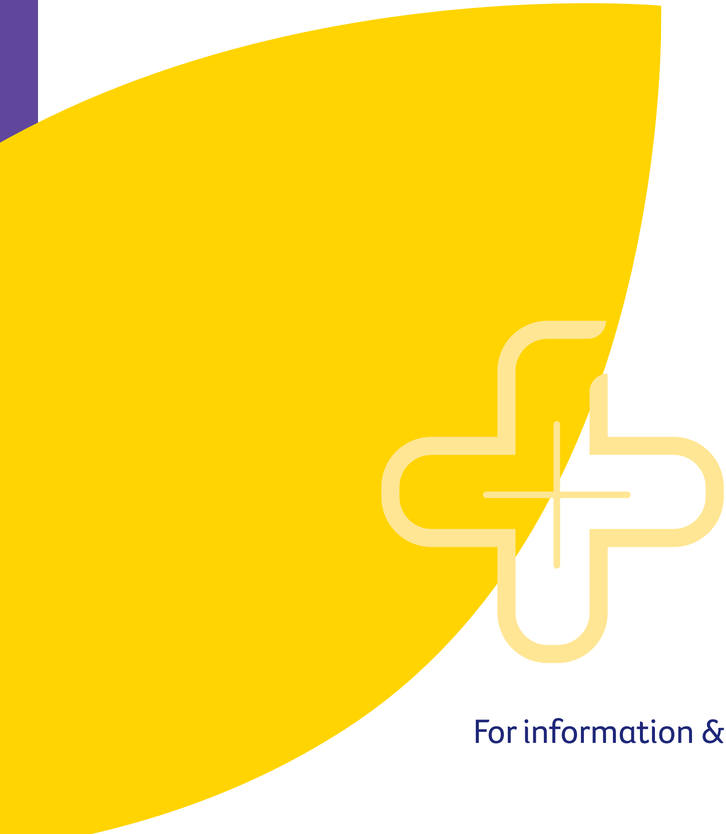
Cancer Council

TREATMENT

Understanding
Palliative Care

A guide for people with cancer, their families and friends



For information & support, call **13 11 20**

Understanding Palliative Care

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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 8 state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.

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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About this booklet

This booklet has been prepared to help you understand more about palliative care (sometimes part of supportive care). Although palliative care is for anyone with a life-limiting illness, this booklet is written for people with advanced cancer and their carers, family and friends.

The aim of palliative care is to improve your quality of life and help you stay independent for as long as possible. It is recommended for anyone diagnosed with 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. Talk to your health care team about the best approach for your situation. This booklet offers general information about palliative care. 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.[1]

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:

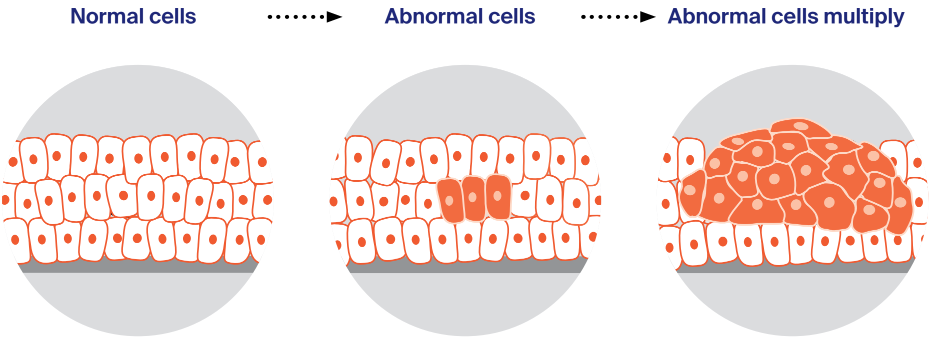
🔍 More information
💬 Personal story
💡 Tips

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 move rapidly, and others behave unpredictably. While some types of cancer respond well to treatment, 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.

How cancer starts

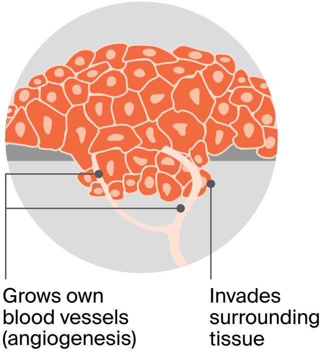


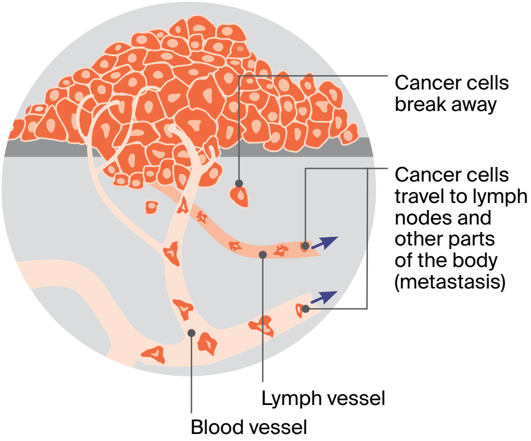
If cancer cells from the primary site break away and travel through the bloodstream or lymph vessels to other parts of the body, they can grow and form another tumour at a new site. This is called advanced cancer, secondary cancer or metastasis. The most common sites a cancer may spread to include the 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 usually can't cure advanced cancer, they may be able to slow its growth or spread, or relieve symptoms. Palliative care can help manage symptoms and reduce side effects at any stage of advanced cancer. This often helps maintain quality of life for months or years.

How cancer spreads

Malignant cancer





Having palliative care

Palliative care can help people with a progressive, life-limiting illness to live as fully and comfortably as possible. The main goal is to maintain your quality of life by identifying and helping you with any physical, emotional, cultural, social and spiritual needs. Because everyone is different, palliative care needs vary from person to person.

You can continue to have cancer treatment while you are also having palliative care. Starting palliative care may improve your quality of life and also be helpful to your carers or family.

Palliative care may be given at home, in a hospital, in a palliative care unit (which may also be called a hospice), in a residential aged care facility or through community-based palliative care providers.

Most often, your general practitioner (GP) or a community nurse will organise and coordinate your palliative care. But sometimes this role may be done by a palliative care doctor at a hospital.

Doctors (including GPs and other specialists), nurses, nurse practitioners, physiotherapists, occupational therapists, social workers, spiritual care practitioners, volunteers and carers are just some of the people who often deliver palliative care. Together, the people who look after your palliative care are called your palliative care team (see pages 18–22).

Palliative care takes a person-centred approach. This means treating you in the way you'd like to be treated; listening to your needs, preferences and values, as well as the needs of your family and carers; and involving you in planning your treatment and ongoing care.

Types of palliative care available to you

Palliative care offers a range of care and support options that can be tailored to meet your individual needs in 5 areas.

Physical needs – You may need relief of symptoms such as pain, breathlessness, nausea, restlessness and constipation or help with medicines. Palliative care practitioners can help you with moving around or they may suggest changes around the house to make things easier and safer for you. You may be offered a referral to services that give your carer a break for a short period of time (respite care).

Emotional needs – Palliative care can offer support for you, your family and carers to talk about the changes advanced cancer brings or other sensitive issues. You may also need help to decide what's important to you, and to plan for your future care and where you would like to receive it. You can seek help to work through feelings with a counsellor or psychologist.

Cultural needs – Palliative care ensures that the care and conversations that you have are sensitive to your culture, ethnicity, background, beliefs and values.

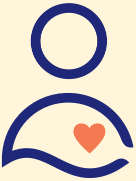
Social needs – You can find help to achieve your goals and get the most out of each day through palliative care. It looks at your day-to-day needs, such as living arrangements, transport to medical appointments, meals, advice on financial issues or help to set up a support network.

Spiritual needs – This support may come from religious leaders you know (e.g. a pastoral carer or chaplain), or it may be available from spiritual care practitioners, or other professionals on the palliative care team.

How palliative care works

Palliative care supports the needs of people living with a life-limiting illness in a holistic and patient-centred way. It aims to maintain your quality of life and make

Person-centred care

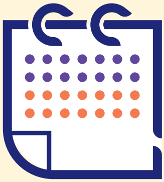


This means that the palliative care team will work with you to assess what you need. They can then make suggestions about treatment and ongoing care. Your care goals may change over time.

Where care is provided

The palliative care team will work with you and your carers to help plan the best place for your care. At different times you 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. Contacting a palliative care team after a diagnosis of advanced cancer can help you work out when is best to start palliative treatment and how to manage symptoms.

Who provides care

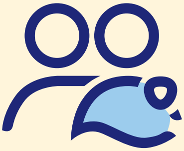
Your palliative care team is made up of people with different skills to help you with a range of issues (see pages 18-22). Your care may be led by a GP, nurse practitioner or community nurse, or by a specialist palliative care team if your needs are complex. Some people may only see their GP.

the time you have as meaningful as it can be. The focus is on what is important to you and your family.

Support services

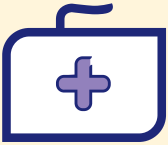
The palliative care team will help you work out how to live in the most fulfilling way you can – this might mean enjoying time with family and friends, recording your memories or reflecting on your life. They can also refer you to organisations and services that can assist with financial, emotional and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

Family and carers



If you agree (consent), the palliative care team will involve your family and carers in decisions about care. They can 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, nausea, loss of appetite, breathlessness or fatigue (see pages 26-32).

Independence

An occupational therapist or physiotherapist can assess you to improve your independence, and suggest equipment or ways to help with daily activities and make it easier for your carers to look after you.

Advance care planning

The palliative care team or a social worker can support you to think about, discuss and record your values, goals and preferences for future care and treatment (see pages 35–37).

Key questions

Q: Does palliative care mean I will die soon?

A: When most people hear about palliative care, they worry it means their treatment team has given up hope or they may die soon. This fear may stop people using palliative care services.

Palliative care aims to maintain quality of life for people living with a life-limiting illness. It's about helping you to live as fully as you can and in a way that is meaningful to you, within the limits of your illness. You don't have to stop your cancer treatment to have palliative care. And you don't always have to be admitted to a hospital or palliative care unit permanently.

Some people live comfortably for months or years after a diagnosis of advanced cancer, and can be supported by palliative care as needed. They may have palliative care for a period of time and then stop when their condition is stable. For others, the cancer advances quickly, and 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 preferences and changing needs.

Q: When should I start palliative care?

A: There is no need to wait until you are close to the end of life – research shows having palliative care early improves quality of life. 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.

Q: How do I get palliative care?

A: Ask your GP, medical specialist or other health professional about what services you may need and a referral. Or you can contact a palliative care service yourself or for someone else. You don't usually need a referral but it can be helpful. Organising care sooner rather than later will reduce stress on you and your family. You can find out what help is available to you now, and what you may want or need in the future. This 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 slow its growth. 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 it or relieve symptoms (see pages 24–33). You may also want to consider joining a clinical trial (see page 17).

If you, or a person you are caring for, is part of the LGBTQI+ community, you may like a copy of our booklet *LGBTQI+ People and Cancer*. You'll find information about palliative care, other cancer-related topics and where to find LGBTQI+ support.

Q: Does palliative care shorten or lengthen life?

A: Palliative care treats death and dying as a normal part of life. The treatment and care provided do not aim to make you live longer, they try to make what time you have as best as it can be.

The palliative care team provides services to improve your quality of life throughout the stages of advanced cancer. 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 or be able to tolerate cancer treatment for longer.

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 usually take 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, you may see a palliative care specialist or nurse practitioner. Usually this will be as an outpatient, but some specialist palliative care services can also visit you at home.

You may need to stay in hospital or a palliative care unit (hospice) for short periods to have medicines adjusted or to get any 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 a period of time, or you may be able to stop having palliative care.

Q: What if I live alone?

A: Some people may live alone or have little or no support from family or friends. They may be living a long distance from anyone who would usually offer practical and emotional support.

Community palliative care services can help you to stay at home for as long as possible. But at some point, you may need 24-hour care. Depending on your circumstances and care needs this may be available in a palliative care unit (hospice), hospital or residential aged care facility.

If you live alone, you could ask for support from:
- your GP or community nurse
- the palliative care team or volunteer palliative care organisations
- Palliative Care Australia (for services available near you)
- My Aged Care
- the local community health service
- culturally-based community services
- your local council
- a church or other religious group
- practical support services (see pages 44–47)
- Cancer Council 13 11 20 or cancer support groups.

It's common to worry about being a burden on friends, family or community organisations. But they may want to help, so talk to them about your needs and ways they can help that work for you both.

"I just have to live my life day by day. I can't predict my future, I can't plan things in the future. But what I can do is love every day and I truly do." ANNE

> *“I see a palliative care person every 8 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 or a family member’s home
- at a residential aged care facility or other out-of-home facility
- in a hospital
- at a specialist palliative care unit (sometimes called a hospice)
- at an outpatient clinic or via telehealth.

An important role for your GP or the palliative care team is to work out the best place for your care. They 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 may be able to choose where you want to receive palliative care, or you may be able to alter arrangements as your needs change. Your choices may depend on what services are available in your area. If you accept palliative care at an inpatient facility, you can still decide to go back home if circumstances allow.

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, to address worsening symptoms, to plan care at home or 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.

Finding hope

Some people avoid palliative care because they hope that a cure will be found for their cancer. But having palliative care does not mean you have to stop seeing your doctor or having treatment, or give up hope.

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. Others make sense of their situation through a creative activity, such as art, music or writing.

You may find that you focus on the things that are most important to you, such as feeling valued, having meaningful relationships or receiving effective pain relief.

As the disease progresses, your goals may change. Palliative care may also help you to be more mobile, or control your pain, so you can achieve more. 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 may help you set and achieve goals.

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

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, in a palliative care unit or hospice, or in hospital (inpatient care).

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

- hiring specialised equipment to use at home
- paying for medicines or wound dressings
- 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
- fees for private allied health professionals, such as a psychologist or physiotherapist (you may be eligible for a Medicare rebate for up to 5 visits per calendar year as part of a chronic disease management plan or 10 visits for a Mental Health Care Plan)
- paying for complementary therapies, such as massage therapy and acupuncture.

Ask what costs may be involved, and what amount may be covered, when making appointments. Cancer Council may be able to connect you to an appropriate financial professional. Call 13 11 20.

Q: Will I lose my independence?

A: Depending on your condition, you may need a little help with a few things or more help with lots of daily tasks. The amount of help you need is likely to change over time.

Your GP or palliative care team will discuss practical ways to maintain your sense of independence for as long as possible. An occupational therapist (your GP or community service can give you a referral) may suggest changes or services to help you stay at home, such as installing handrails or a ramp. An occupational therapist or physiotherapist may also suggest 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. If you feel you are losing your independence, your GP or palliative care team can talk with you about how to keep doing what's important to you as your mobility and health change.

Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial. Clinical trials 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, trials have improved palliative care and the management of common symptoms of advanced cancer. You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

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

The palliative care team

Palliative care is a medical specialty that health professionals receive specific training for. Your palliative care team may 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. This team may include spiritual or pastoral carers and volunteers.

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, such as occupational therapists, physiotherapists and social workers, who are trained to look after people with complex health care issues. Your cancer care team will continue to be involved and work with the palliative care team or your GP at all stages of the illness.

You will have regular appointments or visits with your GP and 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 usually see all these people – some roles overlap and the availability of palliative care specialists varies across Australia. Your GP, nurse, nurse practitioner or palliative care specialist can help you work out the services you’ll need.

If you are at the end of life and have cultural or religious beliefs and practices about dying, death and bereavement, or family customs, let your palliative care team know so that they can provide you with care that respects this.

Possible members of the palliative care team

GP or family doctor	• Coordinates palliative care for many people. • Continues to see you for day-to-day health care issues if you are being cared for at home. • May be able to make home visits. • Talks with your nurse or palliative care specialist to coordinate ongoing care and refer you to a palliative care specialist if you have complex needs. • Organises your admission to hospital or a palliative care unit (hospice) if your circumstances change. • Offers support to you, your family and carers, and gives referrals for counselling and other services.
nurse or nurse practitioner	• May be a nurse, community nurse or specialist palliative care nurse at a hospital, community nursing service, residential aged care facility or palliative care service. • Helps you manage pain and other symptoms with medicines, treatments and practical strategies. • Visits you if you are being cared for at home and provides after-hours telephone support. • Coordinates other health professionals and works out what care you need (e.g. home nursing or personal care). • Refers you to a specialist palliative care unit (hospice).
palliative care specialist, physician or nurse practitioner	• Oversees treatment for symptoms such as pain, nausea, constipation, anxiety, depression, breathlessness. • Usually provides care in a palliative care unit (hospice) or hospital (both for inpatients and outpatient clinics), but may 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 or your family to a counsellor, psychologist or other support person, and assist with decisions about care or treatment, including advance care directives.

Possible members of the palliative care team (continued)

cancer specialist	• May be a medical oncologist, surgeon, radiation oncologist or haematologist and may manage some of your palliative care. • Oversees treatment (e.g. surgery, chemotherapy, immunotherapy, targeted therapy, radiation therapy) aimed at slowing cancer growth and/or managing symptoms of the cancer.
counsellor, psychologist or clinical psychologist	• Trained in listening and offering guidance to help you manage your emotional response to diagnosis and treatment. • Allows you to talk about any fears, worries or conflicting emotions and about feelings of loss or grief. • Helps you and your family talk about relationships or emotions. • May suggest strategies for lessening the distress, anxiety or sadness you and others are feeling or teach meditation or relaxation exercises to help ease physical or emotional pain. • Gives grief care and support to your family and carers.
occupational therapist	• Helps manage physical aspects of daily activities, such as walking, bathing, getting in and out of bed and chairs. Shows carers the best way to move you or help you sit or stand. • Suggests physical aids to help you move around and maintain independence, such as a toilet seat raiser, walking frame or pressure-relieving cushions. Organises equipment hire or home modifications to make it safer and more accessible (e.g. handrails, shower chair). • Helps you prioritise activities to conserve energy for important tasks. • Helps manage issues with memory, planning and problem solving.
social worker	• Works out what support you, your family and carers need, and identifies ways you can receive this support. • May refer you to legal services, aged and disability services, and housing support or help with completing advance care directives. • Helps communicate with family or health professionals (including about care goals) and supporting children or dependants. • May provide counselling or suggest other ways of coping.

dietitian	• Helps with issues such as loss of appetite or weight loss. • Suggests changes to diet and suitable foods to eat. • May provide nutritional supplements or protein drinks. • Tries to resolve digestive issues, nausea or constipation. • May work with a speech pathologist for problems swallowing.
speech pathologist	• Helps you eat and drink as safely as possible if you have problems chewing food or with swallowing. • Gives advice on consistency of food and helps with good mouth care (e.g. dry mouth, too much saliva). • Helps with communication, such as voice problems and speaking or understanding language. • Recommends communication devices and talking boards for patients who have trouble speaking. • May help with memory, planning and problem solving.
physiotherapist	• Suggests physical aids to help you move safely and maintain independence, such as a walking frame or walking stick. • Helps you improve or maintain your balance when moving. • Offers pain relief techniques, such as positioning your body, stimulating nerves in your body and using hot or cold packs. • Shows how to safely exercise to reduce pain and stiffness. • Can help clear congestion from your lungs, and teach you breathing exercises to better manage breathlessness. • May work with a massage therapist to relieve stiff and sore muscles or swelling, or a podiatrist for foot-related issues.
pharmacist	• Dispenses medicine, gives advice about medicines, doses and possible side effects or interactions with other drugs. • Can organise a medicine pack (e.g. Webster-pak) that sets out all the doses that need to be taken throughout the week. Communicates with the prescribing doctor if needed. • Can help you keep track of medicines, including costs on the Pharmaceutical Benefits Scheme (PBS).

Possible members of the palliative care team (continued)

spiritual or pastoral care practitioner	• May be called a spiritual adviser, pastoral carer, priest, deacon, rabbi, mufti or reverend. • Supports you and your family to talk about spiritual matters. Helps you reflect on your life and, if you want, on your search for meaning. • May help you to feel hopeful and develop ways to enjoy your life despite the cancer. • Can organise prayer services and religious rituals for you and connect you with other members of your faith. • May discuss emotional issues (many are also counsellors).
cultural adviser or patient care navigator	• Cultural advisers, such as Aboriginal Liaison Officers, help to make sure you feel supported, safe and respected while using health services and help the people looking after you to provide care that is respectful to culture. • Patient care navigators work with you, your family and community to help you navigate the health system and avoid any barriers to receiving timely care. Some may organise care plans for you. Some cancer centres may have a patient care navigator who can also help you organise palliative care or book appointments. • Residential aged care facility outreach support services can help residents or people having high level support in the home to get care.
volunteer	• Offers friendship, support and companionship – their role will vary, depending on the organisation they volunteer with. • May provide practical assistance, such as taking you shopping or to appointments, giving your carer a break, minding children, or doing basic jobs around the house. • You may find a volunteer through a palliative care service (volunteers are screened, trained and supervised) or through a state or territory palliative care organisation. • May be a friend, family member or neighbour. You may not like asking for help, but people usually want to help you.

Pat's story

I was first diagnosed with bowel cancer 2 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 7 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, any other health issues 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 on the opposite page describes cancer treatments that can be used palliatively. Let your health care team know about any side effects that you may have so that they can be managed.

Making treatment decisions

You have the right to say no to any treatment recommended, but your medical team needs to be sure that you understand what treatments you've been offered, and how not having a treatment may affect your prognosis (see page 34), symptoms and quality of life.

You can ask questions about treatments and what side effects or "trade-offs" these may have. It might be important for you to know about recovery times, length of hospital stay or physical benefits or risks. You may want to ask what to expect if you don't have treatment.

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 reduce a cancer that is causing pain because of its size or location; slow the growth of a 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.

Bring a friend or family member to appointments to help you make decisions and use the question checklist on page 48 as a guide.

You do not have to accept treatments on an all-or-nothing basis – you can refuse some and accept others. You can try a medicine to see if it helps you and then talk to your doctor about whether to continue. 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 your treatment team, GP or family and friends, or call Cancer Council 13 11 20.
▸ See our *Living with Advanced Cancer* booklet.

Managing symptoms

One of the main aims of palliative treatment is to relieve your symptoms. These symptoms can impact your quality of life and be distressing for your family. While it may not be possible to lessen all of your 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 offer an alternative. For more information and links to support, call Cancer Council 13 11 20.

Visit Palliative Care Australia for more information on 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 and other resources, as well as links to support, at palliativecare.org.au.

Your feelings and emotional needs

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. Some people 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. For 24-hour crisis support, call Lifeline 13 11 14 or visit 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, or perhaps stop driving or other activities that are important to you. These changes can cause further sadness or stress.

It will often help to talk to someone. Your partner, family and close friends may be able to offer support, or you might like 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 47)
- 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 have different levels of pain. Some people may not have difficulties with 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, methadone 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 (such as massage and acupuncture) and psychological interventions (including relaxation, mindfulness, distraction techniques)
- surgery, drug therapies and radiation therapy (see page 25).

It's important to treat pain early before it becomes severe. It's easier to control a lower level of pain and stop it getting worse, than it is to treat very bad pain. Being in pain makes you tired and reduces your energy.

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. The aim is to give enough medicine to be able to do your usual activities without causing side effects. Taking high-strength opioids (such as morphine) as prescribed should not shorten your life – people may even live longer with better quality of life when their pain is treated effectively.

Pain medicines can be long acting and short acting. Short-acting medicine is used for breakthrough pain or as a top-up if you're on a long-acting medicine but still need more pain relief. Keep a diary of your "breakthrough" medicine. This can help your doctor to adjust your dose as needed.

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 uncontrolled pain or you have side effects from the pain medicine.
▸ See our *Understanding Cancer Pain* booklet.

Ways to manage your medicines

- Ask your palliative care team for a list of your 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 to keep track of medicines, or create your own list on paper or on a computer. You will also find helpful information about medicines at nps.org.au.

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, having food and drink helps 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 or dietitian if you are concerned. They may suggest you drink nutritional supplements.

Sometimes towards the end of life, eating is less important. If you are moving less often, your need for fuel will be less too. It might be important to save your appetite for your favourite foods or just sit with family and friends during mealtimes.

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 they can see what may be causing the nausea, adjust the dose or try another medicine. Constipation (see opposite) can also cause nausea and reduced appetite.

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 or sipping ginger tea.

Difficulty swallowing – If chewing and swallowing become difficult, you may need to change the consistency of your food by chopping, mincing or puréeing. A speech pathologist can check how well you're swallowing and advise the best food texture.
▶ See our *Nutrition for People Living with 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.

Fatigue

Fatigue is when you feel very tired, weak, drained and worn out. Cancer-related fatigue is different from tiredness because it is more severe, not the result of recent physical or mental activity, and usually doesn't get better 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 also help with ways to conserve your energy.

It is important to allow time in the day to rest and save your energy for fun or important things. 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 *Understanding Fatigue and Cancer* fact sheet.

Breathlessness

Breathlessness (dyspnoea) 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 by taking medicine (such as low-dose morphine), draining fluid from around the lungs, or having oxygen therapy (if your oxygen levels are low). Other 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 any other podcast app
- see a psychologist to help you manage any anxiety, if the breathlessness leads to panic
- plan out daily activities and take rest breaks – an occupational therapist can help you plan how to conserve your energy.

Complementary and alternative therapies

People often use the terms “complementary” and “alternative” as though they mean the same thing, but it is important to understand how they are different.

Complementary therapies are widely used alongside conventional medical treatments, usually to help manage side effects of cancer or its treatment. Therapies such as meditation, massage and acupuncture may increase your sense of control, decrease stress and anxiety, and improve your mood.

Alternative therapies are used instead of conventional medical treatments. Many alternative therapies have not been scientifically tested, so there is no evidence that they stop cancer growing or spreading. Others have been tested and shown to be harmful to people with cancer or not to work. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Let your doctors know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based, or may not work well with your current treatment.
▸ See our *Understanding Complementary Therapies* booklet.

Sex, intimacy and palliative care

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

For many people, intimacy can provide comfort and maintain connection. Even if sexual intercourse is no longer possible or what you want, you may enjoy physical closeness through cuddling, stroking or massage.

If you feel that you can, talk with your partner/s about your feelings and concerns about the sexual changes in your relationship, and discuss ways that you can maintain intimacy.

If you have concerns or need advice about sexual intimacy, talk to your GP, nurse, social worker, counsellor or psychologist. For more information, see our *Sexuality, Intimacy and Cancer* booklet.

Looking ahead

This chapter covers some of the practical and legal issues to consider when having palliative care. Planning for the future may help you to feel more in control and give you a sense of relief that plans have been made and you don't need to worry about that later on.

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. Every cancer diagnosis is different and everyone will have a different prognosis. Your doctor can't say exactly what will happen to you, but they can give you an idea based on what usually happens to someone in your situation. Your doctor will probably talk in terms of days, days to weeks, weeks to months, or months to years. As everyone responds to treatment differently, the actual time could be shorter or longer. Having an idea of how much time may be left allows you to focus on what you'd like to do.

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.

Talking about facing the end of life is difficult and confronting for most people and their families. Sharing any emotions you are experiencing may help you come to terms with your situation. See pages 27 and 44–45 or call Cancer Council on 13 11 20.

Feeling low or depressed is common after a diagnosis of advanced cancer and when you are trying to adjust to changes in your health or lifestyle. Discussing this with your family and friends, your GP or a counsellor, social worker, psychologist or spiritual adviser may help.

▶ See our *Emotions and Cancer*, *Living with Advanced Cancer* and *Facing End of Life* booklets.

Advance care planning

When diagnosed with a life-limiting illness, some people start to 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.

Advance care planning can help your family, friends and treatment team understand your goals, values and beliefs. This helps to make sure that your wishes are respected if you lose the capacity to make decisions for yourself or if you are unable to communicate your wishes for any reason. Advance care planning can involve:

- talking and making decisions about what is important to you for quality of life
- discussing what treatments you may or may not want, including where you want to receive care (e.g. at home if possible)
- completing advance care documents (see page 36)
- appointing a substitute decision-maker (see page 37).

Advance care planning can be started any time, whether you are healthy or ill. While it may be difficult to think about, some people find knowing they have made plans for the future – whatever it may be – can be a relief.

As well as giving you peace of mind, studies show that families of people who have done advance care planning feel less anxiety and stress when asked to make important health decisions for them.

Think about what matters to you most. You may want to find a balance between what medical care can achieve and the side effects of treatments. How you feel may change as your circumstances change. And it's okay to add to or make changes to your advance care plans. You and your family may find it useful to start thinking about these issues before they are raised by a health professional.

Making an advance care directive

You can write down your goals and instructions for your future medical care in a legal 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 is a legal document which provides a record of your values and treatment preferences. Doctors, family, carers and substitute decision-makers (see opposite page) must consider this record if you become unable to communicate or make decisions. You may need the help of your doctor or lawyer to complete the advance care directive

Why you need to talk about advance care planning

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 think about and regularly review your plan when you are well enough. 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. Visit palliativecare.org.au/campaign/discussion-starters to download a free booklet.

forms and make sure it is signed, dated and witnessed. Some hospitals use their own forms. 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.

> *“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

Appointing a substitute decision-maker

The ability to make a legally binding decision is called capacity. In general, capacity means you can understand and remember information about the available choices, understand the consequences of your decisions, and communicate your decisions. A substitute decision-maker is someone you legally appoint to make medical decisions for you if you lose capacity in the future. It should be someone you trust, who understands your values and preferences for future care, and is able to make decisions you would want.

Depending on where you live, the documents for appointing this person may be called an enduring power of guardianship, appointment of enduring guardian or medical treatment decision-maker, or it may be nominated in an advance care directive. An enduring power of attorney is usually for financial/legal matters. If you lose capacity and don’t have an advance care directive or substitute decision-maker, the law in each state and territory outlines who may make medical treatment decisions for you. This is usually someone close to you, such as your spouse, partner, family member or close friend. For more information visit end-of-life.qut.edu.au.

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

Voluntary assisted dying

Voluntary assisted dying (VAD) is when a person with an incurable, life-limiting condition or illness chooses to end their life with the assistance of a doctor or health practitioner – using specially prescribed medicines from a doctor. “Voluntary” means that it is the choice of the unwell person to end their life.

VAD is not part of any palliative care services. However, if you are considering this option, know that palliative care remains available to you right up until the end of your life, no matter how you die. Many people accessing VAD will want palliative care as well, and that’s okay.

At the time of going to print (December 2023), laws around VAD have commenced in all Australian states. VAD remains unlawful in the Northern Territory and Australian Capital Territory at the time of going to print (December 2023).

VAD is only available to people who meet all the strict conditions and follow certain steps as required by the laws in their state or territory.

It is essential to check the latest updates and know the law and rules around making this choice. Laws and rules around VAD may be different in the state or territory where you live.

For information and updates on VAD for your state or territory, visit Queensland University of Technology’s End of Life Law in Australia website at end-of-life.qut.edu.au/assisteddying.

Care for young people

Palliative care for babies, children and teenagers focuses on maintaining quality of life by managing their physical, emotional, cultural, social and spiritual needs, and supporting the family.

Palliative care for young people is provided by health professionals who specialise in the care of children (paediatrics), as well as palliative care experts. It considers the young person's stage of development, their understanding of their illness and their ability to make decisions.

Most children's hospitals have specialist paediatric palliative care teams. Family are considered part of the palliative care team. Depending on needs and availability, palliative care may be at home, in hospital or in a children's palliative care unit.

Organisations that specifically support young people with cancer and their families by providing palliative care, financial assistance, counselling, resources and respite care are listed on page 47.

The hospital social worker can also provide support and share useful networks in your local community. Or for more support and information, call Cancer Council 13 11 20.

Palliative Care Australia and Paediatric Palliative Care Australia and New Zealand provide detailed resources to help families and carers prepare for situations they may face during their child's illness. You can download these resources from paediatricpalliativecare.org.au.

Caring for someone with advanced cancer

Caring for someone with advanced cancer can bring a sense of satisfaction, but it can also be challenging and stressful. As a carer your responsibilities usually increase as the disease progresses. Over time, you may need to help more with managing symptoms, providing personal care, preparing food and organising finances.

It's important to look after your own physical and emotional wellbeing. Give yourself some time out (see opposite) and share your concerns with somebody neutral such as a counsellor or your doctor, or call Cancer Council 13 11 20. A wide range of support is available to help you with various practical and emotional needs (see pages 44–47).

Carers as part of the team

Family and carers play a key role in palliative care and are considered part of the team. You can work with the palliative care team to understand, and be included in, decisions about care and treatment. The person you care for must give written consent (permission) for their doctors to talk with you about their care when they are not present. This consent and your contact details should be formally recorded (written) in the person's medical records case file. Also ask your health care team who you can contact in an emergency or after hours.

Palliative care aims to improve quality of life for both the person with cancer, and their family and carers. The palliative care team can suggest services to support you in your caring role. Carers can sometimes feel they are 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 spend more quality time with the person you're caring for.

Respite (short-term) care

Caring can be demanding and may affect your physical and emotional wellbeing. Respite care lets someone else take over caring for a while, so you can have a break. Some carers feel guilty or worried about leaving the person they are caring for. But by taking a break, you may be able to continue your caring role with more energy and enthusiasm.

You may want respite care for a couple of hours, overnight or several days. You can use respite care for any reason – perhaps to look after your own health, visit friends or family, or catch up on sleep. It can sometimes be given in your home, or the person may go to a respite care centre or residential aged care facility. Hospital and palliative care units (hospices) do not usually take people for respite care.

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.

It's a good idea to find out about respite services before you actually need them. Talk to your doctor, social worker or the palliative care team about available services and how to access them. The Carer Gateway also has 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 information and to organise respite, call 1800 422 737 or visit carergateway.gov.au.

Counselling and support

Carers often feel a range of emotions and it's normal for these to change often. Talking to a counsellor, psychologist or social worker may help you work through your worries and concerns, learn new ways to communicate, and cope with changes in your life.

Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

If the person you are caring for is nearing the end of their 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. If you feel you are getting depressed or overly anxious, talk to your GP, another health professional or call Cancer Council 13 11 20. You may be eligible for grief and bereavement counselling through the palliative care team. For practical, financial and emotional support, see pages 44–47.

Where to find more information for carers

- Read our *Caring for Someone with Cancer*, *Living with Advanced Cancer* and *Facing End of Life* booklets.
- Listen to *The Thing About Advanced Cancer* podcast episodes for carers.
- Find fact sheets and videos for carers on the Palliative Care Australia website. Visit palliativecare.org.au/im-a-carer. Topics include what is palliative care, managing symptoms, and caring for yourself.

Anna’s story

My husband had been having treatment for lung cancer for around 8 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 2 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 6 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.

Support and information

There are a range of palliative care services, with availability depending on where you live. Some are free, others may have a cost. Talk to your health care team or call Cancer Council 13 11 20 for services near you.

Useful contacts

Carer services

Carer Gateway 1800 422 737 **carergateway.gov.au**	Information, resources, counselling, support, links to other services, home help or visiting nurses and respite care.
Carer Help **carerhelp.com.au**	Information for people caring for someone at the end of life.
Young Carers **youngcarersnetwork.com.au**	Support for young people under 25 caring for a family member or friend.

Counselling and mentoring services

Cancer Council 13 11 20	Referrals to counselling services and peer support programs.
Australian Psychological Society **psychology.org.au**	Use the "Find a Psychologist" search to look for a practitioner in your area.
Better Access initiative **health.gov.au/our-work/better-access-initiative**	Information about Medicare rebates for mental health services. Talk to your GP for more details and to organise a referral.
Beyond Blue 1300 22 4636 **beyondblue.org.au**	24-hour telephone counselling service; online and email counselling 7 days a week.

Counselling and mentoring services (continued)	
Carer Gateway Counselling Service 1800 422 737 **counselling.carergateway.gov.au**	Free counselling service for carers. Available each day 8am – 6pm. They can also connect you with other carers in your area or an online carer forum.
Kids Helpline 1800 55 1800 **kidshelpline.com.au**	Telephone and online counselling and crisis support for people aged 5–25.
Lifeline 13 11 14 **lifeline.org.au**	24-hour telephone crisis support and suicide prevention service.
Suicide Call Back Service 1300 659 467 **suicidecallbackservice.org.au**	24-hour telephone and online counselling for people affected by suicide.
Financial assistance	
Cancer Council 13 11 20	Referral service for financial or legal advice; may be free for eligible clients.
Centrelink 132 717 **servicesaustralia.gov.au**	Offers financial support for people with a long-term illness and for carers.
NDIS 1800 800 110 **ndis.gov.au**	Funding and support for people under 65 with a permanent and significant disability.
National Debt Helpline 1800 007 007 **ndh.org.au**	Help with debt problems and finding a financial counsellor.
Pharmaceutical Benefits Scheme (PBS) **pbs.gov.au**	Information about the cost of prescription medicines and safety net thresholds.
Talk to the social worker on the palliative care team	They may be able to help you find legal or financial support.

Future planning

Advance Care Planning Australia 1300 208 582 **advancecareplanning.org.au**	Information about planning for your future health care, including advance care directives.
Discussion Starters **palliativecare.org.au/campaign/discussion-starters**	Palliative Care Australia website encouraging Australians to talk about dying; includes discussion starters.
The Groundswell Project **thegroundswellproject.com**	Community organisation promoting resilience/wellbeing at all phases of life.

Home help and home nursing

Talk to your GP, palliative care team, local council or health fund about home nursing or home help.	Some local councils provide services in the home or in the community. Private services are also available.
My Aged Care 1800 200 422 **myagedcare.gov.au**	Information about different types of aged care services and eligibility.

Legal information

Cancer Council 13 11 20	Information and links to legal services.
End of Life Law in Australia **end-of-life.qut.edu.au**	Legal information about advance care directives, palliative care and VAD.
Public Trustees in Australia Search “public trustee” online	Help you prepare a will and manage your finances in your state or territory.

Palliative care

Care Search **caresearch.com.au**	Information about death and dying and links to services and resources.
Palliative Care Australia **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**	Links to respite care at home, in a respite care centre or, in some cases, in a hospital or palliative care unit.

Support groups and cancer information

Cancer Council Online Community **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.
Telephone support groups Cancer Council 13 11 20	Includes groups for people with advanced cancer, for carers and for the bereaved.
Cancer Council podcasts **cancercouncil.com.au/podcasts**	Information and insights with a separate series about advanced cancer.
Face-to-face groups Call Cancer Council 13 11 20 or ask a hospital social worker.	It can help to meet with others who understand what it is like to have, or care for, someone with cancer.

Young people and children

Camp Quality 1300 662 267 **campquality.org.au**	Support for children aged up to 15 and their families, at each stage of cancer, including palliative care and bereavement.
Canteen 1800 835 932 **canteen.org.au**	For people aged 12–25 affected by cancer or bereavement. Has an app, interactive online forum, counselling services and palliative care resources.
Redkite 1800 733 548 **redkite.org.au**	Emotional guidance (including bereavement support), financial assistance and educational services to young people and their families.
Youth Cancer Services **canteen.org.au/how-we-help/youth-cancer-services**	Hospital-based cancer treatment and support services for people aged 15–25.

Question checklist

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

Palliative care

- Who 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 or research studies 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.

Glossary

advance care planning
When a person thinks about their future health care and discusses their preferences with family, friends and a health care team. The written record of these wishes may be called 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). Treatment can often still control the cancer and manage symptoms.

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.

carer
A person providing unpaid care to someone who needs this assistance because of a medical condition, 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 testing new approaches to prevention, screening, diagnosis or treatment, to see if they are better than current ones.

community nurse
A nurse who provides health care to people in their home or community. May coordinate palliative care or 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. Helps people cope with cancer symptoms and treatment side effects.

consent
When you agree to something.

depression
Very low mood and loss of interest in life, lasting for more than 2 weeks. Depression 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
Difficulty breathing or breathlessness.

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

grief
The way we process and adjust to loss. Grief can affect all parts of your life.

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

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

inpatient
When you stay in hospital to have 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 as well as any other factors affecting their care.

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nurse practitioner
Works in an advanced nursing role; may prescribe some medicines and tests and refer you to other health professionals.

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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
Having hospital 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, spiritual and social needs. Also called supportive care. It's not just for people who are about to die, although it does include end-of-life 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 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, or don't want to be, at home. May offer day care facilities and home visits or be 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.

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

prognosis
The expected outcome of a person's disease.

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

radiation therapy
The use of targeted radiation 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 called radiotherapy.

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

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

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

secondary cancer
See metastasis.

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

spiritual practices (spirituality)
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.

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

supportive care
See palliative care.

targeted therapy
Drugs that target 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 called a life-limiting illness.

voluntary assisted dying (VAD)
When a person with an incurable, life-limiting condition or illness chooses to end their own life with the assistance of a doctor or health practitioner – using medicines specially prescribed by a doctor.

Can't find a word here?

For more cancer-related words, visit:

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

References

1. Australian Government, *National Palliative Care Strategy 2018,* Department of Health, Canberra, 2019.

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 131 450.

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

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:

PalliativeCare
AUSTRALIA

Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancer.org.au/tas

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

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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.

Cancer Council

UNDERSTANDING PALLIATIVE CARE

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