



Understanding Palliative Care

A guide for people with cancer,
their families and friends

A large, abstract yellow shape occupies the bottom half of the page. On its right side, there is a purple circle containing the word "Treatment". A thin orange line extends from the bottom of the purple circle, curves to the left, and ends in a small telephone handset icon pointing towards the phone number.

Treatment

For information & support, call

13 11 20

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

Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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Introduction

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

The aim of palliative care is to enhance your quality of life and help you maintain your independence for as long as possible. Health professionals from different fields work together as a team to meet your physical, practical, emotional and spiritual needs.

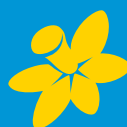
Palliative care is managed in various ways throughout Australia and is tailored to each individual. Talk to your general practitioner (GP) or palliative care team about the best approach for your situation.

Some terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

This information was developed with help from Palliative Care Australia, a range of health professionals, and people using palliative care services.

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



**Cancer
Council
13 11 20**

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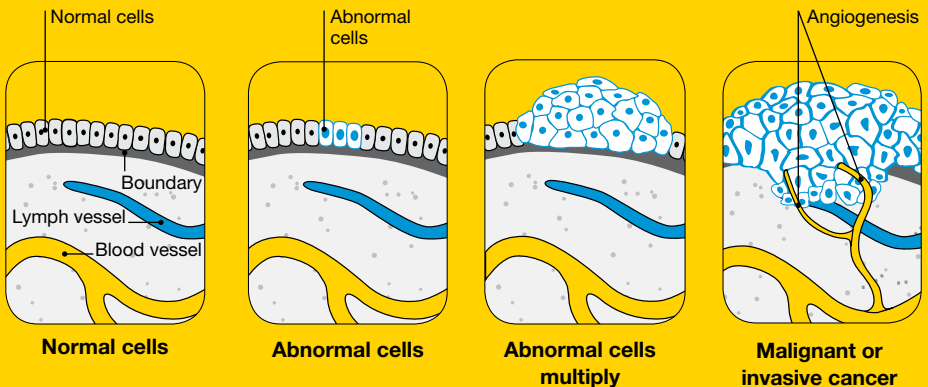
What is advanced cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. It occurs when abnormal cells divide and multiply in an uncontrolled way.

There are many types of cancer and each type develops differently. Some grow slowly, some advance rapidly, and others behave unpredictably. Some types of cancer respond well to treatment, while other types are more difficult to treat successfully.

Advanced cancer is a term used to describe cancer that is unlikely to be cured. It may be primary or secondary cancer. Primary cancer refers to the first mass of cancer cells (tumour) in an organ or tissue. The tumour has not spread from its original site, such as the bowel. This is also called cancer in-situ, carcinoma in-situ or localised cancer.

How cancer starts



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

Although medical interventions may not be able to cure advanced cancer, some treatments may still be able to slow its growth or spread, sometimes for months or even years. Palliative medicine can also help manage cancer symptoms, which may include pain, and can reduce side effects from cancer treatments. At any stage of advanced cancer, a range of other palliative care services can enhance quality of life (see next page).

How cancer spreads

Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

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





The role of palliative care

Palliative care is an approach that allows people with advanced cancer to maintain their quality of life in a way that is meaningful to them. It also provides support to families and carers.

The role of palliative care is to:

- help you achieve the best quality of life that you can for as long as possible
- make sure your physical, practical, emotional and spiritual needs are catered for
- help you feel in control of your situation and make decisions about your treatment and ongoing care
- make the time you have as valuable as can be for you and your family.

Palliative care involves a range of services offered by medical, nursing and allied health professionals, as well as volunteers and carers. This is called a multidisciplinary team (MDT) approach (see pages 16–21). Your care may be coordinated by your general practitioner (GP) or community nurse, or by the specialist palliative care team in your area. It may be provided in or out of the home.

Palliative care providers

Some form of palliative care is offered in almost all health care settings, including:

- hospitals
- general practice (family doctors)
- residential aged care services
- general community services.

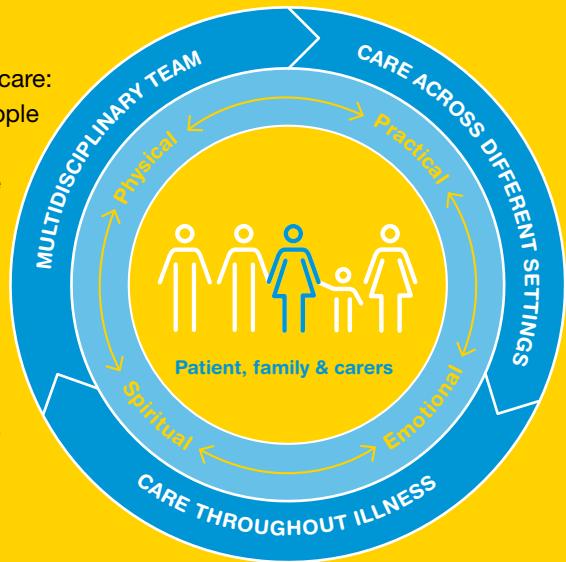
Specialist palliative care services see people with the most complex needs, but can also provide advice to other health care professionals. These services can be accessed through:

- many public and private hospitals
- palliative care units (hospices)
- community-based specialist services
- private specialists.

Each state and territory has its own approach to delivering palliative care, so the services offered will vary. To find out what is available in your area, speak to your health care providers, contact palliative care organisations (see page 38), or call Cancer Council 13 11 20.

Holistic care

Palliative care is holistic care: it involves a range of people with different skills and roles working on a range of issues (physical, practical, emotional and spiritual), across a range of settings (home, residential aged care facilities, hospitals and palliative care units), and at all stages of advanced cancer.





Key questions

Q: Does palliative care mean end-of-life care?

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

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

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

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

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

Q: Does it shorten or lengthen life?

A: Palliative care does not try to end life sooner, but nor does it try to prolong life. Instead, the health care team provides multidisciplinary care to enhance quality of life. This may include managing pain and other symptoms.

Some studies show that controlling symptoms, such as pain, can lead to people feeling better and living longer. ^{1,2}

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

Q: Is palliative care the same as euthanasia?

A: Palliative care and euthanasia are not the same thing. Euthanasia is the act of deliberately ending the life of a person with an incurable condition. Physician-assisted suicide is when a person ends their own life with the help of a doctor. Both euthanasia and physician-assisted suicide are illegal for all parties involved in every state and territory in Australia. They are not part of palliative care practice.

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

Q: When can I start palliative care?

A: Once you know your cancer is advanced, it is a good idea to start exploring the options provided by palliative care. You can find out what the different team members do and which services might be relevant now or in the future. Sorting out problems earlier rather than later will reduce stress on you and your family. It will allow time to better understand and manage any physical symptoms (such as pain or nausea) and to consider your practical, emotional and spiritual needs.

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

Q: Can I still have cancer treatment?

A: You can still have treatment that aims to cure advanced cancer while receiving palliative care. The palliative care team will work with your team of cancer specialists to help maintain your quality of life.

Cancer treatments such as surgery, chemotherapy, targeted therapies and radiotherapy may also be used as part of palliative treatment. In this case, the aim is not to cure the cancer but to control its growth and relieve any symptoms.

Q: Who will coordinate my care?

A: In most cases, a GP or community nurse will coordinate your palliative care. They will consult with a specialist palliative care service to help you maintain the best possible quality of life. Some people also tap into particular hospital and community services themselves as the need arises.

Specialist palliative care services see people with the most complex health care needs. If your GP, community nurse or cancer specialist finds that your care is beyond their capacity to manage, they may refer you to a specialist palliative care service. The service will usually be based in a hospital or a palliative care unit (hospice), or run as a separate community-based service. Less often, people may be referred to a private palliative care specialist.

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

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

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

Q: Where will I receive palliative care?

A: You can have palliative care in different settings depending on your situation, where you live and whether you have family or friends who can help. Care can be provided at home or in a residential aged care facility, or in a hospital or palliative care unit (hospice). Patients often move between these settings as their needs change.

An important role for the palliative care team is to assess the best place for your care. Many people prefer to receive care at home. The team will respect your wishes where possible. They will consider your home environment and support networks before discussing the possibilities with you, your family and carers.

If you are cared for at home, you (and anyone who cares for you) can be supported by community palliative care services.

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



You can search the National Palliative Care Service Directory at palliativecare.org.au/aboutpalliativecare/directoryofservices.

Q: Do I have to pay for palliative care?

- A:** The federal, state and territory governments fund core palliative care services so that they are free in the public health system, whether you receive care at home or in a public setting. However, sometimes you may need to contribute to the costs of care. Some examples are:
- hiring specialised equipment for use at home
 - paying for medications at home
 - paying for your own nursing staff if you choose to stay at home and require 24-hour assistance
 - paying an excess if you have health insurance that covers palliative care and you go to a private hospital
 - accessing respite services that charge a fee
 - paying the fee of a private allied health professional, such as a psychologist, that isn't fully covered by Medicare
 - paying for complementary therapies, such as massage therapy and acupuncture.

tip

If you are admitted to a public hospital, palliative care unit or other facility and you have private health insurance, check with your health fund to find out what is covered.

Q: Will I lose my independence?

- A:** The palliative care team gives you choices to help you remain independent for as long as possible (e.g. a ramp could be put in at home so you don't have to use steps). The team respects your wishes if you don't want to take up their suggestions.

Finding hope

Some people avoid palliative care services because they hope that a cure will be found for their cancer. However, palliative care does not mean giving up hope.

People can have palliative care for several months or years and sometimes still have active treatment for the cancer.

You can continue to enjoy many aspects of your life. You might take pleasure in

completing projects, spending time with friends, or exploring new hobbies. Recording your feelings through a creative activity, such as writing or art, could help you to make sense of your situation.

As the disease progresses, your goals and the things you are hoping for may change. For example, you might hope to live as comfortably as you can for as long as possible. Palliative care can help you achieve this.

Q: How can palliative care help?

A: The palliative care team is there to help make life easier for you, your family and carers. This booklet discusses the specific medical and support services that palliative care offers, but there are also many general benefits:

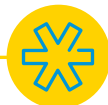
- If you're living at home, the team will call or visit regularly. This can reduce feelings of isolation and fear, help your carers look after you, and keep you out of hospital.
- Your care is usually coordinated by someone, often a community or palliative care nurse, who communicates with the team on your behalf.

- The team can help you to make treatment decisions and to prepare for the changes that advanced cancer brings.
- Learning how to make adjustments around the house can make things easier and safer for you, your family and carers.
- The team can assist you with planning for the future, such as thinking about the type of care you may need and where you would prefer to receive the care.
- Your palliative care service may offer a number you can call for advice in an emergency at any time of day.

The palliative care team can also provide emotional support. A social worker or counsellor can help you work out your goals and how to achieve them. These goals may be specific end-of-life wishes, but can also simply involve making the most out of each day. You might focus your energies on short-term plans, such as enjoying time with friends and family, recording your memories, and reflecting on your life.

The social worker or counsellor can also help you and your family deal with loss and grief. This is often important for people who are close to dying, but can also be worthwhile if you feel grief from the changes that advanced cancer brings.

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





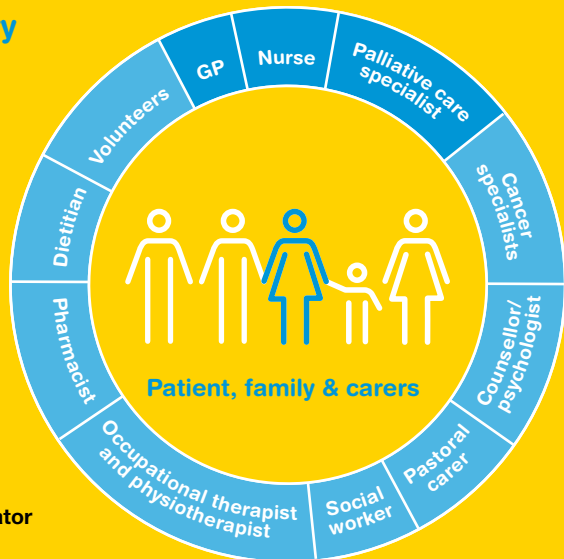
The palliative care team

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, whether you are being cared for at home or in another setting. Volunteers can also offer practical and emotional support, and may form an important part of your team.

Depending on your needs, your palliative care may be coordinated by your GP or a community nurse, or you may be referred to a specialist palliative care service, where the doctors, nurses and allied health professionals are specifically trained to look after people with complex health care issues.

A multidisciplinary team

The people in the palliative care team work together to help meet your physical and emotional needs, and provide support to your family and carers.



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

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)
- liaises with your nurse and/or palliative care specialist about the coordination of your ongoing care
- refers you to a palliative care specialist or organises your admission to hospital or a palliative care unit (hospice) if your circumstances change
- may offer bereavement support to your family and carers, and can refer them to counselling if necessary.

Nurse

- may be a community nurse or a specialist palliative care nurse and may work for a community nursing service, a specialist palliative care service, a hospital or a residential care facility
- coordinates other health professionals and works out what care you need, including home nursing or personal care assistance
- makes sure you have access to medications and other treatments for pain and symptom relief, and talks to you about how to take your medications
- can suggest practical strategies to help you manage your condition (e.g. how to plan your day).

Palliative care specialist or physician

- prescribes or recommends treatment for pain, nausea, constipation, anxiety, depression, shortness of breath or any other symptoms you may have
- usually provides care in a palliative care unit (hospice) or hospital, but may also be able to visit you in your home or residential care facility
- communicates with and advises the oncologist and your GP so your treatment is well coordinated
- may refer you and your family to a grief counsellor or psychologist
- assists with decision-making about care choices.

Cancer specialists (oncologists and surgeons)

- may diagnose the advanced cancer and refer you to a specialist palliative care team
- may continue to provide chemotherapy, targeted therapies, radiotherapy or surgery to manage the symptoms of the cancer.

Counsellor or psychologist

- allows you to talk about any fears, worries or conflicting emotions you may be feeling
- helps you work through feelings of loss or grief
- assists you and your family with relationship issues
- helps you resolve problems so that you can find more pleasure in your life
- teaches you strategies to handle anxiety
- may show you meditation or relaxation exercises to help ease physical and emotional pain
- provides bereavement care to your family and carers.



If you have cultural or religious beliefs about death and bereavement, or certain family customs, talk to your palliative care team early on. Your customs can often become part of your palliative care plan.

Pastoral carer, chaplain or spiritual adviser

- supports you and your family in talking about any spiritual matters on your mind
- reflects with you about your life and helps you search for its meaning, if appropriate
- helps you to feel hopeful and develop ways to enjoy your life despite your illness
- may organise special prayer services for you, if appropriate
- connects you with other members of your faith
- may discuss emotional issues, as many are trained counsellors.

Social worker

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

Occupational therapist and physiotherapist

- help you manage the physical aspects of your daily activities, such as walking, bathing, and getting into and out of bed and chairs safely
- advise you on physical aids to improve your mobility, such as a walking frame or a device to help you put on your socks
- organise equipment hire or modifications to your house for a safer, more accessible environment
- teach carers and family the best ways to move you or help you sit and stand
- assist 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
- show you how to exercise to reduce pain and stiffness, and to increase mobility and energy
- use physical therapy to help clear congestion from your lungs
- may work with a massage therapist to relieve stiff and sore muscles or swelling.

Pharmacist

- gives you access to prescription and over-the-counter medications
- provides information about how to take medications, and any side effects or interactions with other drugs
- communicates with the prescribing doctor, if necessary
- helps you with symptom management so you can achieve the best possible quality of life
- assists you or your carer with keeping track of medications, including the costs on the Pharmaceutical Benefits Scheme (PBS).

Dietitian

- works out the best eating plan for you and your family
- helps you choose appropriate food and nutritional supplements
- tries to resolve any digestive issues, such as poor appetite, nausea or constipation
- may work with a speech pathologist, who can assess and help you deal with eating and swallowing problems.

Volunteers

- offer friendship, companionship, a non-judgemental presence and emotional support
- provide practical support, which might include taking you shopping or to appointments, giving your carer a break, minding children, or doing basic jobs around the house
- are most helpful when you give them specific tasks so that they don't have to guess what you need
- may be accessed through a palliative care service – these volunteers go through a thorough selection process that includes training and criminal history checks
- can also be found through community volunteer groups – check with your GP or local community centre
- can be a friend, neighbour or family member – although you may feel embarrassed about asking for help, you will probably find that many people want to do something for you.

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



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, support and friendship. Cancer Council helped me find house cleaning, which has taken such a burden off me and my husband.

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

With all these palliative care services, I feel like I have a window of time to get my house in order. I want my transition to be easy for my family. I've taught my children how to live, and now I'm teaching them how to die. Strangely, it's an experience I wouldn't have missed – it's brought so many beautiful people into my life and renewed my faith that kindness and love are at the core of all humanity.

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



Treatment and palliative care

Medical treatment for palliative patients is an important part of care. It aims to manage the physical and emotional symptoms of cancer without trying to cure the disease. Some examples of palliative medical treatment are:

- radiotherapy to reduce pain if cancer has spread to the bones
- chemotherapy and new drugs known as targeted therapies to stop the cancer growing into other organs
- surgery to reduce tumours that are causing pain or other symptoms
- medication to relieve constipation, nausea or pain
- medication for depression, anxiety or insomnia.

You have the right to say no to any treatment offered, but your medical team need to be confident that you understand the nature of the treatment proposed and the possible consequences of not having it. You can refuse each treatment separately – you do not have to accept treatment on an all-or-nothing basis.

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

Prognosis

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

However, no-one can tell you exactly when you are going to die. Your doctors may be able to give a general indication of your life expectancy, based on an average patient, but everyone is unique and responds differently to different kinds of medical, practical, spiritual and emotional care.

Dealing with death is difficult and confronting for most people and their families, whatever their cultural background or religious beliefs. Talking over any fears, worries, guilt or other emotions you are experiencing may help you come to terms with your condition.

Consider sharing your thoughts with family and friends, or speak confidentially to a trained counsellor, social worker, psychologist or spiritual adviser. You can also call Cancer Council 13 11 20 and ask for the *Emotions and Cancer* and *Facing End of Life* booklets, or download them from your local Cancer Council website.

If your family and friends want more information about helping someone with a life-limiting illness and about grief and bereavement, they can visit Palliative Care Australia at palliativecare.org.au/aboutpalliativecare/resources.

“When I asked my GP why doctors are so reluctant to suggest palliative care, he said some patients found it too difficult to deal with. Our feeling was that to know the truth about the diagnosis and what may lie ahead was essential.” Janine

Sexuality and palliative care

People with advanced cancer usually experience major physical and psychological changes. These can have an enormous impact on how they feel sexually, but do not mean that intimacy needs to end.

We are all sexual beings, and intimacy can provide comfort and maintain connection. Even if sexual intercourse is no longer possible or desired, you may find physical closeness through cuddling, stroking or massage.

Many people receiving palliative care have said they would welcome the chance to discuss their sexual wellbeing with health professionals.³

If you have concerns about sexual intimacy at any stage, talk to your GP or nurse. You can also call Cancer Council **13 11 20** and ask for a free copy of the *Sexuality, Intimacy and Cancer* booklet, or download it from your local Cancer Council website.

Complementary therapies

You may wonder whether there are any other therapies you could try. Complementary therapies, such as massage and relaxation, are used with conventional medical treatments and may decrease stress and anxiety. Alternative therapies, such as coffee enemas, are chosen by some people instead of conventional treatments and can be harmful. Let your doctor know about any therapies you want to use, as some may not be safe or evidence-based.

To find out more, call 13 11 20 for a free copy of *Understanding Complementary Therapies*, or see your local Cancer Council website.

Advance care planning

It can be a good idea to think about your wishes for your future medical care, and to discuss these with your family, friends and health care team. This process is called advance care planning, and it can be started at any stage, whether you are healthy or ill.

You can write down your wishes in what is known as an advance care plan or advance care directive. Although this may not be legally binding, it does provide a record for doctors, family and carers to consider. Advance care planning doesn't mean you have given up or will die soon – many people review their wishes from time to time.

Substitute decision-maker

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



Each state or territory has different laws about advance care planning and substitute decision-makers. For more information, talk to a social worker, call Cancer Council **13 11 20**, or visit advancecareplanning.org.au or palliativecare.org.au/aboutpalliativecare/advancecareplanning.



Information for carers

Many people are fortunate to have a personal carer to help look after them. Usually a carer is a spouse or an adult child, but often other relatives, friends or neighbours will take on a significant caring role. Carers do not have to live with the person whom they support, but they provide care on a regular basis. Carers are a crucial – but often overlooked – part of the health system.

Carers as part of the team

You may be reading this booklet because you are caring for someone with advanced cancer. 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 needs to give written consent for the team to talk with you about their care. This consent and your contact details should be formally recorded in their case file.

The goal of palliative care is to improve quality of life not only for the person with cancer, but also for the family and carers. There are a range of support services to help you manage throughout the illness and in bereavement.

Cancer Council's *Caring for Someone with Cancer* booklet provides information about the practical and emotional aspects of the caring role. For a free copy, call Cancer Council 13 11 20, or download the booklet from your local Cancer Council website.


Respite care

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

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

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

Your palliative care team may help you find respite care. You can also contact a Commonwealth Respite and Carelink Centre for information on local carer support services and respite options. It's best to make contact early on so they are aware of your situation. You can call them on 1800 052 222 during business hours. For emergency respite support outside business hours, call 1800 059 059.

“It was very hard work, but I found that caring for my mother at home was one of the best things I could have done for her in her greatest time of need.”  Janice

Counselling and support

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

Grief counselling and information – You and your family may be eligible for grief and bereavement counselling provided through the palliative care team. Palliative Care Australia has information on understanding grief that can be downloaded from palliativecare.org.au/aboutpalliativecare/resources.

Cancer Council telephone support group – Cancer Council offers a national telephone support group for carers. It runs twice monthly. For more information about how you can speak to someone who has been in a carer role, call 13 11 20.

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

Young Carers Respite and Information Services

Program – Visit youngcarers.net.au or call 1800 242 636 for age-appropriate information. You can also call 1800 052 222 to find out about respite, practical help and social activities for carers under 25.

LifeCircle – This organisation supports carers of people who wish to die at home. For more information, visit lifecircle.org.au.



Janine's story

My husband, Brian, was diagnosed with a brain tumour when he was 41. He was operated on five days after the diagnosis, and some weeks later, began a course of radiation and chemotherapy.

When the nurses suggested we call in the palliative care team, my first reaction was, "But we don't need palliation." I feared what this meant. But they took the time to explain that it was much more than just nursing a dying person. It was about holistic support and understanding, ensuring that Brian could still 'live' as best he could in the time he had left.

Brian was able to enjoy the services offered while he was still well enough to appreciate it. He was able to join us at our daughter's debutante ball. A nurse helped bathe and dress Brian and escorted him to the reception centre. She returned later to collect him, and stayed

with him until I returned home. It will be a memory that will be forever with us. And the photos we have of that night, we treasure enormously.

The nurses gave Brian love and dignity to the end. These 'angels' visited, medicated and reassured. Brian also enjoyed the massage therapy offered until his death.

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.

Palliative care gave us so much. The team gave Brian the care he needed. They gave the rest of us the strength to see it through. They became a part of our family – they were like angels who would appear, see things right and then leave us to be a family again.



Palliative care for young people

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

Because there may be uncertainty about the course of a child's illness, elements of palliative care are often introduced early and combined with treatment that aims to actively treat the cancer.

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

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

Tailored support

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

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

CanTeen – an organisation for young people aged 12–24 affected by cancer. CanTeen provides an interactive online forum and resources on palliative care and end-of-life issues. It also runs camps and other activities. Visit canteen.org.au or call 1800 226 833.

Camp Quality – an organisation for children aged 0–13 living with cancer, and their families. Camp Quality offers support through each stage of the cancer journey, including palliative care and bereavement. Its services include camps for siblings, one-off house cleaning, camps for bereaved families, and holiday respite. Visit campquality.org.au or call 1300 662 267.

Redkite – a charity that supports young people and their families through cancer by providing emotional guidance (including bereavement support), financial assistance and educational services. For more information about Redkite’s services, talk to the social worker at the hospital, visit redkite.org.au or call 1800 733 548.

Kids with Cancer Foundation Australia – a non-profit group that provides financial assistance to families of children with cancer, and helps fund projects in public hospitals and oncology units. Visit kidswithcancer.org.au or call 1800 255 522.

Palliative Care Australia – the peak national organisation for palliative care. Palliative Care Australia has a detailed resource, *Journeys*, to help families and carers prepare for situations they may face during their child’s illness. To access the resource, visit palliativecare.org.au and find ‘Journeys’ in the ‘Palliative care for children and teenagers’ section.



Seeking support

When you are referred to palliative care or while you are having palliative care, you may have a range of emotions. Many people feel shocked, fearful, sad or angry. Others may feel relief or have a sense of inner peace. On some days they may feel hopeful, and on other days they may feel anxious.

Some people may also have ongoing depression after they are referred to palliative care. Signs of depression include trouble thinking clearly, losing interest in things you used to enjoy, or not wanting to get up in the morning. If you think you may be depressed, it is important to talk to your doctor, as counselling and medication can help.

You may find that while some people you know are supportive, others may avoid you or not know what to say. This can be difficult, and you may feel lonely, rejected, isolated or upset.

At some point, you may need to leave work or give up other activities that are important to you. These changes can cause further sadness or stress.

It will probably help to talk about the different feelings you have. Your partner, family members and close friends can be a good source of support, or you might prefer to talk to:

- members of your palliative care or treatment team
- a counsellor, social worker or psychologist
- your religious leader or spiritual adviser
- a telephone support group – see page 36
- Cancer Council 13 11 20.

Financial support

For many people, an illness in the family can be a financial strain. This may be caused by extra out-of-pocket costs or from loss of income. For example, if you have to stay at home round-the-clock, household bills will increase and you and your family may eat more prepackaged meals to save time and energy. You may need to pay for child care, transport, medications and equipment.

These extra costs can cause you and your family a lot of stress. Ask your social worker about any financial or practical assistance available to you and your carer, and apply for it as soon as possible. You may be eligible for assistance from the government, volunteer bodies, church groups or your local council.

Your local Cancer Council may be able to organise legal and financial advice on issues such as substitute decision-makers, will preparation, and early access to superannuation (see opposite). Contact Cancer Council 13 11 20 to find out what is available in your area and whether you are eligible for this assistance.

Government assistance

The Department of Human Services (also known as Centrelink) offers special payments and provisions for people with a long-term illness and for their primary carers. Some of these are described below. For more information, call the department on 13 27 17, visit humanservices.gov.au, or speak to your social worker.


Sickness Allowance – This payment is for people who temporarily cannot work because of an illness. It is income and assets tested.

Disability Support Pension – This payment is for people who are unable to work for two years or more because of a physical, intellectual or psychiatric impairment. It is income and assets tested.

Carer Payment – This payment is for carers who provide constant care in the home of the person they are caring for. It is income and assets tested.

Carer Allowance – This allowance is for carers who provide a significant amount of assistance, either in their own home or in the home of the person with cancer. It is not income and assets tested, so you may be eligible even if you are working or receiving another type of pension.

Early release of superannuation – In particular circumstances, people who are receiving palliative care, or who have a dependant receiving palliative care, can get an early release of their superannuation savings (retirement fund). Visit the Department of Human Services website at humanservices.gov.au and search for ‘superannuation’ to find out more about accessing your super early.

“ Find out about practical and financial services and apply for them early on. Then be realistic that you will have to pay for some things yourself, and be grateful if you are granted some assistance down the track. ”  Xavier



Cancer Council services

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

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

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

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

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

Online discussion forums – You can also visit the online discussion forums at cancerconnections.com.au. Here you can connect at any time with other people affected by cancer, or write a blog about your palliative care experience.

Printed, online and audiovisual resources – In addition to this booklet, there is a wide variety of free information available about cancer-related topics. Cancer Council produces easy-to-read booklets and fact sheets on more than 20 types of cancer, treatment options, and emotional and practical issues.

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

Related publications

You might also find the following publications and audiovisual resources* useful:

- *Living with Advanced Cancer*
- *Facing End of Life*
- *Overcoming Cancer Pain*
- *Caring for Someone with Cancer*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Complementary Therapies*
- *Mindful Meditation (CD)*
- *Relaxation (CD)*
- *Emotions and Cancer*
- *Sexuality, Intimacy and Cancer*
- *Cancer Care and Your Rights*
- *When Cancer Changes Your Financial Plans*
- *Talking to Kids About Cancer*

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

* May not be available in all states and territories.



Other key services

The following organisations can provide information and link you and your carers with other services.

Commonwealth Respite and Carelink Centres – These provide free, confidential information about services that can help with your care. Advisers can talk to you or your carer about equipment hire, nursing care, allied health services, and programs such as Home and Community Care (HACC), which provides eligible people with subsidised domestic help. Call 1800 052 222 to talk to an adviser. For online information about respite care options, you can visit myagedcare.gov.au/caring-someone/respice-care.

Palliative Care Australia – This national peak body and its state and territory member organisations work to raise awareness of palliative and end-of-life care, and to improve the understanding and availability of services across Australia. Its online National Palliative Care Service Directory lists services that support people with a life-limiting illness. It also provides information for people living with a life-limiting illness and their families, carers and health professionals. Visit palliativecare.org.au to use the directory, download resources and find links to state and territory organisations. You can also call the head office on 02 6232 4433.



Currently available only in NSW and WA, **Pets Of Older Persons (POOPs)** is a program for people receiving palliative care who don't have friends or relatives who can help look after their pets. Visit rspcansw.org.au or pooptswa.org.au.



Useful websites

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

Australian

Palliative Care Australia.....	palliativecare.org.au
National Palliative Care Service Directory	palliativecare.org.au/ aboutpalliativecare/directoryofservices
CareSearch palliative care knowledge network	caresearch.com.au
PalAssist: 24-hour helpline (Qld only).....	palassist.org.au
The Palliative Care Bridge	palliativecarebridge.com.au
Cancer Council Australia.....	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Carers Australia	carersaustralia.com.au
Young Carers	youngcarers.net.au
Living, Caring, Working	www.livingcaringworking.com
Department of Health	health.gov.au
Department of Human Services (Centrelink and Medicare)	humanservices.gov.au
Advance Care Planning Australia	advancecareplanning.org.au
Bereavement Care Centre	bereavementcare.com.au
beyondblue.....	beyondblue.org.au
Lifeline	lifeline.org.au
Australian Psychological Society	psychology.org.au

International

ehospice: global palliative care news resource.....	ehospice.com
American Cancer Society.....	cancer.org
Macmillan Cancer Support.....	macmillan.org.uk
National Cancer Institute.....	cancer.gov



Question checklist

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

- Are there other treatments available that might cure the cancer?
- Will I receive treatment for the cancer if I have palliative care?
- Who will be a part of my palliative care team, and who will coordinate my care?
- Do I have to pay for any palliative care services?
- Where will I receive palliative care?
- If I'm at home, what kind of help will be available?
- Can my family or carers access respite care or other assistance?
- Can I call the palliative care team at any time?
- How long will I need palliative care for? What is my prognosis?
- What if my condition unexpectedly improves?
- I am worried about being unable to support my children financially and emotionally. What help is available?
- Can you help me talk to my family about what is happening?
- Are there any complementary therapies that might help?
- How can I get a second opinion about my need for palliative care?



For more suggestions, go to palliativecare.org.au, and look in the 'Resources' section for *Palliative Care Australia's Asking Questions Can Help: An aid for people seeing the palliative care team.*



Glossary

advance care planning

When an individual thinks about their future health care and discusses their wishes with their family, friends and health care team. The written record of these wishes may be called an advance care plan or advance care directive.

advanced cancer

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

allied health professional

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

alternative therapies

Unproven therapies that are used in place of conventional treatment, often in the hope that they will provide a cure.

angiogenesis

The formation of new blood vessels. It enables tumours to develop their own blood supply, which helps them grow.

chemotherapy

The use of drugs to treat cancer by killing cancer cells or slowing their growth. Chemotherapy can also be used as a palliative treatment to reduce the size of the cancer and help lessen pain.

community nurse

A nurse who provides primary health care to people in their homes and

communities and may coordinate their palliative care. Community nurses usually work for local health services.

complementary therapies

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

depression

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

end-of-life care

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

euthanasia

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

holistic care

Care that incorporates different types of therapies and services to ensure that your physical, emotional, spiritual and practical needs are met.

hospice

See palliative care unit.

life-limiting illness

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

malignant

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

metastasis

A cancer that has spread from a primary cancer in another part of the body. Also known as secondary cancer.

multidisciplinary care

A system where all members of the treatment team collaborate to discuss a patient's physical and emotional needs as well as any other factors affecting their care. The team meets to review cases and decide on treatments.

oncologist

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

palliative care

The holistic care of people who have a life-limiting illness, their families and carers. It aims to improve quality of life by addressing physical, emotional, spiritual and practical needs. It is 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 specialist (physician)

A doctor who has specialised in palliative medicine. The palliative care specialist prescribes medical treatment for pain and other symptoms, and also supports and advises other members

of the palliative care team, 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. Also known as a hospice.

palliative treatment

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

primary cancer

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

primary health care

A person's main health care, which is provided by a general practitioner (GP) or a community nurse. It can include initial tests and diagnoses of disease, health promotion, disease prevention, and chronic illness management.

primary health care provider

A health professional, such as a GP or community nurse, who provides the first point of contact for a person with the health care system and helps them with a range of health-related matters.

prognosis

The likely outcome of a person's disease.

quality of life

A person's comfort and satisfaction, based on how well their physical, emotional, spiritual, sexual, social and financial needs are met within the limits of their illness.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow. Also used to control cancer pain.

relapse

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

remission

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

respite care

Care given to a sick person to give their regular carer a break. Respite care can be given in the home or in a respite care centre, hospital or palliative care unit.

secondary cancer

See metastasis.

specialist palliative care team

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

substitute decision-maker

A person who makes decisions on your behalf if you become incapable of making them yourself. Documents

used to make someone a substitute decision-maker may be called enduring power of attorney, enduring power of guardianship, or appointment of enduring guardian.

targeted therapies

Treatments that attack specific weaknesses of cancer cells while sparing healthy cells.

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.

References

1. J Temel et al., 'Early palliative care for patients with metastatic non-small-cell lung cancer', *The New England Journal of Medicine*, vol. 363, 2010, pp. 733–42.
2. K Rowland & S-A Schumann, 'Palliative care: Earlier is better', *The Journal of Family Practice*, vol. 59, no. 12, 2010, pp. 695–98.
3. L Lemieux et al., 'Sexuality in palliative care: patient perspectives', *Palliative Medicine*, vol. 18, no. 7, 2004, pp. 630–37.

Can't find a word here?

For more cancer-related words, visit:

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



How you can help

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

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

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

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

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

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

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



Cancer Council 13 11 20

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

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

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

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

Cancer Council services and programs vary in each area.

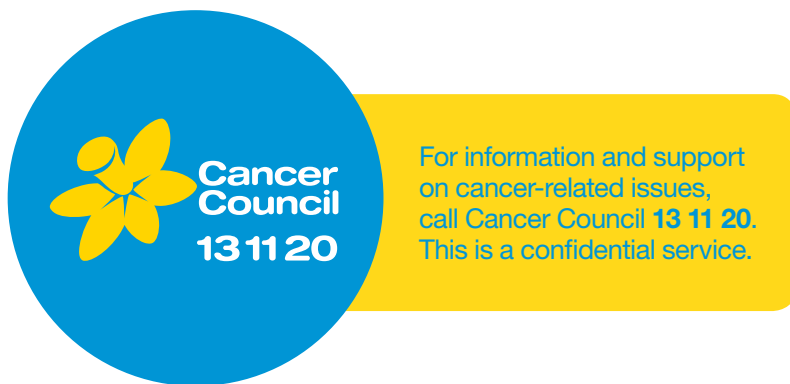
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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



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



Produced in collaboration with:



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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