

You may feel you need respite care 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 sleep. 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).

It's a good idea to start looking into respite services before you actually need them. Talk to your doctor, social worker or the palliative care team about what services are available and how you can access them. Carer Gateway also provides information on local carer support services, respite options and other support that may suit your needs. What respite care is available can vary depending on where you live. For more information and to organise emergency respite, visit [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737.

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 have a range of emotions. Talking to a counsellor or social worker may help you work through your worries and concerns, learn ways to communicate, and cope with changes in your life.

If the person you are caring for is nearing the end of life, the palliative care team can 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. Some carers may experience depression and/or anxiety (see page 35). 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.

**Carer Gateway** – This service can connect you with carer services in your area. You can also talk to the Carer Gateway Counselling Service about your concerns and how you feel about your carer role. Carer Gateway can also put you in touch with other carers in your area or you can join an online carer forum. For more information, call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**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](http://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 or for support in your local community, call 13 11 20.

**Young Carers** – For age-appropriate information, visit The Young Carers Network at [youngcarersnetwork.com.au](http://youngcarersnetwork.com.au). To find respite services for carers under 25, call Carer Gateway on 1800 422 737.

*“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

# Support and information

There is a range of services that can help with palliative care. The availability of services may vary depending on where you live. Some services are free, but others may have a cost. Talk to your health care team or call Cancer Council 13 11 20 to find out what services are available.

## Useful contacts

### Carer services

Carer Gateway  
1800 422 737  
[carergateway.gov.au](http://carergateway.gov.au)

Practical information, support and useful resources for carers.

Carers Australia  
[carersaustralia.com.au](http://carersaustralia.com.au)

National body working with state and territory Carers Associations to provide information and advocacy for carers.

Young Carers  
[youngcarersnetwork.com.au](http://youngcarersnetwork.com.au)

Support for young people under 25 caring for a family member or friend.

### Counselling and mentoring services

Australian Psychological Society  
[psychology.org.au](http://psychology.org.au)

Use the “Find a Psychologist” search to look for a practitioner in your area.

Better Access initiative  
[health.gov.au/mentalhealth-betteraccess](http://health.gov.au/mentalhealth-betteraccess)

Information about Medicare rebates for mental health services organised through your GP.

## Counselling and mentoring services – continued

Beyond Blue 1300 22 4636 <a href="http://beyondblue.org.au">beyondblue.org.au</a>	24-hour telephone counselling service; online and email counselling available seven days a week.
Cancer Council's peer support programs 13 11 20	Connect with others affected by cancer online, by phone or in person.
Suicide Call Back Service 1300 659 467 <a href="http://suicidecallbackservice.org.au">suicidecallbackservice.org.au</a>	24-hour telephone and online counselling for people affected by suicide.

## Equipment and aids

Independent Living Centres Australia 1300 885 886	Advice on products and services to help with aspects of day-to-day living, including mobility, sleeping, eating and transport.
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## Financial assistance

Cancer Council's Legal and Financial Referral Service 13 11 20	Referral service for people affected by cancer needing professional advice; free for eligible clients.
Centrelink 132 717 <a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>	Offers financial support for people with a long-term illness and for carers.
NDIS 1800 800 110 <a href="http://ndis.gov.au">ndis.gov.au</a>	Funding and support for people aged under 65 who have a permanent and significant disability.
National Debt Helpline 1800 007 007 <a href="http://ndh.org.au">ndh.org.au</a>	Help with debt problems and finding a financial counsellor.
Pharmaceutical Benefits Scheme (PBS) <a href="http://pbs.gov.au">pbs.gov.au</a>	Assistance with the cost of prescription medicines.
Talk to social worker on the palliative care team.	May be able to help you find legal or financial support.

## Future planning

Advance Care Planning Australia  
1300 208 582  
[www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)

Information about planning for your future health care, including advance care directives.

Dying to Talk  
[dyingtotalk.org.au](http://dyingtotalk.org.au)

Palliative Care Australia website encouraging Australians to talk about dying; includes discussion starters.

The Groundswell Project  
[thegroundswellproject.com](http://thegroundswellproject.com)

Community organisation using creativity to promote resilience and wellbeing throughout all phases of life.

## Home help

Talk to your palliative care team, GP and/or health fund.

Some local councils provide services in the home or in the community.

My Aged Care  
1800 200 422  
[myagedcare.gov.au](http://myagedcare.gov.au)

Information about different types of aged care services and eligibility.

## Home nursing

Ask your local council or your palliative care team.

Private services are also available.

## Legal information

End of Life Law in Australia  
[end-of-life.qut.edu.au](http://end-of-life.qut.edu.au)

Information from the Australian Centre for Health Law Research on the law relating to advance directives, stopping treatment, palliative care and voluntary assisted dying.

Public Trustees Australia

Help you prepare a will and manage your finances. Type “public trustee” in your search engine to find the public trustee in your state or territory.

## Palliative care

CareSearch  
[caresearch.com.au](http://caresearch.com.au)

Evidence-based palliative care information and links to services, as well as resources for health professionals.

Palliative Care Australia  
[palliativecare.org.au](http://palliativecare.org.au)

Information and resources; can link you to your local palliative care office. Also has a directory of services.

## Respite care

Carer Gateway  
1800 422 737  
[carergateway.gov.au](http://carergateway.gov.au)

Links to respite care at home, in a respite care centre or, in some cases, in a hospital or palliative care unit.

## Spiritual or pastoral care

Talk to your palliative care team or GP.

Many hospitals have a spiritual care practitioner (pastoral carer).

## Support and information

Cancer Council Online Community  
[cancerCouncil.com.au/OC](http://cancerCouncil.com.au/OC)

An online discussion forum where people can connect with each other any time, ask or answer questions, or write a blog about their experiences.

Cancer Council's telephone support groups  
13 11 20

Includes groups for people with advanced cancer, for carers and for the bereaved.

Cancer Council podcasts  
[cancerCouncil.com.au/podcasts](http://cancerCouncil.com.au/podcasts)

Information and insights for anyone affected by cancer. Separate series about advanced cancer.

## Support from Cancer Council

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

### Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

### Information resources



Cancer Council produces booklets and fact sheets on more than 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.

### 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.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

### 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](http://cancerCouncil.com.au/OC).

# Question checklist

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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.

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## Palliative care

- Who can refer me to 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 contact the palliative care team at any time? Who do I call 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?
  - If the cancer cannot be cured, what is the aim of the treatments?
  - Will I receive active 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 has developed more questions after discussions with people receiving palliative care and their families and friends. Visit [palliativecare.org.au/asking-questions](http://palliativecare.org.au/asking-questions).

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# Glossary

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## **advance care planning**

When a person thinks about their future health care and discusses their preferences 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. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer).

## **allied health professional**

A university qualified 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.

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## **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.

## **clinical trial**

A research study that tests new approaches to prevention, screening, diagnosis or treatment, to see if they are better than current approaches.

## **community nurse**

A nurse who provides 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.

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## **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.

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

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

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## **holistic care**

Care of the whole person. It can include different types of therapies and services to ensure that a person’s physical, emotional, cultural, social and spiritual needs are met. Palliative care is holistic care.

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## **immunotherapy**

Drugs that use the body’s own immune system to fight cancer.

## **inpatient**

A person who stays in hospital while having treatment.

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## **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.

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**malignant**

Cancerous. Malignant cells can spread (metastasise) 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 or advanced cancer.

**multidisciplinary care**

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

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**oncologist**

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

**opioids**

The strongest pain medicines available. They are used to reduce some types of pain.

**outpatient**

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

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**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, social and spiritual needs. Also called 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 manage complex care, including referral to other health professionals, prescribing some medicines and ordering 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, and the patient, family and carers.

**palliative care unit**

A place that provides 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.

**person-centred care**

Care that is respectful of, and responsive to, the preferences, needs and values of the individual patient.

**practice nurse**

A nurse who works in general practice.

**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.

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**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.

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### **radiation therapy**

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also known as radiotherapy.

### **recurrence**

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

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### **secondary cancer**

See metastasis.

### **specialist palliative care service**

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

### **spiritual practices**

Connection with a higher being or one's inner self, which often brings comfort and understanding about the world, one's place in it and the reasons behind life's challenges. Also called spirituality.

### **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.

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### **targeted therapy**

Drugs that attack specific features of cancer cells to stop the cancer growing and spreading.

### **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.

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### **voluntary assisted dying**

When a person with an incurable condition or illness chooses to end their life and uses medicines specially prescribed by a health practitioner. It is legal in Victoria and Western Australia for people who meet all the strict conditions. The law has recently changed in Tasmania and South Australia, but voluntary assisted dying is illegal until the laws begin. It is illegal in all other states and territories.

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### **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).

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## **References**

1. Australian Government, *National Palliative Care Strategy 2018*, Department of Health, Canberra, 2018.
2. B White, L Willmont and P Neller, *End of Life Law in Australia*, End of Life Law in Australia website, viewed 30 June 2021, available from [end-of-life.qut.edu.au](http://end-of-life.qut.edu.au).



# 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 experienced health professionals 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.



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. [communications.gov.au/accesshub/nrs](https://communications.gov.au/accesshub/nrs)

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

For information & support  
on cancer-related issues,  
call **Cancer Council 13 11 20**

Produced in collaboration with:



## Visit your local Cancer Council website

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**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council Tasmania**  
[cancer.org.au/tas](http://cancer.org.au/tas)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council Australia**  
[cancer.org.au](http://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.*

