



# Facing End of Life

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

Practical  
and support  
information

For information & support, call

**13 11 20**



## **Facing End of Life**

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## **Note to reader**

Always consult your doctor about matters that affect your health, a financial adviser or financial counsellor about matters concerning your finances, and a lawyer about legal matters. 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 may change. Laws, regulations and entitlements that affect people with cancer may change. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

## **Cancer Council**

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



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# About this booklet

This booklet has been prepared to help you understand more about the issues facing people who are dying with cancer.

If you have had cancer diagnosed at a late stage, or if the treatments have stopped working and remission is no longer possible, you may be told that the cancer is end stage or terminal. Everyone copes in their own way with this news. Your reaction may depend on your age, family situation, cultural background and spiritual beliefs.

The chapters in this booklet outline how you might feel knowing you are dying, what might happen physically, and how you can prepare for death. There is also information for carers, family and friends. This may be the first time you have read about end-of-life issues. Take your time and read the introduction to each chapter first to see if it has information you want at this stage. Read what seems useful now and leave the rest until you're ready.

Cancer Council also produces the booklets *Living with Advanced Cancer* and *Understanding Palliative Care*. You may find that one of these is more useful at this time.

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer  
Council**  
**13 11 20**

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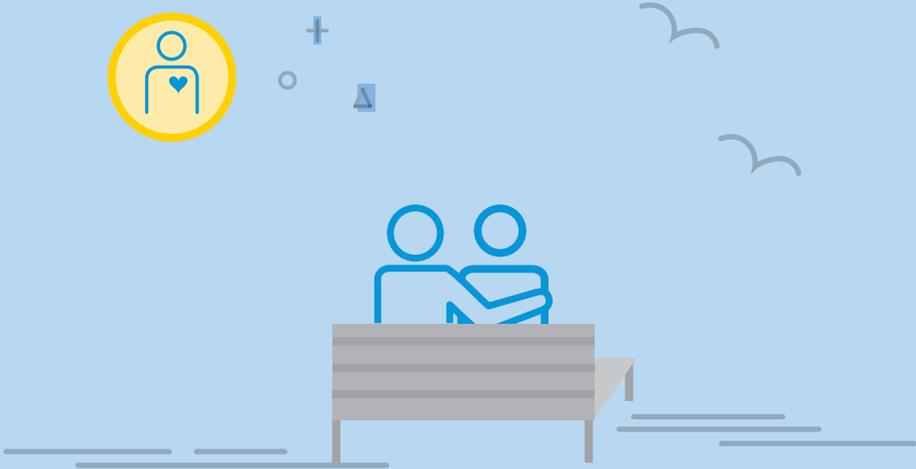
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# Coping with the news that you're dying

This chapter discusses some ways you may cope with the news that you're approaching the end of life, and how your family and friends may react. Everyone copes in their own way. It is natural to experience a range of strong emotions and for these feelings to change often.

## Hearing the news

Learning that you may not have long to live is shocking news. Even if you are aware that the cancer has spread, hearing that you are dying can be extremely upsetting.

We all know that death is a natural part of life and that it will happen to us all one day, but most of us hope that we won't die anytime soon. Realising that death is close can be frightening and hard to believe. For some people, it may be a relief. You may have questions right away, or you might need time to absorb the news and come to terms with the expected outcome of your disease (prognosis).

## How you might feel

You will probably have many strong emotions. After the initial shock, feelings of fear, denial, anger, despair, helplessness and anxiety are common. You may also worry about how your family and friends will cope – emotionally, physically, socially and financially. The news will mean that you can't live the future you'd planned. It may mean leaving behind a partner, children, family, friends and pets.

You may find that your emotions change, sometimes from day to day or even from hour to hour. This is often part of the process of making sense of what is happening. How you respond to these feelings will vary. You may find it hard to think clearly. It's natural to cry or feel completely overwhelmed; you don't need to put on a brave face.

Some people compare these feelings to waves at the beach. The first waves may knock you off your feet, then your footing becomes a little

“ It’s a hugely shocking thing, but we are all mortal and we all live as if we are not. And that’s one of the hardest things I think; we live as if life will go on forever and we’re so shocked when we find out that it doesn’t. ” Susan

stronger. But, at any time, a large wave can suddenly come back and knock you off your feet again. The waves of emotions may not hit in any particular order, but people often say that their fears are stronger when it’s quieter at night, and that they rarely share how they’re feeling with others.

You may be able to work out your own ways to cope with these feelings. Find someone you can talk to, perhaps a family member or friend. You could also consider seeking professional help through a palliative care specialist or nurse, general practitioner (GP), counsellor, psychologist, psychiatrist or spiritual adviser. Other people nearing the end of life offer a unique perspective, so you may want to consider joining a support group (see page 76 for details).

## Telling others

There is no easy way to start this conversation, but you may find it helps to practise what you are going to say.

- When you feel ready, decide who to tell and what you want to say. Think of answers to possible questions, but only respond if you feel comfortable. You don’t have to share every detail.

- Choose a quiet time and place.
- Accept that people may react in different ways. They may be uncomfortable and perhaps not know what to say. If they get upset, you may find yourself comforting them, even though you are the one dying. Another common reaction is denial – they may be convinced that a cure will be found or that the doctors are wrong.
- Call Cancer Council 13 11 20 if you need help telling people. They can help you find the words that feel right for you. Another option is to ask your doctor or nurse to help you share the news.

For ways to talk to people (including children) about dying, see *Emotional and spiritual concerns* on pages 19–26.

### **Do people who are dying need to be told?**

Sometimes family members learn the cancer is terminal before the person who is dying. They may think the person is too young or too old to be told the truth. Some cultures may also think it's best that the person is not told.

Usually people who are dying know what is happening. Trying to keep it a secret from them may mean they feel alone just when they most need support. Ask the person if they would want to know and follow their wishes. The health care team can help you with this conversation and also with an approach for complex situations, such as when the person dying has dementia.



# Common questions about dying

Knowing that you have a short time to live raises many questions. Sometimes, you may not be sure if you want to know the answers. This chapter discusses some of the questions you may want to ask when you feel ready.

## How long have I got?

Some people want to know how long they have left to live. Others prefer not to know. It's a very personal decision.

Knowing can help you prepare for and plan the time you have left. If you want to know, you can ask your doctor. They won't be able to give you an exact answer. As everyone is different, a doctor can only give you an estimate (prognosis) based on what usually happens to people in your situation, but can't say exactly what will happen to you.

Some doctors may sound very definite about how long you have left to live, but it is only ever an estimate. Other doctors may be hesitant in case they overestimate or underestimate the time. They will probably talk about the time in terms of days, days to weeks, weeks to months, or perhaps even longer.

It is likely to be very difficult if you are told that the time you have left to live will probably be short. Even if it is only a matter of weeks, having a sense of how much time might be left can give you a chance to focus on what you'd like to do. If you live longer than the estimated time, you may feel unsettled and like you're waiting to die, or you might feel lucky to be living beyond that time. It may help to talk about how you're feeling with your family, the palliative care team (see opposite page), your doctor or a counsellor.

“ My doctors haven't 'given me a date' but I'm preparing for the day. I'm getting my affairs in order and trying to make sense of things. ” Agnes

## Will palliative care help?

Palliative care is person-centred care that helps people with a progressive, life-limiting illness to live as fully and as comfortably as possible. It's sometimes called supportive care. The main goal is to help you maintain your quality of life by identifying and dealing with your physical, practical, emotional, cultural, social and spiritual needs. Palliative care also offers support to families and carers.

A team of health professionals, as well as volunteers and carers, work together to offer a range of palliative care services. The services will be tailored to your individual needs, and may include:

- relief of pain and other symptoms such as fatigue, nausea, vomiting, and shortness of breath
- resources such as equipment to aid care at home
- assistance for families to come together to talk about sensitive or complex issues
- links to other services such as home help and financial support
- support for emotional, cultural, social and spiritual concerns
- referrals to respite care services.

Your palliative care may be coordinated by your GP, a palliative care nurse or the specialist palliative care team in your area. Palliative care teams see people with the most complex needs, but they can also advise other health professionals on ways to manage symptoms. Palliative care can be provided in the home, in a hospital, in a palliative care unit or hospice, or in a residential aged care facility. Services vary, because palliative care is different in each state and territory.

- See our *Understanding Palliative Care* booklet or listen to *The Thing About Advanced Cancer* podcast.

## Who can help?

Wherever you receive end-of-life care, the different health professionals in your palliative care team can offer a range of services to assist you. You may not need to see all of the people listed below,

### The palliative care team

<b>GP</b>	continues to see you for day-to-day health care issues and may coordinate your palliative care
<b>specialist palliative care nurse</b>	may work in a community or hospital setting, can provide ongoing care and may coordinate your palliative care
<b>community nurse</b>	visits you at home to supervise medical care, assesses your needs for supportive care, and works with your GP
<b>palliative care specialist* (physician)</b>	treats pain and other symptoms to maximise wellbeing and improve quality of life; usually works in collaboration with your GP or palliative care nurse
<b>cancer specialists* (oncologists and surgeons)</b>	may refer you to the specialist palliative care team and continue to provide cancer treatment to help manage your symptoms
<b>counsellor, psychologist</b>	help you manage your emotional response to diagnosis and treatment
<b>psychiatrist*</b>	specialises in the diagnosis and treatment of mental illness, can prescribe medicine and uses evidence-based strategies to manage emotional conditions
<b>spiritual care practitioner (pastoral carer)</b>	discusses any spiritual matters and helps you reflect on your life and search for meaning; if appropriate, may arrange prayer services and other religious rituals

but understanding the different roles can help you work out what support is available and who to ask about particular issues. Your care may be coordinated by your GP, a community or hospital palliative care nurse, or the specialist palliative care team.

<b>pharmacist</b>	dispenses medicines and gives you advice about dosage and side effects
<b>occupational therapist</b>	assists in adapting your living and working environment; can suggest equipment, such as a hospital bed, wheelchair and bedside commode (toilet chair)
<b>physiotherapist</b>	helps with restoring movement and mobility, and preventing further injury
<b>diversional therapist</b>	offers recreational activities to improve your wellbeing
<b>dietitian</b>	recommends an eating plan and tries to use diet to assist with digestive issues, such as nausea or constipation
<b>speech pathologist</b>	helps with communication and swallowing problems
<b>social worker</b>	links you to support services and helps you with emotional, practical and financial issues; may also be called a welfare officer
<b>volunteers</b>	can help with home or personal care and transport, and also offer companionship

*\*Specialist doctor*

## Is now the time to try complementary or alternative therapies?

If your doctor has told you that the cancer cannot be cured, you may wonder whether there are any other therapies you could try. Complementary therapies tend to focus on the whole person, not just the cancer. They are used alongside conventional medical treatments, while alternative therapies are used in place of conventional treatments.

Many people use complementary therapies to help them feel better and cope with cancer and its treatment. This is also true for people who are dying with cancer. Complementary therapies may help you relax and reduce anxiety. They can also be useful in managing symptoms such as pain and nausea. Some people find gentle therapies, such as massage and aromatherapy, helpful. People who find it uncomfortable or painful to be touched may prefer meditation or visualisation.

Alternative therapies are often promoted as cancer cures, and family members, friends or even strangers may suggest you try them when you explain your prognosis. Unlike conventional medical treatments, alternative therapies have not been scientifically tested, so there is no proof they stop cancer growing or spreading. They can be very expensive and could interfere with other medicines.

If you are considering trying an alternative therapy, discuss this with your doctor first. Cancer Council does not recommend the use of alternative therapies as a treatment for cancer.

➤ See our *Understanding Complementary Therapies* booklet.

## What is a “good death”?

People often talk about wanting to have a “good death”. What dying well means is different for each person, shaped by their attitudes, cultural background, spiritual beliefs and medical treatments.

Think about what dying well means to you. You might find it is important to:

- know that death is coming and have some understanding of what to expect
- have some control over pain relief and other symptoms
- be able to retain some control over where death occurs and how it happens
- maintain a sense of dignity
- have the opportunity to prepare for death
- reconcile damaged or broken relationships
- have the chance to say goodbye
- resolve regrets
- be able to have a say in end-of-life care and ensure your wishes are respected.

There are different ways to die well. Some people see staying at home (see pages 35–36) as the key to dying well, but others feel more supported spending their last days in a hospital or palliative care unit. It is important that your family, friends and health care team understand what matters most to you. Open conversations and planning ahead for dying can also help family members and friends cope better with the grief and loss they may experience (bereavement). They may feel a sense of peace knowing your preferences were respected.

## Thoughts about euthanasia

If an illness is prolonged or causing uncomfortable symptoms, some people think about speeding things up. Euthanasia is the act of deliberately ending the life of a person with an incurable condition or illness. Voluntary assisted dying is when a person ends their own life with the help of a doctor.

At the time of publication (2020), euthanasia and voluntary assisted dying are illegal in most states and territories in Australia. Voluntary assisted dying for people who meet strict criteria is legal in Victoria. To find out more, visit [health.vic.gov.au](https://www.health.vic.gov.au) and search for “voluntary assisted dying”. There is currently much discussion of these issues. The law has recently changed in Western Australia, and the laws are under review in some other states and territories (visit [end-of-life.qut.edu.au](https://www.end-of-life.qut.edu.au) for updates).

Regardless of the law, some seriously ill people consider this path. Sometimes a person with cancer may decide they want their death hastened, but later

decide that they don't. They may have thought that way because they were feeling particularly ill, scared, or worried about the strain they were putting on others.

If this is how you feel, discuss your concerns with a doctor, counsellor or social worker. Sometimes these feelings are due to depression or a sense of helplessness, or because pain or other symptoms are not well controlled.

Pain and depression can almost always be treated, and help is generally available for other symptoms. It is important that you talk to your doctor or nurse about any physical or emotional symptoms that are causing you pain or distress, and find ways to make your final days more comfortable.

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

## What is dying going to be like?

It's common to have misconceptions or fears about what the process of dying is like. Many people say they don't fear death as much as the unknowns of dying. Having some idea of what to expect can make the process easier. Not being prepared for what might happen can be distressing for you as well as for your family and friends.

If you've been with a person who has died, this experience will influence how you feel about dying. It may have left you reassured, thoughtful, sad, angry or scared. You may have been disturbed by some of the physical changes that happened to the person. For example, perhaps it appeared they were having trouble breathing, or they seemed to be in pain or uncomfortable.

It will help to talk to your doctor or to the palliative care staff. They can explain the physical process of dying and reassure you that you will be cared for. You might not be aware of physical changes because you may be drowsy or unconscious.

Modern health care means that people should not die in pain or distress. If you have symptoms that are not well controlled, you can ask your doctor or the palliative care team to help. The information on the next page also describes the physical process of dying in more detail.

🗣️ When patients ask me about the dying process, I describe it as the physical and emotional experience of gradually becoming weaker and letting go of their attachment to living. 🗣️ *Nurse*

## How will I know that the end is near?

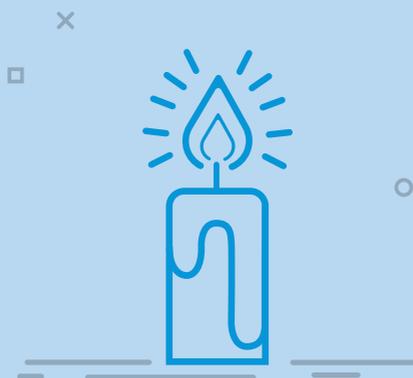
For many, dying is a process that happens gradually. As the body slowly shuts down, energy levels vary and there are good days along with days when you can't do much at all. Your appetite will reduce, and sips of water or a teaspoon of food here and there may be enough.

As death gets closer, it's common to have little interest in talking and the outside world. You may find your attention withdraws from family and friends, and you may sleep more and more during the day.

Near the end, some people may require sedation for symptom management. Many people slip into unconsciousness before dying, although some remain alert almost until the end. Others may have periods of being awake, and then slip back into unconsciousness.

No-one knows how a dying person experiences the moment of death. Whatever happens, it is thought to be a peaceful moment.

More information about the dying process is covered in *Caring for someone nearing the end of life* on pages 53–72.



# Emotional and spiritual concerns

As you approach the end of life, you may struggle with talking about death and dying, and finding hope and meaning. This chapter offers ideas for starting conversations, and managing emotional and spiritual concerns.

## Talking about dying

Most people are not used to talking about death and dying, and it's common to avoid this conversation or to use different words such as “passed away”, “departed”, “gone” or “slipped away”.

### Why it helps to talk

There may be days when you feel like talking about approaching the end of life, and days when you don't. This may even change from minute to minute. In general, it can help to discuss your fears and concerns about death with trusted family and friends. When you share how you think and feel with people you trust, it can help support all of you through the sadness, anxiety and uncertainty.

Some people dying with cancer have said that the process can feel isolating and lonely, even with a stream of visitors. This is particularly true if family and friends avoid talking about what is happening. If you are comfortable with people acknowledging that you are dying with cancer, let them know.

### When you don't want to talk

You may find that you don't want to talk about dying, or that you want to discuss it with some people but not others. You may be the type of person who would prefer to focus on making the most of the time you have left, rather than talking about death. In some cultures, people think it's disrespectful to talk about dying, or they may feel that talking about death makes it happen sooner.

Everyone handles dying in their own way. If you don't want to talk about facing the end of life, your wishes should be respected.

## The effect on people close to you

You may sometimes feel that the hardest part about dying is the effect it will have on your family and friends.

People living with terminal cancer often say family and friends react in a range of ways when they find out the disease is at the end stage.

Different family members and friends may:

- offer to help in any way they can
- be overprotective, not wanting to leave you alone
- refuse to believe the prognosis, saying things like “I’m sure you’ll get better” or “You’ll beat this”, or suggest various forms of treatment or alternative therapies
- volunteer the story of a friend or celebrity who experienced a miraculous recovery from something everyone had deemed hopeless and fatal
- pull away and withdraw from your life
- start to regard you as already gone.

Some of these reactions can be hurtful and frustrating, but they don’t mean that your family and friends don’t care. They need time to adjust to the news and come to terms with how they’re feeling. While you may be disappointed by the reactions of some people, you may also be surprised by how much support is offered and who offers it.

“People saying ‘You’ll get well’ makes me really cross. I know I won’t get well. I want to say, ‘I am going to die and don’t you dare deny me this business of dying’.” Catherine

## How to tell children

If you have children or grandchildren, telling them that you are dying will be difficult. There is no easy way to approach this conversation, but it is important to let them know what is happening.

Like adults, children of all ages need time to prepare for the death of someone close to them. It's natural to want to protect children, but they will often sense that something has changed. Not sharing the prognosis can add to their anxiety – and yours.

How you tell your children or grandchildren will depend on their age, but these suggestions may help:

- It may be easier to have your partner or a support person with you when you have the initial discussion.
  - Be honest with your children and explain the situation using straightforward words, such as “dying” and “death”. Avoid terms such as “pass away” or “going to sleep”, which can be confusing or alarming for them.
  - Keep your explanations as simple as possible, and be guided by their questions so you don't offer more information than they may want or can handle.
  - Depending on their age, children may benefit from seeing a counsellor or play therapist.
- See our *Talking to Kids About Cancer* booklet.

## If you live alone

Some people with advanced cancer may live alone and have little or no support from family or friends. If you live alone, you can seek assistance from other sources, including:

- your GP
- the palliative care team
- the local community health service
- the local council
- a church or other religious group
- practical support services (see pages 73–76)
- Cancer Council 13 11 20.

Community palliative care services can help you stay at home for as long as possible. But at some point, you may need 24-hour care. This is usually available in a palliative care unit (hospice), hospital or residential aged care facility.

If your preference is to die at home, you will need support from family and friends, and ongoing visits by your GP and other health professionals. You may wish to consider using private nursing services, which can be expensive.

## Coping with change and loss

Finding a way to cope with knowing you are dying can depend on many factors, including your age, whether or not you have children, your relationships with a partner or family members, and your cultural or spiritual beliefs. It may also depend on how your family and friends cope with the news.

Everyone will find their own way at their own pace. There is no right or wrong way. For some people, learning more about the physical process of dying can make it easier to cope. Others find it helps not to think too far ahead, but to focus on a month, a week or even a day at a time.

## **Finding hope**

When you've been told that you're dying with cancer, you may find it hard to feel hopeful. While it may be unrealistic to hope for a cure, you can find hope in other things, such as sharing some special times with those you love. Studies of people dying with cancer show that people's hope can be maintained when their health professionals:

- involve them in decision-making, especially about palliative care treatment options and where they would like to die
- reassure them that any pain and other symptoms will be well controlled.

Finding a balance between knowing you are dying and still trying to live as fully as possible is sometimes called “living with dying”. This may mean focusing more on the present. You may find that some days it's easier to achieve this than others.

## **Maintaining a sense of control**

When you're approaching the end of life, you may feel like you've lost control. One way to maintain some control is to make decisions about your current and future health care and medical treatment, and to record your preferences in advance care paperwork (see pages 43–47).

## Loss and grief

Other losses and changes happen throughout a terminal illness – loss of work, loss of social roles, loss of friendships, loss of connection to community, and loss of independence. A dying person often needs to spend time grieving for these losses.

You might also experience preparatory grief, which means reacting to the impending loss of your life. You may grieve for events that you won't be around for, such as marriages, graduations and new babies in the family. If you don't have a partner or children, you may mourn the lost opportunity to have these relationships or experiences. You can also grieve for small pleasures such as not being able to have a morning cup of coffee.

Gradually, you may feel less able to do things or you may lose interest in activities you previously enjoyed. For many people, this is a natural part of coming to terms with death. It may make you feel sad and very low, but you may also move towards a sense of peace.

## Spirituality at the end of life

Spirituality is an individual concept. For some people, it means being part of established religious beliefs and practices, such as Christianity, Judaism, Islam, Buddhism, or Indigenous belief systems. For others, spirituality is expressed as a personal philosophy.

For many people at the end of life, spirituality is a source of comfort and strength. Others find their beliefs are challenged by their situation and no longer find comfort in their spirituality.

It may help to talk about your thoughts and feelings with a spiritual care practitioner (sometimes called a pastoral carer or chaplain). A spiritual care practitioner is part of the palliative care team and has the expertise to discuss spiritual issues, whatever your beliefs. You may wish to discuss the meaning of life or your beliefs about death. A spiritual care practitioner can also provide companionship.

People often say that knowing they're dying makes them feel more spiritual, and they want to think about and discuss these issues. In some cases, they may embrace a belief system that they have not been interested in before or abandoned many years ago. Although many people do look for meaning at the end of their life, others are not interested in spirituality.

Some people find comfort in prayer or meditation, and gain support from knowing that other people are praying for them or sending positive thoughts their way. Many religions have specific practices for when people are dying. If you want to follow certain rites in a hospital or hospice, it's best to discuss this with the staff in advance. They will be able to help you find the space and time to do this, and your customs can often become part of your palliative care plan.



# Physical concerns

**Near the end of life, the focus of medical care is usually on maintaining your quality of life, and controlling pain and other symptoms. This chapter describes the common symptoms experienced towards the end of life and how they can be managed.**

## Symptoms at the end of life

As cancer progresses, it can cause various symptoms. These symptoms may not occur in everyone, and some may not occur until near the end. People who are dying, and their families and carers, often worry about how these symptoms will be managed. The health professionals in your palliative care team (see pages 12–13) will provide you with the highest possible level of comfort and care during your last days.

## Pain

Many people with end-stage cancer worry they could spend their final days in pain, but not everyone has pain. Those who do have pain may not be in pain all the time – it may come and go. The various health professionals caring for you will help you control any pain as much as possible.

Everyone experiences pain differently, so it might take time to find the right pain management for you. Controlling the pain may allow you to continue with your regular activities for some time and offer a better quality of life.

The right pain relief for you depends on the type of pain you have and how intense it is. Often a combination is used. You might be offered:

- mild pain medicine, such as paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs)
- moderate pain medicine, such as codeine
- strong pain medicine, such as morphine, oxycodone, hydromorphone and fentanyl
- complementary therapies such as massage or meditation.

You may also be given other types of medicine along with the main pain medicine. These could include:

- antidepressants and anticonvulsants for nerve pain
- local anaesthetics for nerve pain
- anti-anxiety drugs for muscle spasms
- a nerve block or epidurals (for pain that is difficult to manage).

Palliative care specialists are highly experienced in managing pain and won't let you suffer with unrelieved pain. Some people worry about becoming addicted to pain medicine, but this is not a concern with end-stage cancer.

- ▶ See our *Overcoming Cancer Pain* booklet, and listen to our podcast episodes on pain.

## Tiredness and fatigue

Most people with a terminal illness feel extreme or constant tiredness (fatigue). Try to pace yourself and save your energy for the activities that are most important to you.

Fatigue may affect your ability to think clearly and make decisions. This can be frustrating, particularly if you are trying to put your affairs in order. You may want to deal with these practical concerns at a time of day when you have more energy.

“ The biggest side effect of the medication he started last year has been fatigue. He feels like he could sleep forever. ” Susan

While some people sleep a lot at the end of life, others find it hard to sleep, which can make fatigue worse. If you're having trouble sleeping, it may be because of anxiety, pain, a side effect of a medicine you are taking or a change in your sleep-wake cycle. Let your palliative care team know, as they may be able to adjust your medicines or offer another medicine to help you sleep. They may also suggest you try complementary therapies such as meditation and relaxation. Improving the quality of your sleep will improve the quality of your waking hours.

## Loss of appetite

Many people find they do not feel like eating as they near the end of life. This loss of appetite may be because of the cancer itself or symptoms such as pain, nausea, constipation or breathlessness, or because the body's energy needs have slowed down and it's no longer necessary to eat as much.

Don't force yourself to eat – eating more than you feel like may only make you uncomfortable, and can cause vomiting and stomach pain. Try having small meals or eating your favourite foods more frequently. You could also eat soft foods or have food-type nutritional supplements. Ask your doctor, nurse or dietitian to recommend something suitable; some are available as ready-made drinks at pharmacies.

It's common for family and friends to want to encourage you to eat, as preparing food for you is how they show they care. You may need to let them know that you don't feel like eating, and suggest other ways they can show their love, such as sitting with you.

As the disease progresses, the body reaches a point where it can no longer absorb or get nutrients from food. You may not be able to eat, and clear fluids such as water or weak tea may be all you can handle. There will come a time when even water isn't wanted, and family or friends can help keep your mouth moist. See *How you can help in the final stages* on page 66 for ways others can offer comfort.

➤ See our *Nutrition and Cancer* booklet.

## Feeling sick

You may feel sick or have trouble keeping food down, either because of the cancer or because of side effects from medicines you're taking. Anti-nausea medicines (antiemetics) can help manage nausea and vomiting. These can be taken as tablets or, if swallowing is difficult, as wafers that dissolve on the tongue, as injections under the skin, or as suppositories, which are inserted into the bottom.

## Shortness of breath

Breathlessness (dyspnoea) is common at the end of life. Breathing may become uneven, change rhythm and become noisy. Your palliative care team will assess the cause of the breathlessness and manage it with medicine or practical measures. These include sitting near an open window, having a fan in the room or doing relaxation exercises. Adjusting your position in bed can also help.

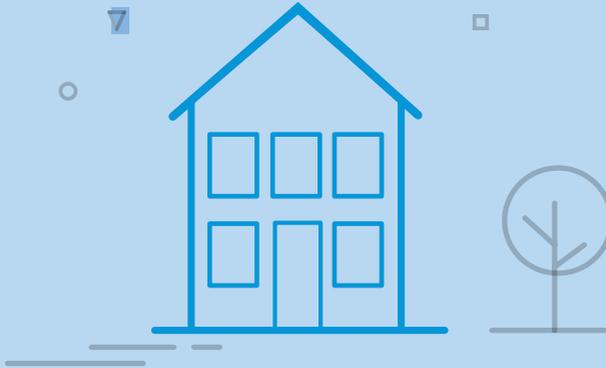
Breathlessness may make you feel distressed, and this is likely to make the shortness of breath worse. Talk to your doctor about medicines that can ease your anxiety.

## Other symptoms

As you approach the final days or hours of life, the body's systems start shutting down. This may affect breathing, bladder and bowel function, and behaviour. Any changes can be managed to help you feel more comfortable.

It is natural to feel concerned about others witnessing some of these physical changes. Your medical team understand this and can help explain what is happening to your family and friends.

Some people find it reassuring to know more about what might happen in the last stages, when they may no longer be fully conscious, but others find it distressing. If you would like to know more, see pages 63–67.



## Where to die

**Choosing where you would like to die is a personal decision. This chapter outlines the options of dying in your own home, in a palliative care unit or hospice, in hospital, or in a residential aged care facility.**

## Making your choice

Deciding where you would like to be cared for as you approach the end of life can be difficult. Having some control over where death occurs is often considered a key factor in dying well. Where that place might be will be different for everyone.

The options include:

- your own home
- a palliative care unit or hospice
- a hospital
- a residential aged care facility.

Where you would like to die may change as your situation progresses. You may want to spend as much time as possible at home, but feel more comfortable moving to a palliative care unit or hospital near the end. This is understandable and your wishes should be respected whenever possible.

It can take time to arrange somewhere to stay. Keep in mind that sometimes there isn't space when you need it.

You may need to have ongoing conversations with your carers and medical team about the best place for your end-of-life care. This may include being in a familiar environment, being surrounded by family and friends, having good symptom control, and maintaining your dignity. It's a good idea to find out the views and preferences of your carers and family. Although dying is a natural process, few people have experience or knowledge of looking after someone who is dying, and they may be uncomfortable with some options. Talking about

where you would like to be cared for and planning ahead can increase the likelihood of receiving care in your place of choice.

In some cases, you may feel like your choice is limited, and that your situation helps decide the setting. This may be because you have medical needs that only a hospital or palliative care unit (hospice) can meet, or you may live in an area too remote for home visits. Your house may be unsuitable, perhaps because of stairs or a small bathroom, or your family or friends may say they feel unable to cope with caring for you at home. Talk to the palliative care team about your concerns and find out what options are available in your area.

## In your own home

If asked, many people say they want to die at home. This may be because they want to be around familiar surroundings and people.

While this option is not for everyone, if you do want to be at home, support is available. This may vary from a few hours a week to a few hours a day to 24-hour care. Your GP, nurse, palliative care specialist or palliative care nurse practitioner can suggest services to manage symptoms such as pain or breathlessness. They can also teach carers how to assist with day-to-day activities such as bathing and eating. Even if you live alone, with planning you can stay as long as possible in your own home.

Some carers may appreciate having you nearby and not having to deal with hospital disruptions or fit in with the hospital routines. Caring for someone who is dying at home can be a meaningful and comforting

experience, but it can also be challenging. For more information, read *Caring for someone nearing the end of life* on pages 53–72.

Sometimes people go into a hospice or hospital to have symptoms managed or to give their carers a break (respite), and then return home. Or they may decide it's not possible to stay at home, even with home help, and that they would be more comfortable in a palliative care unit or hospital. You can decide at any stage to change your mind about staying at home and explore other options.

If you are planning to die at home, talk to your GP or palliative care team about ways of dealing with unexpected medical events. Keep a list of phone numbers handy to call if you need advice and support.



### Home: key points

- Being cared for in a familiar environment surrounded by people you know well may help you maintain emotional wellbeing.
- Lets you spend more time with family and friends.
- Depending on your situation and preferences, your family and friends can be at your side at all times.
- May offer more opportunities to maximise quality of life.
- May feel more natural and less clinical, while still giving you access to expert medical advice and symptom control.
- Allows you a sense of control over the last part of your life.
- Your family and friends may find comfort in providing most of your care.
- After death, family and friends can grieve at their own pace and decide when to call the ambulance or funeral home.

## In a palliative care unit or hospice

Specialised palliative care facilities may be called palliative care units or hospices. Some hospices have rooms within a hospital. Palliative care units focus on caring for people with a life-limiting illness and aim to maintain quality of life. They are run by health professionals who specialise in providing physical and emotional comfort to the patient, and supporting the family before and after the death.

Palliative care units and hospices are different from most hospital wards. They are usually quieter and calmer, and have a more homely environment. Many people value the relaxed surroundings, as well as the skilled staff and expert symptom management.

These facilities often provide short-term respite care as well as longer-term care for the dying person. Sometimes you can go back and forth between a palliative care unit and another setting during your final weeks. Many now have a maximum length of stay, so you may want to check this with them ahead of time.

You may choose this option if you want to relieve your family from caring for you while you are dying, although they can still be involved. This can include feeding, bathing or simply being present.

Some people and their family and friends are unsure of when to contact a palliative care unit. They may wait to call until the final days, possibly missing out on the support that a palliative care unit or hospice has to offer. Some facilities have waiting lists, so talk to your palliative care team about when would be an appropriate time to make the first contact.



## Palliative care unit or hospice: key points

- Offers a welcoming and comfortable physical environment.
- Provides 24-hour care with expert pain and symptom control.
- Focus is on quality, not length, of life.
- Allows the patient and their family and friends to focus on being together.
- Direct access to a team of professionals and volunteers trained to meet the needs of the dying person, and carers.
- Carers can leave at the end of the day and get some rest.
- Some families prefer not to live in a house where someone has died (although others find this a comfort).

## In hospital

Even when death is expected, more people approaching the end of life die in hospital than anywhere else. While some people feel more secure being near health professionals, others feel anxious about hospital care, believing it will be too impersonal.

If you have spent a lot of time in hospital during your illness, you may want to stay on the same ward where you are familiar with staff and surroundings, they know you and they understand your specific needs. You'll need to check if this is possible – sometimes people are moved to a different ward as their medical needs change.

To help create a more homely environment, ask if you, your carers, family or friends can bring in familiar items from home, such as a favourite blanket or photos.

Decisions about your care may be made without your input. Hospitals sometimes provide medical interventions, such as resuscitation and intravenous lines, that may not be what you want in the final weeks or days of life. Your health care team should work with you to make sure your care plan matches your preferences. If you are concerned, talk to the hospital staff and request that you don't receive such interventions. You can arrange to have your wishes recorded in an advance care directive before an emergency occurs. It is a good idea to keep a copy at home so your carers and your family and friends know your wishes.

The different aspects of end-of-life care in a hospital can be managed with communication and advance care planning. Preparing an advance care directive can help give you control over the type of medical treatment you receive. See page 47 for further details on what this is and how it can help ensure your wishes are followed.

### Hospital: key points

- Experienced medical and nursing staff are available at short notice to manage physical symptoms (e.g. pain, fatigue, breathlessness, delirium) and emotional needs (e.g. anxiety, agitation).
- Able to make organ donation. For more details, see page 47 and [donatelife.gov.au](https://donatelife.gov.au).
- Carers can leave at the end of the day and go home to get some rest. But some carers may find leaving you to go home difficult.
- Provides 24-hour care.
- Some families prefer not to live in a house where someone has died.



## In a residential aged care facility

A residential aged care facility (formerly called a nursing home) is a place where people stay who need continual care and help with daily living. These facilities cater for people with a range of chronic conditions, and nurses and aged care workers can provide care 24 hours a day. Some aged care facilities also provide respite and hospice care.

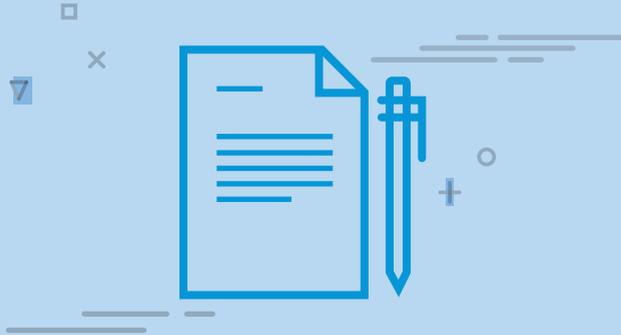
Some people fear that dying in residential aged care will be unpleasant and perhaps impersonal. But dying in an aged care facility can be comforting, particularly if it has been your home for a period of time and you are familiar with the staff, who will try to make you comfortable.

If you want to die in a residential aged care facility, ensure that you have an advance care directive in place (see page 47). Talk to your care providers about avoiding an unnecessary transfer to hospital at the end of life.



### Residential aged care facility: key points

- A less clinical environment than some hospitals.
- Experienced staff to manage symptoms and needs.
- May be located close to carers, family or friends.
- Provides 24-hour care.
- Family and friends can go home to get some rest. But some carers may find this difficult.
- Some families prefer not to live in a house where someone has died.



# Practical concerns

Getting your affairs in order can be an important task in the final stages of life. This chapter explains the purpose of advance care planning, and discusses medical, legal and other practical issues to consider at this time.

## Planning for the end of life

The process of planning for the end of life can be both rewarding and difficult. It may help you feel more in control of the situation or give you a sense of relief that the people and possessions that mean something to you will be looked after in the future. Or you may wish to ease the burden on family members or friends.

## Organising your paperwork

Having all of your paperwork up to date and in one place will make it easier if a family member has to help you with financial and legal matters. Important documents might include:

- birth, marriage, divorce and citizenship certificates
- financial documents such as bank and credit card information, details of investments (e.g. shares, funds) or any safe deposit boxes
- Centrelink and Medicare details
- list of social media and other online accounts (see page 46)
- superannuation and insurance information
- loan details (e.g. house, car) and house title/lease documents
- passport
- will
- document appointing a substitute decision-maker (see page 46)
- advance care directive (see page 47)
- funeral information, including any funeral insurance or any prearrangements you have made.

It's a good idea to check or update who you have nominated as beneficiaries on your superannuation and life insurance policies. Let someone close to you know how to contact your lawyer.

## Advance care planning

If you have not already done so, it is important to plan for your future medical care, and to discuss your preferences and values with your family, friends and health care team. This process is called advance care planning. You need to be an adult and have capacity (see next page) to complete advance care documents.

Although advance care planning is often done when people are told their condition is terminal, or as they approach the end of life, it can be started at any time, whether you are healthy or ill.

It is hard to know what medical care you're going to want until the situation arises. Many people find their attitudes and preferences for medical care change as they get closer to death, and they may need to revisit their decision regularly. To help you consider what care you'd like, think about what is important to you and talk with your health professionals. This may take several appointments.

For some people, quality of life is more important than length, but for others, it may be the reverse. Some people may feel there's nothing worse than death, and will do anything to avoid it. Others may prefer to die comfortably without unnecessary and sometimes uncomfortable procedures. You may want to find a balance between what medical care can achieve and the side effects of treatments.

Discussing these issues with others will help them understand your goals, values and beliefs, and help to ensure that your preferences are respected should you lose the capacity to make your own decisions. Without these conversations, it's not uncommon for distressed

family members to have disagreements about whether to keep you alive using any means possible or focus on your quality of life. You might like to use one of Palliative Care Australia's discussion starters at [dyingtotalk.org.au/discussion-starters](http://dyingtotalk.org.au/discussion-starters) or Advance Care Planning Australia's conversation starters at [advancecareplanning.org.au/individuals/how-to-start-the-conversation](http://advancecareplanning.org.au/individuals/how-to-start-the-conversation).

Your advance care documents can be as simple or as detailed as you like. As part of your advance care planning, you may appoint a substitute decision-maker and record your wishes in an advance care directive. See pages 46–47 for more information.

Each state and territory has different laws about advance care directives and substitute decision-makers. To find out more, visit [advancecareplanning.org.au](http://advancecareplanning.org.au) or call 1300 208 582.

## Preparing legal documents

If you have not already done so, now is the time to think about making a will, appointing a substitute decision-maker and preparing an advance care directive.

For any of these documents to be legally binding, you need to have capacity at the time of signing the document. Having capacity refers to an adult's ability to make a decision for themselves. It means you are able to understand the choices that are available and the consequences of your decisions, and are able to communicate your choices. For more information, talk to your lawyer and doctor, or visit [end-of-life.qut.edu.au/capacity](http://end-of-life.qut.edu.au/capacity).

## Making a will

A will is a legal document that sets out what you want to happen to your assets after you die. These assets are called your estate and may include your house, land, car, bank accounts, jewellery, clothes, household goods or investments. A will can also record your wishes regarding who will look after any children (guardianship).

Making a will is not difficult but it needs to be prepared and written in the right way to be legally valid. A will should be reviewed and updated as circumstances change. It is best to ask a lawyer to help you, or contact the Public Trustee in your state or territory. For more information on preparing a will, call Cancer Council's Legal and Financial Referral Service on 13 11 20.

If you die without a valid will, you are said to die intestate. Your assets are distributed to family members according to a formula provided by the law. Although a will can be challenged in court, a valid will usually means your assets go to the people you choose. It can also help avoid extra expenses, and simplify the process for your family.

“It's tough for anyone to confront their own mortality, but it's unavoidable when you get a terminal illness. Suddenly I had to start thinking about practical things like getting a will and a power of attorney. Something else that was tough to talk to my wife about was the funeral plans, but I'm glad I got it out of the way because it's one less thing to worry about.”  Ian

## Appointing a substitute decision-maker

You can appoint someone to make medical decisions for you if in the future you lose capacity to make these decisions yourself. This person is called a substitute decision-maker.

A substitute decision-maker should be someone you trust, who understands your values and preferences for future care and can make the decision you would have wanted. Depending on where you live, the documents for appointing this person may be known as an enduring power of attorney, enduring power of guardianship, or appointment of a medical treatment decision maker.

### Managing your digital legacy

If you use social media, such as Facebook, Twitter, Instagram and LinkedIn, you may want to think about what happens to your accounts after your death.

Each social media platform has different rules for deactivating accounts, while some allow your account to be turned into a memorial page.

It is a good idea to prepare a list of all your social media accounts, passwords and instructions and

leave it with someone you trust, so they can manage your ongoing digital presence according to your wishes.

If your family or friends need to delete or deactivate your account after your death, they may need to provide proof of death documentation.

For more information, download Palliative Care Australia's *Guide to a Social Media Afterlife* at [palliativecare.org.au/resources](http://palliativecare.org.au/resources).

## Donating organs and tissue

Organ and tissue donation is possible for some people with cancer. This will depend on the cancer type and spread, and will be assessed by a doctor after the death. You need to be in a hospital to donate organs but this isn't necessary for tissue. To record your wish to donate tissue or organs, visit [donatelife.gov.au](https://donatelife.gov.au). Share your decision with family as they will be asked to give consent after your death.

## Making an advance care directive

You can record your wishes for your future medical care in an advance care directive. This will only come into effect if you are unable to make decisions for yourself. It provides a record for doctors, family and carers to consider, and may be legally binding in some states and territories. Depending on where you live, the advance care directive may have a different name, such as an advance health directive or advance personal plan.

Keep a copy of your advance care directive for yourself and share copies with your GP, oncologist, substitute decision-maker, family member or friend. Ask your doctor or the hospital to place your directive on your medical record. You can also save a digital version to My Health Record, a government website that stores your health information – find out more at [myhealthrecord.gov.au](https://myhealthrecord.gov.au). You can update your advance care directive when your preferences change.

For more information, visit Advance Care Planning Australia at [advancecareplanning.org.au](https://advancecareplanning.org.au) or call 1300 208 582.

## What to consider when getting your affairs in order

### Financial/legal matters



- Have you arranged your financial affairs?
- Do you want someone to make legal or financial decisions for you if you are not able to?
- Does someone know where important papers or valuables are stored in the home or elsewhere?
- Do you have a valid will?
- If you have life insurance, is the beneficiary information up to date?
- If you have superannuation, have you nominated a beneficiary? This person must be your dependant. If it is a “lapsing” nomination, you must confirm it in writing every three years, so check when you did this last.

### Relationships



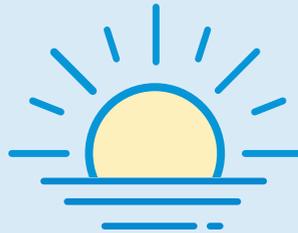
- If you'd like to prepare letters for family or friends, have you done so?
- Who would you like to have around you as you get closer to death? Do they know? Are there people you don't want around?
- Are there unresolved issues that you would like to sort out with particular people?
- Have you left instructions and passwords for your social media accounts?

## Medical care



- Are there certain treatments that you don't want to have?
- Have you discussed your wishes for end-of-life care with your family, carers and health professionals?
- Have you considered who can make decisions about your care if you're not able to make them yourself?
- Have you recorded your wishes for future medical care in an advance care directive and appointed a substitute decision-maker?

## Spiritual issues



- Are there any cultural, spiritual or religious practices that you would like carried out before or after your death? Who do you need to ask to make sure this happens?
- Do you want a minister, priest, rabbi, imam or another spiritual practitioner present at the end?
- Do you want to be buried or cremated? Do you have a burial plot? Would you like your ashes scattered in a specific place?
- What are your preferences for a memorial service? Have you shared your wishes with family and friends?

“ 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. ” Pat

## Making funeral plans

Some people may find planning their own funeral difficult or morbid. Others may be comforted that the funeral will be carried out according to their wishes and that their family or friends won't have to guess what they would have wanted. Still others think that funerals are for the family, and should be organised by them. Some people decide they don't want a funeral at all, or are concerned it will be too expensive or sad. People may prefer to have a memorial service or a living wake. It's a good idea to discuss your choice with family and friends ahead of time. A funeral or memorial service can be a comfort for family and friends.

Most people do have a funeral of some sort. It is probably not easy for most of us to hear or think about funerals. However, there can be a satisfaction in leaving your mark on the occasion, and in involving your family in the planning. If you'd like to make preparations but you can't do the work, or prefer not to, talk to a spiritual care practitioner, funeral celebrant or end-of-life doula for assistance.

You might simply discuss your preferences with your family and executor. Or you may record them in writing or lodge a plan with a funeral director of your choice. There are no rules. You can plan your funeral to meet any cultural or spiritual preferences. You may just have a few simple requests for music you want played or poems you'd like read, or you may have detailed plans for the full service.

For more information on prearranging or prepaying a funeral, talk to a funeral director or visit the Australian Funeral Directors Association website at [afda.org.au](http://afda.org.au). Provide copies of a prepaid funeral contract to members of your family or file it with your will. If the funeral is not prepaid, payment may be made a few days before, or sometimes after, the service.

## Saying goodbye

Knowing you will die offers you a special opportunity – the chance to say goodbye to those you love and care about. It is a sad and difficult thing to do, but some people say they feel lucky that they've had the time to prepare.

Saying goodbye is a personal experience and you need to do what is right for you. When you feel you are ready, consider how you

### Making a memory box

A memory box is a collection of keepsakes for your family. What you put into a memory box will be your personal choice, but some possibilities include a:

- treasured photo
- video of a family event
- special birthday card
- favourite cap, tie, scarf or another item of clothing
- list of shared memories
- lock of hair
- family recipe
- pressed flower from your garden
- bottle of your favourite perfume or aftershave.

will say goodbye. You might set aside a time to talk to each person individually. Or, if you are physically up to it, you might have a gathering for friends and family. Other ways to say goodbye include documenting insights, requests, thanks, advice, recipes, memories or anything else that is important to you. Some people record these thoughts in a letter or recording, but you can be as creative as you like. You may also want to consider who to pass keepsakes to.

If you have children or grandchildren, you could specify that any letter or recording is to be given to them at a specific age or time in their life. You (or your friends) could also create a slideshow or scrapbook of special photos. A memory box (see previous page) can be another special keepsake for your family.

You may find it hard to think about a time when you won't be there for your children, but these actions can be helpful and comforting for them. If your children are very young, they'll understand your words and sentiments when they're older.

If you have a pet, you may want to consider who will care for them. Talk to your local RSPCA to see whether they have a program for rehoming pets.



# Caring for someone nearing the end of life

Even when you know the end of life is approaching for a family member or friend, you might not feel prepared. This chapter covers the practical, emotional and physical issues to expect, and outlines how you can provide comfort and support.

## Coping as a carer

Looking after a person who is dying can be stressful. It's common to feel like you don't know what to do, what to say and how to cope. If you've never been around someone who is dying before, you may be afraid of what will happen. Learning what to expect can help you feel less frightened and confused, and allow you to plan ways to manage the emotional and physical challenges ahead.

- ▶ See our *Caring for Someone with Cancer* booklet, and listen to our "Caring for Someone in Their Last Months" podcast episode.

## Providing practical support

Many people worry about how they'll manage the day-to-day tasks of caring for someone. To make it easier and safer to care for the person at home, you may need to modify the environment (e.g. handrails in the shower) or buy or rent equipment (e.g. shower and toilet chairs, bedpans, hospital bed).

Some carers prefer to provide practical support themselves and just need some guidance from a health professional. Other carers find providing personal care awkward or overwhelming and prefer to have it given by someone else. The palliative care team (see pages 12–13) can help reduce your stress and free you up to spend time with the person you're caring for in a way that is comfortable for you.

You may feel unable to care for someone at home and prefer they receive specialist care in a residential facility. Even if they are in a hospice or aged care facility, you can help provide personal care such as helping with feeding, bathing and toileting.



## Susan's story

My partner, Peter, was diagnosed with prostate cancer in 2015. We found out basically straightaway that it was advanced. So that was a huge shock.

We're both quite up-front people – we like to know the facts of things. Peter just asked straightaway was it terminal. And the GP just said, "Well yes, I'm afraid it is".

Peter was very ill. He managed to sit in a chair for about six weeks and basically not move except hobble to bed and hobble to the toilet and hobble back to the chair. And I remember thinking I could look after him, but if he becomes any less mobile then things would need to change.

I'm more than happy to be his carer. I think sometimes trying to be his carer, his partner, his lover, his companion – just swapping between roles can sometimes be a bit tricky. It can be a bit tiring but I'm happy to do it. It's more an issue of making sure I don't lose myself and my own life in all of this.

We do try to talk about death. At first, I found that enormously scary. It felt like I was staring down an abyss and I just could barely even go there. I would cry and I would just have this huge wave of emotion, but I don't feel like that now.

I know it will be enormously sad and I find it very hard to even imagine how I'll be on my own. Peter's very reassuring. He says, "You'll be fine". And I know I will, even though, of course, I'll miss him enormously. I will want to come home and tell him about how the funeral was and he won't be there. So, it's horribly sad but I like that we can actually talk about it. I find it really helpful.

We've talked about things like a cremation and about how he doesn't want flowers. He would like to die at home. Hopefully he might just slip away nice and peacefully. When I see him struggling, I think maybe it will just be easier for him to just die in his sleep. I think it's very reassuring for both of us to be able to put that into words.

## Practical ways to help

There are many things that family and friends can do to help support someone at the end of life.



### Prepare meals

Preparing meals for someone who is sick can become challenging as their needs and illness change. Try cooking simple, small meals. You may have to mash food so it's easier to swallow – the palliative care team will have a dietitian who can advise you on how to prepare food. As the disease progresses, the person may lose their appetite and not be able to eat or drink. You don't need to force them to eat or drink. If the person cannot drink, chips of ice can help to moisten the mouth.

### Help with bathing and toileting

If the person you are caring for can't move around easily, you may have to give them a sponge bath or wash their hair over a basin. You may have to help the person get on and off the toilet or commode, help them use urine bottles or bedpans if they can't get out of bed, and sometimes help them to wipe themselves. An occupational therapist can help you choose suitable equipment and teach you how to lift correctly.



### Sort out the paperwork

For many people who are dying, getting their affairs in order can help them feel like they've given closure to their life. You can help gather important documents, discuss the person's choices for their future health care, and arrange legal advice if needed.

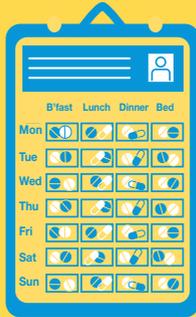
## Record social media details

People often have more of a social media presence than they realise. You can help the person work out which social media accounts they have and what they want to happen to these accounts after they die, and then help compile a list of passwords and instructions.



## Do odd jobs and run errands

Friends can help with walking the dog, mowing the lawn, picking up the kids, or doing the shopping or laundry – anything that eases the workload of the main carer.

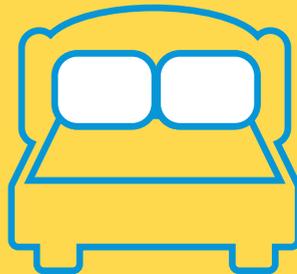


## Manage medicines

If you need to give medicines and feel overwhelmed, ask your doctor, pharmacist or nurses for suggestions. A pharmacist can put your tablets and capsules into a blister pack (e.g. Webster-pak), which separates them into the days and times you need to take them. Cancer Council's *Caring for Someone with Cancer* booklet includes tips for managing medicines.

## Help with getting in and out of bed

It's common for a dying person to spend more time in bed. You may need to help them get in and out of bed, roll them over regularly so they don't get bedsores, or lift them to change the sheets. You can use equipment to help with lifting. Many people create space in the living room for the bed, particularly if bedrooms are located upstairs. The palliative care team can help you provide this care and arrange equipment such as a hospital bed.



## Providing emotional support

The diagnosis of a terminal illness may be a crisis for family and friends. How everyone responds may depend on their relationship with the person dying and their own beliefs about death. It is natural to feel shocked, angry, scared, sad or relieved, or a combination of these emotions.

You may be worried about discussing the end of life with the person who is dying because you think you'll upset them. It may be helpful to know that people who are dying often want to talk about what is happening but are afraid the topic will upset their carer, family member or friend. Starting the conversation can be difficult, but the opportunity to share feelings can be valuable for both of you.

As the person you are caring for nears the final days of life, there are still many ways to spend time together: sit with them without talking; read a book; sing a song; share some special memory or experiences you've had together; or tell them that you love them and that family send their love. See *When you don't know what to say* on the opposite page for more information.

When someone is ill for some time, their family and friends often begin to grieve their death before it happens. This is known as anticipatory grief. You may find yourself wishing for the person's life to be over. It's also not unusual to start thinking about how you'll cope, about other events in your life, the funeral, and so on. All of these responses and thoughts are natural and okay. It may help to speak to a health professional or counsellor about your feelings, or to call Cancer Council 13 11 20.

## Saying goodbye

A life-limiting illness offers you time to say goodbye. You can encourage the person who is dying to share their feelings, and you can share your own in return. Sharing how you both feel can start important conversations that can be memorable. This is also an opportunity for you to tell the person who is dying what they mean to you and how you might remember them.

The person nearing the end of life may want to make a legacy, such as writing their life story or letters to family and friends. They may want to visit a special place or contact someone they've lost touch with. You can help the person with all these tasks. They are all part of the process of saying goodbye, for all of you.

## When you don't know what to say

People often wonder what they should say to a person who is dying. It's understandable that you don't know what to say – what you feel might be so complex that it's hard to find the right words, or any words at all. It is common to worry about saying the wrong thing. Most times, the person who is dying will find comfort in you being there, rather than feeling the need to find “the right words”.

You may want to say something that would help them cope but don't know what that is. It's usually better to say something than to pretend that nothing is wrong.

Someone who is dying will probably appreciate knowing that family and friends are thinking of them. Even if you feel you're not doing anything, just being there sends the message that you care.

In her book *The Etiquette of Illness*, Susan Halpern suggests asking, “Do you want to talk about how you’re feeling?” rather than “How are you feeling?” This approach is gentle and less intrusive. It also gives the person the choice to respond or to say no.

- Listen to what the person who is dying tells you. They may want to talk about dying, their fears or plans. Try not to prompt an answer that confirms what you think or your hope that things could be better. If you think they’d find it easier to talk to a spiritual care practitioner, offer to put them in touch with one.
- Try to treat someone who is dying as normally as possible and chat about what’s happening in your life. This makes it clear that they’re still a part of your life.
- Avoid talking in an overly optimistic way, for example, “You’ll be up in no time”. Such comments block the possibility of discussing how they’re really feeling – their anger, fears, faith and so on.
- Apologise if you think you’ve said the wrong thing.
- Let them know if you feel uncomfortable. They might be feeling uncomfortable too. It’s okay to say you don’t know what to say.
- Accept that you or the person dying may cry or express anger. These are natural responses to a distressing situation.
- Ask questions. Depending on how comfortable you feel asking direct questions and on their willingness to talk, you could ask,

“Are you frightened of dying?” or you may prefer a softer approach, “I wonder whether there’s something you want to talk about?”

- Encourage them to talk about their life, if they’re able to and interested. Talking about memories can help affirm that their life mattered and that they’ll be remembered.
- Just be there. Sometimes it’s the companionship that is most appreciated – sit together and watch television or read.
- Even if they’ve shown no religious interest in the past, that could change as death approaches. You could offer to pray together, but respect their wishes if this is not something they want.

## Keeping a vigil

For many people, being with the dying person is a way to show support and love. This is called keeping a vigil. The person may be sedated or unconscious at this time. You can simply sit with them, perhaps holding hands. Hearing is said to be the last sense to go, so you may want to talk, read aloud, sing or play music. Your cultural or spiritual traditions may require someone to be present, and this may also be the time to perform any rituals.

Some people find keeping a vigil exhausting and draining, and it can be hard to estimate how long it will last. Plan to take breaks or organise shifts with other family members and friends. You may worry that leaving the room could mean missing the moment of death. If this happens, it may be reassuring to know that sometimes a person seems to wait to be alone before they die.

## **Making arrangements**

As death approaches, speak to the palliative care team about what to expect. You may want to consider the following.

**Rituals** – Ask the person whether a clergy member or other spiritual leader or practitioner should be at the bedside, and what rituals or ceremonies should be performed.

**Contact list** – Ask the person whether they'd like visitors in their final days and who to call after the death.

**Funeral home** – Notify the chosen funeral home that a death is expected soon. Some people want to have the body at home for several days, so let the funeral home know if this is your wish.

**Ceremony** – Find out what the person would like done with their body after death or if they'd like to donate tissue or organs (see page 47). Some people have strong views about whether they want to be buried or cremated, what sort of ceremony they want, and what type of memorial they would like.

**Ambulance service** – Ask your health professionals who to contact if complications arise at home. Your first reaction might be to call an ambulance, but an ambulance officer's duty of care may mean they have to resuscitate. If this is something the person you are caring for would prefer didn't happen, speak to your doctor about completing an authorised care plan for ambulance officers to follow. Contact the ambulance service in your state or territory to fill in a form so they are not compelled to resuscitate.

## Providing physical support

When a person is dying, carers often have lots of questions: Can they hear me? Are they in pain? What can I do to make this process easier? How long will it be now?

There will probably be gradual changes. Watching the physical changes can be upsetting. It may help to know that they are a normal part of the dying process, and don't mean that the person is distressed or uncomfortable.

You don't have to face these changes alone. The palliative care team (see pages 12–13) can help you provide physical, emotional and practical comfort. You can also call Cancer Council 13 11 20 to find out what support is available.

## Signs that someone is dying

Some family and friends find that information about the physical process of dying helps ease their fear and anxiety. Others prefer to take one day at a time and ask health professionals for explanations as the need arises. If you would like to know what to expect, this section describes the physical changes in the last days and hours of life.

Each death is different, but as a person nears the end of life there are often common signs. These physical changes don't occur in any particular order. In medical terms, the dying process is viewed as the body's systems closing down.

**Sleeping more** – The dying person has less energy, and often they may spend most of the day sleeping or resting.

**Eating and drinking less** – As the body slows down it uses less energy and the person doesn't need to eat or drink as much. The person may begin to resist or refuse food or drink, and weight loss can occur. Giving fluids at this time doesn't improve symptoms.

**Little interest in the outside world** – The dying person may gradually lose interest in people nearby. They may find it hard to concentrate and they may stop talking. Withdrawing is part of letting go. Near the end, some people have a sudden burst of alert behaviour.

**Breathing changes** – Breathing may become rattly, irregular and laboured. You may hear an irregular breathing pattern known as Cheyne-Stokes. This is a loud, deep breath followed by a long pause (may last from five seconds to as long as a minute), before a loud, deep breath starts again.

If mucus builds up in the throat, it can create loud, gurgling sounds, which some people call a “death rattle”. Medicines can help dry up any mucus or you can try changing the person's position in the bed. Listening to this change in breathing pattern can be upsetting, but it is thought that it is not painful for the person.

**Bladder and bowel changes** – As the body's systems slow down, the person may have trouble emptying their bladder. A catheter may be inserted into the bladder to drain urine and avoid a blockage. Medicines may be prescribed for constipation, a common side effect of some pain medicines. As the person eats and drinks less, they will produce less urine and faeces. Loss of bladder and bowel control sometimes happens in the last stages of the dying process, but does not always happen.

**Disorientation and confusion** – Carers are often unprepared for the person becoming disoriented and confused. This is known as delirium. It can involve a lower level of consciousness; memory loss; hallucinations (seeing or hearing things that aren't there); delusions (false beliefs); mood swings; and sleep disturbances. A person who is dying may not be aware of where they are or who else is in the room, may speak or reply less often, or may respond to people who can't be seen by others in the room. The person may drift in and out of consciousness and eventually become unresponsive.

Delirium may occur when waste chemicals (toxins) build up in the brain as vital organs begin to shut down, but it can also have a range of other causes, such as fever or constipation. Talk to the palliative care team about how delirium can be controlled.

**Restless moving, twitching, groaning or calling out** – These symptoms are part of terminal restlessness, a type of delirium that may include agitation, anxiety, anguish and anger, all of which can be very distressing for carers to see. These symptoms are common and not necessarily uncomfortable for the dying person.

**Cool skin, especially the hands and feet** – As circulation slows down, the hands, feet, fingers and toes (the extremities) become cooler and turn a bluish colour. It's thought that the person will be unaware of feeling cold.

**Dry mouth and dry or cracked lips** – This can happen if the person is dehydrated or has been breathing through their mouth, or it may be due to some medicines.

## How you can help in the final stages

Wherever someone chooses to die, family and friends can help in the final stages. If you are providing care at home, ask the palliative care team how you can help. In a palliative care unit, hospital or residential aged care facility, ask the staff how you can be involved.

### Offer comfort

Apply lip balm to dry lips, and keep the mouth moist with ice cubes or moist mouth swabs. Put incontinence sheets or pads under the bedsheets. Use a vaporiser in the room to help with breathing. Keep the person warm with a blanket and use cushions to make them more comfortable. Help the person change positions frequently. A nurse or occupational therapist can show you suitable positions.



### Be a gentle presence

Sit with the person and talk or hold their hand. Often just being there is all that is needed so that they don't feel alone. Gently massage their hands or feet with a non-alcohol-based lotion. Speak gently, and occasionally remind the person of the time, place and who is with them. Don't force-feed even though you may be distressed by their loss of interest in eating.

### Create a calm atmosphere

Use soft lighting. Have their favourite music playing in the background to create a gentle and peaceful atmosphere. Quietly read a favourite poem, passage from a book, or spiritual or religious text.



## Choosing the moment to die

Sometimes people appear to pick the moment to die. You may have heard stories of some people holding out until a particular relative or friend arrives at their bedside, or until a special occasion occurs, before dying. Others appear to wait until their family or friends have left the room before they die.

It can be difficult if you've been sitting with someone for many days, and they die while you are taking a break. You may feel guilty or regretful for not being there for them at that crucial moment, but it may help to know that this might be the person's preference.

## What happens at death

No-one really knows what death feels like, but we know what death looks like from those who have nursed a dying relative or friend. The person's breathing will cease, although they may stop breathing for a time and then take one or two final breaths. As soon as the heart stops beating, the body rapidly cools down and takes on a pale appearance.

The moment of death is sometimes described as being peaceful. Many carers say it was a profoundly moving experience and it felt like a privilege to be there. The memory of the final moments are likely to stay with you for a long time.

“ We had all surrounded my father-in-law's bedside, then we started to share the vigil in turns. When there were fewer people around, he passed away. ” *Judith*

## After the death

Even when death is expected, it's common to feel upset, sad or shocked. An expected death is not an emergency and what you need to do depends on the circumstances.

### What to do after the death

If the person was being cared for at home and was expected to die at home, there is no need to call an ambulance or the police. You can take some time to sit with the person. If you would prefer not to be alone, call a friend or family member. If the person dies during the night, you may choose to wait until the morning to take further action.

When you feel ready, call the person's doctor and a funeral home. The doctor will sign a medical certificate confirming the death. This is needed to make funeral arrangements. The funeral director can register the death with the registry of births, deaths and marriages in your local state or territory, who will provide a death certificate.

If the death occurs in a palliative care unit, hospital or residential aged care facility, there's usually no need to rush. You can have time alone with the person before the nurses explain what needs to be done. Some people want to wait until other family members or friends have had the opportunity to say goodbye.

Several organisations will need to be told of the death. The Department of Human Services has a useful checklist of who may need to be notified. Visit their website at [humanservices.gov.au](http://humanservices.gov.au) and search for "What to do following a death".

“ I had promised Mum that after she died, I would make sure she had her favourite lippy on. I did this at the funeral parlour before the final viewing of her body. She was wearing the dress we had chosen together. ” *Judith*

## Funeral and religious services

Many people have no previous experience organising a funeral and little knowledge of what to do. Funerals can be an important part of the grieving process. They allow family and friends to share their grief, say goodbye and celebrate the person's life. Funerals can be personalised to suit cultural or spiritual beliefs.

The executor of the will or a family member usually arranges the funeral. Most people use a funeral director, who can organise the service, coffin, newspaper notices and flowers, and help with many of the legal responsibilities such as registering the death. You can organise these details yourself if you prefer; you do not need to use a funeral director.

If the person has a prepaid funeral plan, it will usually include details of what they wanted and also which funeral director to use. Sometimes a person may not have prepaid their funeral plan, but may still have left written instructions or talked to you about their wishes.

If you don't know the person's wishes, you might need to decide. This can be difficult and stressful, especially as other family members may have different ideas about what should happen.

To find a funeral director, visit the Australian Funeral Directors Association website at [afda.org.au](http://afda.org.au) or Funeral Directors Australia at [funeraldirectorsaustralia.com.au](http://funeraldirectorsaustralia.com.au). To compare different funeral companies, visit [gatheredhere.com.au](http://gatheredhere.com.au).

You can also choose not to have a funeral or to have a non-traditional event such as a celebration of life.

## Wills and probate

A will is a legal document stating how the deceased person's belongings (assets or estate) are to be distributed after their death. The executor of the will is responsible for distributing the person's assets to the people named in the will. This happens after any debts are paid.

Before the executor can release any of the assets, they need to have the will validated by the courts. This process is known as probate.

› See our online fact sheet *Your role as executor*.

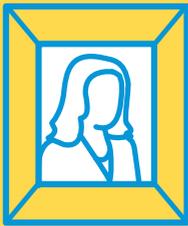
## Financial matters

You may be eligible for financial assistance after an immediate family member has died. The Department of Human Services provides a number of payments and services to the spouse, partner or children. Check to see if you're eligible for a bereavement allowance or payment, double orphan pension, widow allowance or pension bonus bereavement payment at [humanservices.gov.au](http://humanservices.gov.au).

› See our online legal and financial fact sheets about what happens to the superannuation, income, assets or unpaid debts of someone who has died.

## Ways to remember

You may want to do something special to acknowledge and honour the life of your family member or friend after they've died. Some people find this helps them cope with their loss.



Frame a photo or a cherished note or other memento.

Cook their favourite meal or cake on their birthday.



Plant a special tree or flower.



Organise to have a memorial plaque put in a favourite spot.



Light a candle.

Create a scholarship or annual award in their memory.



Create an online memorial page with photos and stories.



Make a contribution to their preferred charity or community group.

## Grief

The physical and emotional response you have to losing someone you love is known as grief.

The feelings you may experience include sadness, numbness, disbelief, loneliness, guilt, anger, relief and acceptance. You might have trouble sleeping, cry a lot or have difficulty crying, lose your appetite, or not be interested in your usual activities.

There's no right or wrong way to grieve, and everyone mourns in their own way and in their own time. Coping with grief doesn't mean getting over the person's death. It's about finding ways to adapt to the loss. It may be according to religious or spiritual practices, but it can also be more personal. Even though your relative or friend is no longer physically present, they remain part of you and your life. This ongoing connection can be a source of comfort in your grief.

You might feel pressure from yourself or others to get over it and get on with life, but grief has no set time line. It can seem like a roller-coaster – sometimes you might feel yourself “coming good” and then swiftly go downhill again for a while. The sorrow may never go away completely, but most people gradually adapt to the loss. The pain will usually become less intense as you come to terms with how your life has changed.

Sometimes, the pain does not seem to ease over time. If you're concerned that your grief is stopping you from living your life, professional support may be helpful (see page 75).

➤ See our *Understanding Grief* booklet.



# Getting help and support

A range of services are available to help people throughout the process of dying, and to support their family and friends.

## Useful organisations

### Carer services

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

Practical information and resources for carers.

**Carers Australia**  
1800 242 636  
[carersaustralia.com.au](http://carersaustralia.com.au)

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

**Young Carers**  
1800 242 636  
[youngcarersnetwork.com.au](http://youngcarersnetwork.com.au)

Support and information for young people under 25 who are caring for someone who is ill.

### Counselling and mentoring services

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

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

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

Information about the Medicare-subsidised referral to counselling through your GP.

**Beyond Blue**  
1300 22 4636  
[beyondblue.org.au](http://beyondblue.org.au)

24-hour telephone counselling service; online and email counselling available seven days a week.

**Kids Helpline**  
1800 55 1800  
[kidshelpline.com.au](http://kidshelpline.com.au)

Telephone and online counselling service and crisis support for young people aged 5–25.

## Useful organisations – continued

<b>Lifeline</b> 13 11 14 lifeline.org.au	24-hour telephone crisis support and suicide prevention service.
<b>Suicide Call Back Service</b> 1300 659 467 suicidecallbackservice.org.au	24-hour telephone and online counselling for people affected by suicide.
<b>Funerals</b>	
<b>Australian Funeral Directors Association</b> 1300 888 188 afda.org.au	Listing of funeral directors and information about planning a funeral.
<b>Funeral Celebrants Association Australia</b> funeralcelebrants.org.au	Directory for finding a funeral celebrant in your local area.
<b>Funeral Directors Australia</b> funeraldirectorsaustralia.com.au	Listing of independent funeral directors and information about planning a funeral.
<b>Future planning</b>	
<b>Advance Care Planning Australia</b> 1300 208 582 advancecareplanning.org.au	Information about planning for your future health care, including advance care directives.
<b>Dying to Talk</b> dyingtotalk.org.au	Palliative Care Australia website encouraging Australians to talk about dying; includes discussion starters.

## Useful organisations – continued

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

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

### Grief

**Australian Centre for Grief and Bereavement**  
1800 642 066  
[grief.org.au](http://grief.org.au)

Online information for people experiencing grief.

**GriefLine**  
1300 845 745  
[griefline.org.au](http://griefline.org.au)

Telephone counselling service for all Australians who have experienced a loss.

**GriefLink**  
[grieflink.org.au](http://grieflink.org.au)

Online information for the bereaved and grieving, their carers, friends and colleagues.

### Legal and financial information

**Cancer Council's Legal and Financial Referral Service**  
13 11 20

Referral service for people affected by cancer needing professional advice about legal or financial issues; free for eligible clients.

**Centrelink**  
132 717  
[humanservices.gov.au](http://humanservices.gov.au)

Offers financial support for people with a long-term illness and for primary carers.

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

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

## Useful organisations – continued

<b>Public Trustees Australia</b> <b>publictrusteesaustralia.com</b>	Gateway to all public and state trustees in Australia, who can help you prepare a will and manage your finances.
<b>The social worker on the palliative care team</b>	May be able to help you access legal or financial support.
<b>Palliative care</b>	
<b>CareSearch</b> <b>www.caresearch.com.au</b>	Australian Government website that provides palliative care information and links to services for people affected by cancer, as well as resources for health professionals.
<b>Palliative Care Australia</b> <b>palliativecare.org.au</b>	Information and resources; can link you to your local palliative care office.
<b>Support and information</b>	
<b>Cancer Council Online Community</b> <b>cancercouncil.com.au/OC</b>	An online discussion forum where people can connect with each other at any time, ask or answer questions, or write a blog of their experiences.
<b>Telephone support groups</b> <b>Cancer Council 13 11 20</b>	Includes groups for people with advanced cancer, for carers and for the bereaved.
<b>The Thing About Cancer podcasts</b> <b>cancercouncil.com.au/podcasts</b>	Information and insights for anyone affected by cancer. Separate series about advanced cancer.



# Glossary

## **advance care directive**

A written document intended to apply to a point in the future when you don't have the capacity to make medical treatment decisions. It provides a legal means for a competent adult to appoint a substitute decision-maker and/or record their preferences for future medical and personal care. May be called a health direction, an advance health directive or an advance personal plan.

## **advance care planning**

When a person thinks about their future health care and discusses their values, beliefs and preferences with their family, friends and health care team.

## **advanced cancer**

Cancer that is unlikely to be cured. The cancer may have spread to other parts of the body (secondary or metastatic cancer). Treatment can often control advanced cancer and manage symptoms.

## **alternative therapy**

A therapy that is used in place of conventional treatment, often in the hope that it will provide a cure.

## **anticipatory grief**

Grief that occurs before an impending loss, usually of a close friend or family member.

## **bereavement**

The state of having experienced the loss of someone important to you.

## **capacity**

Having the ability to understand and think things through to make decisions.

## **carer**

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

## **Cheyne-Stokes breathing**

Irregular breathing pattern of loud, deep breaths and long pauses.

## **complementary therapy**

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

## **delirium**

A disturbed mental state that can have a range of physical causes and can involve: a lower level of consciousness; memory loss; seeing things that aren't there; mood swings; and sleep disturbances. It is sometimes experienced near the end of life.

## **depression**

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

## **dyspnoea**

The medical term for difficulty in breathing. Also called breathlessness.

## **end-of-life doula**

An end-of-life doula works with other professionals, family and friends in a non-medical role providing services in home, palliative care unit, hospital and aged care settings. They provide emotional support, resources, education and companionship to the dying person and their family, friends and carers.

**enduring power of attorney/enduring power of guardianship**

See substitute decision-maker.

**ethanasia**

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

**executor**

Person responsible for carrying out the terms of a will.

**grief**

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

**hospice**

See palliative care unit.

**life-limiting illness**

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

**malignant**

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

**metastasis (plural: metastases)**

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

**morphine**

An opioid. A strong and effective pain reliever commonly used for people with cancer who have pain.

**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 dealing with physical, emotional, cultural, spiritual and social needs. Also known as supportive care.

**palliative care nurse**

A nurse who has specialised in the field of palliative care. Provides support to the person affected by cancer, their family and carers, and may coordinate the palliative care team.

**palliative care nurse practitioner**

A palliative care nurse with additional qualifications who can provide complex care management, including making referrals to other health professionals, prescribing some medicines and ordering tests.

**palliative care specialist or physician**

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

**palliative care unit**

A place that provides comprehensive care for people with a life-limiting illness. This includes inpatient medical care, respite care, and end-of-life care for people. It may also offer day care facilities and home visiting teams. Also called a hospice.

**preparatory grief**

Grief that occurs when someone knows that they are dying.

**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.

**recurrence**

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

**respite care**

Alternative care arrangements that allow the carer and person with cancer a short break from their usual care arrangements.

**spiritual care practitioner**

A professional who offers emotional and spiritual care to patients and their families. Often part of the palliative care team and sometimes called a pastoral carer or chaplain.

**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 for appointing this person may be called an enduring power of attorney, an enduring power of guardianship or appointment of medical treatment decision maker.

**supportive care**

See palliative care.

**terminal**

See life-limiting illness.

**terminal restlessness**

A type of delirium featuring agitation that can occur near the end of life.

**voluntary assisted dying**

When a person ends their own life with the help of a doctor. It is illegal in most states and territories in Australia. It is legal in Victoria for people who meet strict criteria, and the law has recently changed in Western Australia.

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

*For more cancer-related words, visit:*

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



## How you can help

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

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

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

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

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

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

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



# Cancer Council 13 11 20

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

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

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

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

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



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

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



**Cancer Council**  
**13 11 20**

For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.

Produced in collaboration with:



## Visit your local Cancer Council website

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

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

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

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

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

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

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

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

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

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