Cancer Council

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Facing End of Life

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

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Note to reader
Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

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

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

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About this booklet

This booklet provides information for people who are dying with cancer, and the people who are caring for them.

If you have had cancer diagnosed at a late stage, or if the treatments have stopped working and it is unlikely the cancer will go away, or if you no longer wish to continue the recommended treatment, you may be told that the cancer is end stage or terminal. Everyone copes in their own way with this news.

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.

Note to readers – This booklet includes a frank discussion of issues that can happen near the end of life. It uses the words death and dying. Some readers may find this confronting. Cancer Council also has booklets called *Living with Advanced Cancer* and *Understanding Palliative Care*. You may find one of these booklets more useful at this time, or you might prefer to talk to someone at Cancer Connect (see below). We are here to support you in a way that works for you.

If you or your family have any questions or concerns, call **Cancer Connect on 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit the Cancer Connect website at cancerconnect.org.au.

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Key to icons

Icons are used throughout this booklet to indicate:


More information


Alert


Personal story


Tips

Is this Cancer Council booklet helpful?
Please follow this QR code for a quick 3-minute survey, or call 13 11 20 to provide your feedback.

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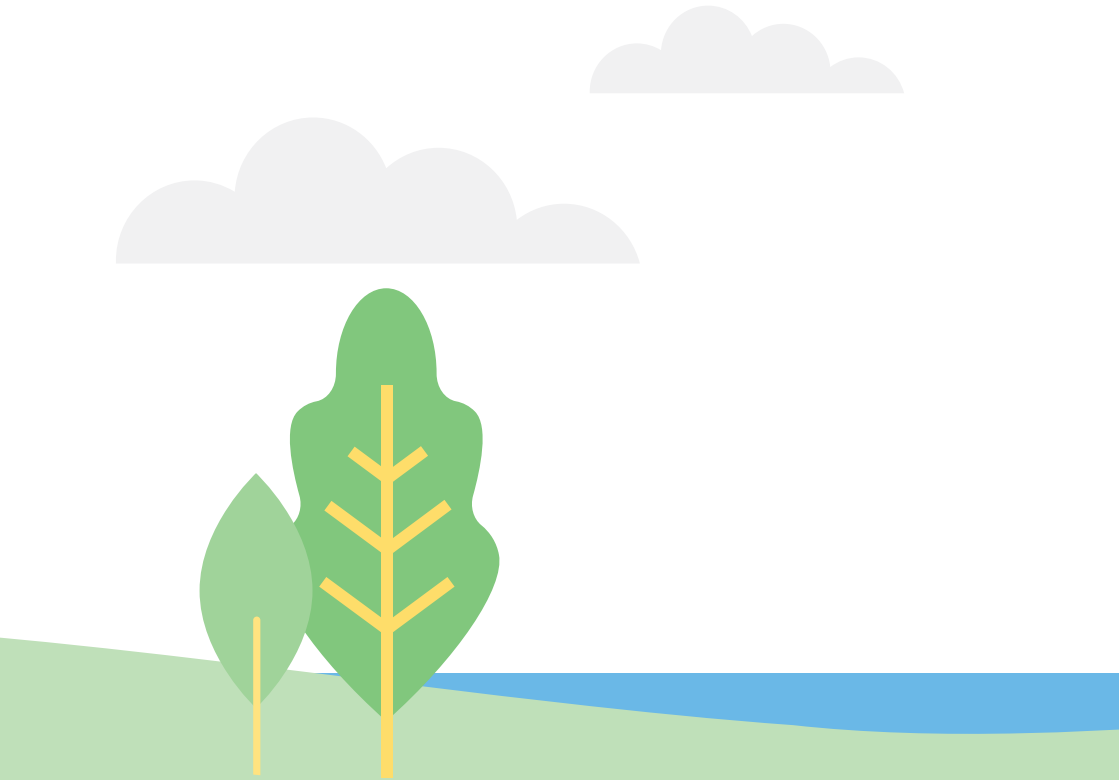


Finding out that you are near the end of life

This chapter covers how you may feel after being told you have a life-limiting illness and are approaching the end of life. It also discusses how family and friends may react. Everyone copes in their own way, but it's natural to experience a range of strong emotions and for these feelings to change often.

Hearing the news

We all know that death will happen to us one day, but most of us hope it won't be anytime soon. Learning that you may not have long to live can be a shock – even if you were in some way expecting it. You may already know that the cancer has spread, or you may have been feeling unwell, but hearing that you are dying can be extremely upsetting. It may take a while for the news to sink in.

For some people, being told that the cancer can no longer be cured or treated may feel frightening or seem hard to accept. For others, it may be a kind of relief.

There is no right or wrong way to react. Give yourself time and space to take in what is happening. Reach out to friends or family or seek professional help – especially in the early days. See pages 73–75 for a list of support services or call Cancer Connect on 13 11 20.

You may have lots of questions. This booklet might help you with information about practical, physical and emotional matters. You could be focused on getting everything sorted and your affairs in order, or you might not want to think about it for a while. You may not take much information in right away, so try to avoid making big decisions in the first day or two after being told if you can.

"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

How you might feel

Most people have many strong emotions. After the initial shock, it's common to have feelings of fear, denial, anger, despair, helplessness, anxiety or depression. Your emotions might change, sometimes from day to day or even from hour to hour. This is 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 at times. It's natural to cry or feel completely overwhelmed; you don't need to put on a brave face. Other times you may feel quiet and reflective – you may avoid people and not want to talk. You might get a burst of energy or anxiety and start making plans. People often say their fears are stronger when it's quieter at night.

Some people compare these feelings to waves at the beach. The first wave may knock you off your feet, and then your footing becomes a little stronger. But, at any time, a large wave can suddenly come back and knock you off your feet again. There may also be calm periods between these waves. Your mood may fluctuate up and down.

It may help to talk – You may have your own ways to respond to these emotions. At first you may not feel able to share your feelings, but as you start to process things it may help to talk about them and find a path forward.

You may feel comfortable talking to a trusted family member or friend. Or you could consider seeking professional help through a palliative care specialist or nurse, general practitioner (GP), counsellor, psychologist, psychiatrist or spiritual adviser. Other people in a similar situation can offer a unique perspective, so you may want to join a support group (see pages 73–75).

Telling people

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.
- People react in different ways. They may be uncomfortable or not know what to say. If they get upset, you may end up comforting them, even though you are the one dying. Denial is a common reaction – they may be convinced there's a cure or that the doctors are wrong.
- If you'd like help telling people, call Cancer Connect on 13 11 20. They can help you find the words that feel right for you. Another option is to ask your doctor or nurse about ways to help you share the news.

For ways to talk to people (including children) about dying, see *Emotional and spiritual needs* on pages 19–26. Our *Talking to Kids About Cancer* booklet may also help.

Do people who are dying need to be told?

Sometimes family members learn cancer is terminal before the person who is dying. They may think the person is too young, old or sick to be told the truth. They may worry about the health or emotional impact on the person if they know they are dying. People who are dying usually have a sense of what is happening. Trying to keep it a secret may mean they feel alone when they most need support. Ask the person how much detail they want to know and follow their wishes. Knowing they are dying can give them time to prepare for death. The healthcare team can help you have this conversation. They can also suggest ways to explain the situation if the person has dementia, memory problems or issues understanding.

Common questions about dying

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

How long have I got?

The first thing some people will want to know is how long they have left to live. Others prefer not to know. It's a very personal decision.

Knowing can help you prepare and make plans for the time you have left. If you want to know, you can ask your doctor. Because everyone is different, a doctor can only ever give you an estimate (called a prognosis) based on what usually happens to people in your situation. But they 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 to give you a prognosis 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 months to years.

Why it can be good to know – Being told you probably don't have long to live is difficult. But having a sense of how much time may be left can give you a chance to focus on what is most important to you.

If you live longer than the estimated time, you may feel lucky to be living beyond that time or you may feel unsettled, like you're waiting to die.

It may help to talk about how you're feeling with trusted family or friends, the palliative care team (see opposite page) or your doctor. There are counsellors who specialise in facing end of life.

"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

What is palliative care?

Palliative care is a person-centred approach to care that can sometimes be called supportive care. It can help people who have a progressive, life-limiting illness to live as fully and as comfortably as possible.

Many people think palliative care is only for end of life. However, its main aim is to improve your quality of life by identifying and managing your physical needs. It can also support your practical, emotional, cultural, social and spiritual needs. Palliative care also offers support to family and carers.

Palliative care may include:

- relief of pain and other symptoms such as fatigue, nausea, vomiting and shortness of breath
- access to resources, such as equipment to help you manage your care at home
- help for families to gather and talk about sensitive or complex issues
- links to other services such as home help and financial or legal support
- support for emotional, cultural, social and spiritual concerns
- referrals to respite care services (short-term care up to several days so that carers can take a break).

Your specialist, GP or community nurse often provides general elements of palliative care. If you have more complex needs, your care may be led by a specialist palliative care service. They can also provide advice to other health professionals on how to best manage your symptoms. Palliative care may be provided at home, in a hospital, in a palliative care unit (sometimes called a hospice) or in a residential aged care home. Find your local palliative care body at palliativecare.org.au.

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

Who will I see for my care?

Wherever you receive end-of-life care, the various health professionals in your healthcare or palliative care team can offer a range of services

Possible members of your health care team	
GP or family doctor	may coordinate your palliative care and work alongside a palliative care team; continues day-to-day health care
physiotherapist	helps with movement and mobility, and preventing further injury
social worker	links you to support services and helps you with emotional, practical and financial issues
cancer specialist	may be a medical oncologist, surgeon, haematologist, radiation oncologist or cancer nurse practitioner; may refer you to the specialist palliative care team and continue to provide treatment to help manage cancer symptoms
counsellor	helps you manage your emotional response to diagnosis and treatment and may support you to explore your hopes for your life and your relationships
psychologist	uses evidence-based strategies to help you manage emotional conditions, usually in the long term; also works to support family
psychiatrist	specialises in the diagnosis and treatment of mental illness, can prescribe medicine and uses evidence-based strategies to manage emotional conditions
spiritual care practitioner (pastoral carer, priest, chaplain, minister of religion)	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

to help you. You may not need to see all the people listed on these pages, but understanding the different roles can help you work out what support is available and who to ask about particular issues.

occupational therapist	assists in adapting your living environment; can suggest equipment, such as a hospital bed, walker, wheelchair and bedside commode (toilet chair)
volunteer	can help with home or personal care and transport, and also offer support and companionship
diversional therapist	offers recreational activities to improve your wellbeing
dietitian	helps with nutrition concerns and recommends changes to diet
speech pathologist	helps with communication and swallowing problems
community nurse	visits you at home to supervise medical care, assesses your needs for supportive care, and works with your GP as required; may coordinate your palliative care
end-of-life doula	helps you understand your choices and offers (often for a fee) emotional and practical support, such as help with paperwork, finding services that can help you, and speaking up for your needs
palliative care specialist, physician or nurse practitioner	treats pain and other symptoms to maximise wellbeing and improve quality of life; usually works in collaboration with your GP

Could complementary therapies help me?

If your doctor has told you that the cancer cannot be cured, you may wonder whether there are any other therapies that could help. Complementary therapies are used alongside medical treatments and tend to focus on the whole person, not just the cancer. They include practices like acupuncture, mindfulness and herbal medicines.

Complementary therapies may help you relax and feel calmer. Some can also manage symptoms such as pain and nausea. Some people find gentle therapies helpful, such as massage and aromatherapy. People who find physical touch uncomfortable or painful may prefer other therapies such as meditation or visualisation.

Talk to your doctor about what complementary therapies are right for you, as some may interact with your cancer treatment, make side effects worse, or make treatment less effective.

▸ See our *Understanding Complementary Therapies* booklet.

Alternative therapies are different to complementary therapies – They are used instead of approved medical treatment, and are often promoted as cancer cures. Family, friends or strangers may suggest you try alternative therapies when they hear of your prognosis. Unlike conventional medical treatments, many alternative therapies have not been scientifically tested, so there is no proof they stop cancer growing or spreading. Some alternative therapies have been tested and shown to be harmful. They may also 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.

What does "dying well" mean?

People often talk about a "good death". What dying well means is different for each person. It is shaped by their values, cultural background, spiritual beliefs and medical treatments.

You may want to think about what dying well means to you. You may feel it is important to:

- know that death is coming and understand what to expect
- have some control over pain relief and other symptoms
- have as much control as you can over where you die 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
- honour spiritual or religious beliefs
- have a say in end-of-life care and know your wishes are respected
- have your affairs in order and plans in place for family and friends.

There are different ways to die well. Some people see staying at home as the key to dying well, while others feel more supported spending their last days in a hospital or palliative care unit (see pages 33–40). You don't have to decide in advance and it is okay to change your mind later. But it is important that your family, friends and healthcare team understand what matters most to you. Knowing your wishes have been explained clearly can make decision-making easier later on.

Open conversations and planning ahead for your last weeks and days of life can help family members and friends with their grief. They may feel a sense of peace knowing your preferences were respected (e.g. where you want to be cared for or where you prefer to die).

What is dying going to be like?

You may start to think about what the last few days or hours of your life will be like. It's common to have fears about the process of dying. Many people say they worry about the unknowns of dying more than actually fearing death. Having some idea of what to expect can help some people. Not being prepared, or imagining what might happen, can be distressing for you and for your family and friends too.

If you have been with someone when they died, the experience may influence how you feel about dying. It may have left you feeling reassured, thoughtful, sad, angry or scared. You may have been disturbed by some of the physical changes that happened to the person. Perhaps it appeared that they were having trouble breathing, or they seemed to be in pain or uncomfortable.

Talk about what you can expect – When you feel ready, it may help to talk to a doctor or palliative care specialists. They can explain the physical process of dying and reassure you that you will be cared for. You may not be aware of physical changes if you are sleepy (drowsy) or unconscious.

Make a plan with your healthcare or palliative care team – Ask what support they will provide for symptoms, and discuss it with your family, for reassurance and support. You may also have specific concerns and your team can talk with you about what options there are and prepare a plan. Knowing you have a plan may help to put your mind at ease.

Control pain and distress – Today there are many ways for pain to be controlled and managed quite well. If you have symptoms of pain or distress, you or your family can ask your doctor for help. The next page 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 people, dying happens gradually. As the body slowly shuts down, energy and concentration levels change. There will be good days along with days when you can't do much. Your appetite will reduce, and sips of water or a spoon of food here and there may be enough.

As death gets closer, it's common to lose interest in talking and the outside world. You may want to be alone more, or away from family and friends, and you may sleep more throughout the day and night.

Near the end, some people may need pain relief or other medicine to keep them comfortable, which may have a sedative effect. 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, in many cultures it is thought to be a peaceful moment. There is often a couple of deep breaths or sighs before the final breath, when breathing stops.

More information about the dying process is covered in *Caring for someone who is dying* on pages 53–72. This information may be confronting, so consider if this is the right time to read it.

What if I feel distressed?

It is natural to feel sad or worried, and some days will be harder than others, but there is support available. It is especially important to reach out for support if you feel very distressed. Distress might build if you are feeling depressed or have a sense of helplessness, or if you have pain, difficulty breathing (breathlessness) or other symptoms that are not well controlled.

Pain and depression can often be treated, and support 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.

Sometimes a person with cancer may become so distressed that they wish that death would come more quickly. This might happen if they are feeling particularly ill, scared, or perhaps worried about the strain that they are putting on others.

If this is how you feel, discuss your concerns with a doctor, nurse, counsellor or social worker. 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 phone counselling at any time.

"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." IAN

Emotional and spiritual needs

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 needs.

Talking about dying

Most people avoid talking about death or dying – and when they do, they may use different words, such as "passed away", "departed", "gone" or "slipped away".

It's up to you when, or even if, you tell those around you that you're dying. Take what time you need, but delaying the conversation usually doesn't make it any easier. It may help to be in control of what information is given out and when, rather than people hearing the news from others or guessing what is going on.

You might find it easier if you practise what you will say. Sometimes family members may seem more distressed than the person with cancer, which can be hard to cope with alongside your own emotions.

Explain to family and friends how much or how little you want to talk about dying, and any other practical or legal issues you want to discuss.

Why it can help to talk

There may be days (or hours) when you feel like talking about approaching the end of life, and times when you don't. 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.

"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

When you don't want to talk

You may not want to talk about dying, or want to discuss it with some people but not others. You may prefer to focus on making the most of the time you have left, rather than talking about death. Some 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

Your family and friends, like you, may feel shocked and overwhelmed when they find out cancer is at the end stage. They may have a range of reactions.

They may become overprotective and offer to help in any way they can, not wanting to leave you alone, or they may pull away and withdraw from your life. They might 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.

Some reactions can feel surprising, frustrating or even hurtful. But family and friends also need time to adjust to the news and come to terms with how they're feeling.

Partners

The emotional support provided by partners can be vital. But partners can feel just as distressed and depressed as the person who is dying. Be open and honest about the roles you expect each other to play. Do you want a partner to be "hands on" with your care, or would you prefer that a health professional looks after you, especially in the end stages of dying? Does your partner want to care for you? Listening to what each other wants, or feels they can take on, may help you both cope better.

If you live alone

Some people may live alone and have little or no support from family or friends. Or they might have people who would like to help, but they live too far away for regular care.

If you live alone, you could seek assistance from:

- your GP
- the palliative care team
- local community health services
- the local council
- a church or religious group
- practical support services (see pages 73–75)
- Cancer Connect on 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 home.

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

How to tell young children

If you have young 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.

Talking openly to children about death may help them to feel more comfortable spending time with someone who is dying. Older children are likely to appreciate being trusted with the news.

How you tell 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.
- Practice what you are going to say in front of a mirror beforehand.
- Be honest with 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 simple. Be guided by their questions so you don't offer more information than they may want or can handle.
- You may ask children what they know about death and what they think it means. This can help you to clear up any misconceptions about death.
- Depending on their age, children may benefit from seeing a counsellor or play therapist.

▸ See our *Talking to Kids About Cancer* booklet.

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 cultural or spiritual beliefs. It may also depend on how your family and friends cope with the news.

Everyone will find their own way to deal with the knowledge that they are dying, and at their own pace. There is no right or wrong way to deal with knowing that you are dying.

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 no longer be realistic 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 good palliative care can help maintain people's hope, especially when they:

- are involved in decisions about their care
- feel reassured that any pain and other symptoms will be well controlled.[1]

Finding a balance between knowing that 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 do 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 feel more in control is to make decisions about your current and future health care and medical treatment, and to share or record your preferences (see pages 41–52).

Loss and grief

There are losses and changes that happen throughout a terminal illness – loss of work, loss of social roles, loss of friendships, loss of connection to community and loss of independence. You will probably find it helpful to spend time grieving for these losses.

You might have preparatory grief, which means feeling sad because you know loss is coming. You may grieve for events that you won't be around for, such as holidays, marriages, graduations and new babies.

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 coffee or go for a walk.

Gradually, you may feel less able to do things or you may lose interest in activities you used to enjoy. 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.

"Living with uncertainty is the hardest thing. All our friends think 'We might do this, we might do that in a few years' and we don't have that any more." SUSAN

Spirituality at the end of life

Spirituality means different things to different people but is essentially a belief in a higher meaning or purpose. 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. In some cases, people may embrace a completely new belief system or one they had abandoned many years ago. Although many people do look for meaning at the end of their life, others are not interested in spirituality.

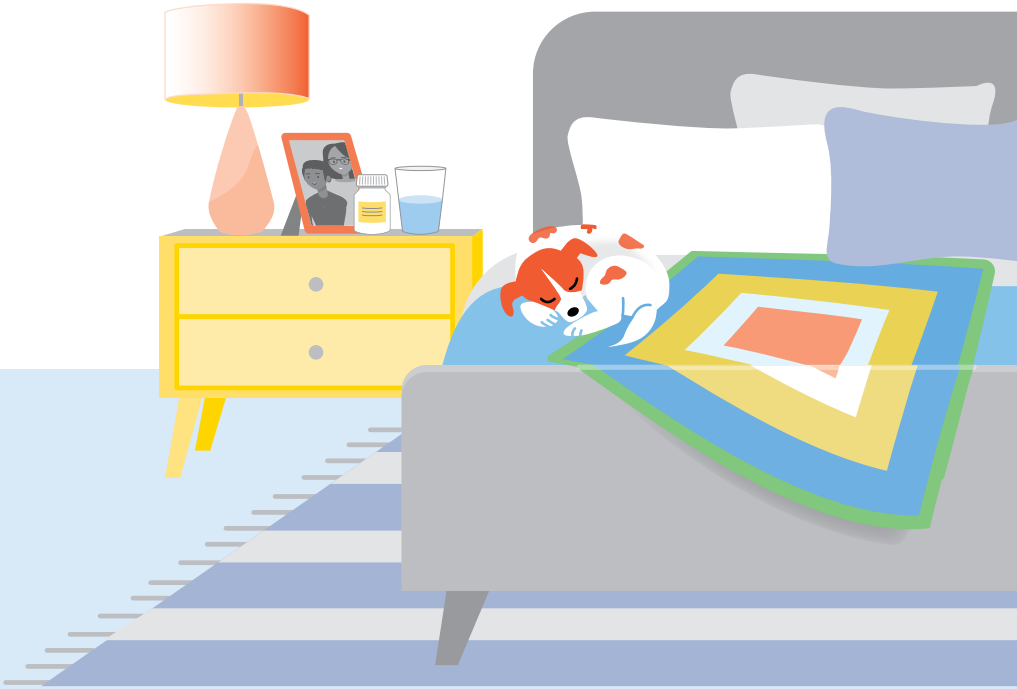
Talk about what you need – It may help to discuss your thoughts and feelings with a spiritual care practitioner (pastoral carer or chaplain). They may be part of the palliative care team and have the expertise to discuss spiritual issues, whatever your beliefs. You may wish to discuss the meaning of life or your beliefs about death. A spiritual care practitioner can also provide companionship.

Following spiritual practices – 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, residential aged care home or palliative care unit, it's best to discuss this with the staff in advance. They will be able to help you do this, and your customs can often become part of your palliative care plan.

Physical changes

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. You may find this information reassuring but it can also be confronting, so consider if this is the right time to read about end-of-life symptoms.



Symptoms at the end of life

As cancer progresses, it can cause various symptoms – but not everyone will experience them, or they may only happen near the end. People who are dying, and their families and carers, often worry about how these symptoms will be managed. Your healthcare team will keep you as comfortable as possible during your last days. If you experience symptoms, let them know so they can help.

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. An occupational therapist may be able to help with equipment at home to reduce the energy needed for daily activities such as showering.

Fatigue may affect your ability to think clearly and make decisions. You will also probably be told when you need to stop driving and doing other activities. This can be frustrating, particularly if you are trying to put your affairs in order. You may want to deal with any demanding or practical concerns at a time of day when you have more energy.

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 doctor or palliative care team know. They may be able to adjust your medicines or offer another medicine to help you sleep. They may suggest you try complementary therapies such as meditation and relaxation. Improving the quality of your sleep will improve the quality of your waking hours.

▸ See our *Understanding Complementary Therapies* booklet.

Pain

Many people with cancer worry about spending their final days in pain, but not everyone has pain. For some, pain comes and goes. The health professionals caring for you won't let you suffer with unrelieved pain, and will help you to manage it as much as possible. GPs are experienced in managing pain, and they can seek advice from or involve the specialist palliative care team if required. It's important not to just "put up with" pain and assume it's normal. Controlling pain lets you continue activities for longer and offers a better quality of life.

Finding the right pain relief

The way pain is managed depends on the type of pain and its intensity. It may take time to find what works best for you. Your doctor may prescribe a combination of pain medicines. You could be offered:

mild pain medicine	paracetamol and anti-inflammatory drugs, such as ibuprofen or diclofenac (Voltaren)
strong pain medicine	opioids such as morphine, oxycodone, fentanyl and hydromorphone
other medicines	• antidepressant and anticonvulsant medicines for nerve pain • local anaesthetics for severe nerve pain • certain anti-anxiety medicines, also used for muscle spasms • a nerve block or epidural (for pain that is difficult to manage)

Sometimes pain medicine can be given as a continuous infusion, where a small needle (cannula) is inserted under the skin and the medicine is delivered slowly by a pump. You can have many types of pain relief at home.

▸ See our *Understanding Cancer Pain* booklet, and listen to our "Managing Cancer Pain" episode from *The Thing About Cancer* podcast series.

Loss of appetite

Many people find they don't feel like eating as they near the end of life. This may happen because of the cancer itself or symptoms such as pain, nausea, constipation or breathlessness. It can also happen when the body's energy needs slow down and you don't need to eat as much.

Eat what you want when you want it – don't force yourself to eat. Eating more than you feel like might make you uncomfortable, or cause vomiting and stomach pain. Instead, try having small meals or eating little bits of your favourite foods more often. Soft foods can be easier to eat.

You could also try food-type nutritional supplements. Ask your doctor, nurse or dietitian to suggest something suitable; some are available as ready-made drinks at pharmacies.

It's common for family and friends to keep encouraging you to eat, as preparing food for you is often how they show they care. They may worry that not eating will make you feel worse. You may need to let them know that you don't feel like eating, and suggest other ways that 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 want.

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 65 for ways that others can offer comfort.

▸ See our *Nutrition for People Living with 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. This can be distressing but your healthcare or palliative care team can help manage nausea and vomiting with anti-nausea medicines (called antiemetics). 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.

"I hated certain smells and did all I could to avoid them. My mouth felt very dry, which made food unappetising. Adding extra sauce helped." HELEN

Breathlessness

Breathlessness (dyspnoea) is common at the end of life. Breathing may become uneven and noisy in the final days or hours.

Your healthcare or specialist palliative care team will assess the cause of the breathlessness and manage it with medicine or other practical measures. These may include sitting near an open window, having a fan in the room or doing relaxation exercises. Having a comfortable bed, leaning on a pillow while sitting, or changing your position when you're in bed can also help.

Breathlessness can be distressing, and feeling anxious about it can make it worse. Talk to your doctor about medicines that can ease your anxiety or try relaxation techniques like mindfulness and meditation.

- Listen to our "Managing Breathlessness when Cancer Is Advanced" episode from *The Thing About Advanced Cancer* podcast series.

Other symptoms

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

It's natural to feel concerned about others seeing 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 62–64.

Donating organs and tissue

Organ and tissue donation is possible for some people with cancer, depending on the cancer type and spread. You will need to organise paperwork for this ahead of time. Ultimately, whether your organs or tissue can be used will be decided 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. Share your decision with your family as they will be asked to give their consent after your death.

Choosing where to die

Deciding 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, 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 you die is often considered a key factor in dying well. Where that place might be will be different for everyone.

The options available to you may include:

- your own home
- a palliative care unit (hospice)
- a hospital
- a residential aged care home.

Where you would like to die may change as your situation progresses, or as practical concerns arise. 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 may not be space available when you need it.

You may need to have ongoing conversations with your carers and healthcare 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 being able to maintain 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 the idea of caring for you at home.

If you talk together about where you would like to be cared for and plan ahead, you are more likely to get the care you want.

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 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.

Talk to your healthcare or palliative care team about your concerns and find out what options may be 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 (although 24-hour care involves high additional costs). You may have to modify your surroundings (e.g. handrails) or buy special equipment (e.g. shower chairs).

Your GP, nurse, palliative care specialist or palliative care nurse practitioner can help you arrange this support. They 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. See myagedcare.gov.au for more information and to see if you are eligible for government-subsidised support services.

Some carers may find having you nearby easier. It may mean that they don't have to travel, or fit in with a hospital or palliative care routine. Caring for someone who is dying at home can be a meaningful experience, but it can also be challenging. For more information, read *Caring for someone who is dying* on pages 53–72.

You can decide at any stage to change your mind about staying at home and explore other options. If you are planning to stay at home until the end, talk to your GP or palliative care team about ways of dealing with unexpected medical events.

Key points about dying at home

- Being cared for in a familiar environment, surrounded by people you know, may help your emotional wellbeing.
- You can spend more time with family and friends, as there are no visiting hours.
- Depending on your situation and preferences, you can have family and friends at your side at all times.
- Being at home may offer more flexibility to maximise your quality of life.
- It may feel more natural and less clinical, while still giving you access to expert medical advice and symptom control.
- It 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.
- A range of services can give you and your carers help and support. Keep a list of phone numbers handy for when you need advice and support.
- 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

A palliative care unit is a specialised palliative care facility. It is sometimes called a hospice, and may be a standalone facility or rooms within a hospital.

The focus at a palliative care unit is on caring for people with a life-limiting illness and maintaining quality of life. They are run by health professionals who specialise in providing physical and emotional comfort to the patient, and supporting family before and after death.

Palliative care units and hospices are different from most hospital wards. They are usually quieter and calmer, and may have a more homely environment. Many people value the relaxed surroundings, as well as the skilled staff and expert symptom management. Sometimes you can go back and forth between a palliative care unit and another setting during your final weeks. Many facilities 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 have complex needs or can't be cared for at home. Your family and friends can still be involved and visit you to provide care. They may want to help with meal times or bathing or just be there for company and support.

Some people 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 the palliative care unit has to offer.

Some facilities have waiting lists, and often base their intake on people who have the highest level of care needs, so talk to your doctor or palliative care team early about how you can make arrangements and when it would be an appropriate time to make the first contact.

Key points about a palliative care unit

- Palliative care units offer a welcoming and comfortable physical environment.
- Health professionals can provide 24-hour care, including expert pain and symptom control.
- The focus is on quality, not length, of life.
- Time spent with family and friends can be focused on connection rather than on any care needs.
- It may give direct access to a team of professionals and volunteers trained to meet the needs of the dying person and their carers.
- Carers can come and go so they can 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 and their family 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. 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 can bring in familiar items from home, such as a favourite blanket or photos.

Hospitals sometimes provide medical interventions, such as resuscitation and intravenous drips, that may not be what you want in

the final weeks or days of life. Talk to your team to make sure your care plan matches your preferences. Let the hospital staff know what interventions you are comfortable receiving and what you're not happy to have happen.

End-of-life care in a hospital can be managed with communication and advance care planning. You can arrange to have your preferences and wishes recorded in advance care planning documents (see pages 41–52) before an emergency occurs. It's a good idea to keep a copy at home so your family, friends and carers know your wishes too.

Dying in hospital may mean you are able to donate your organs or tissues (see page 32). Talk to your family in advance about whether you would like this to happen as the hospital will still need their consent. Visit donatelife.gov.au for more information.

Key points about a hospital

- Experienced medical and nursing staff are available at short notice to manage your physical symptoms (e.g. pain, breathlessness, fatigue, delirium) and your emotional needs (e.g. anxiety, agitation).
- You must die in a hospital to donate your organs. For details, see page 32 or visit donatelife.gov.au.
- Care is provided 24 hours a day.
- Carers can come and go to get some rest. But some carers may find leaving you to go home difficult.
- Some facilities allow a carer to remain overnight with the dying person. Ask a staff member if this is possible.
- Some families prefer not to live in a house where someone has died, although others find this a comfort.

In a residential aged care home

A residential aged care home (formerly called a nursing home) is a place for older people who need continual care and help with daily living. These homes cater for people with a range of chronic conditions, and nurses and aged care workers can provide ongoing care. Some aged care homes also provide respite care. For a list of government-subsidised aged care services, see myagedcare.gov.au.

Some people fear that dying in residential aged care will be unpleasant and perhaps impersonal. But dying in an aged care home can be comforting, particularly if you have been there for a period of time and you are familiar with the people there. Staff will try to make you comfortable and give you and your family privacy.

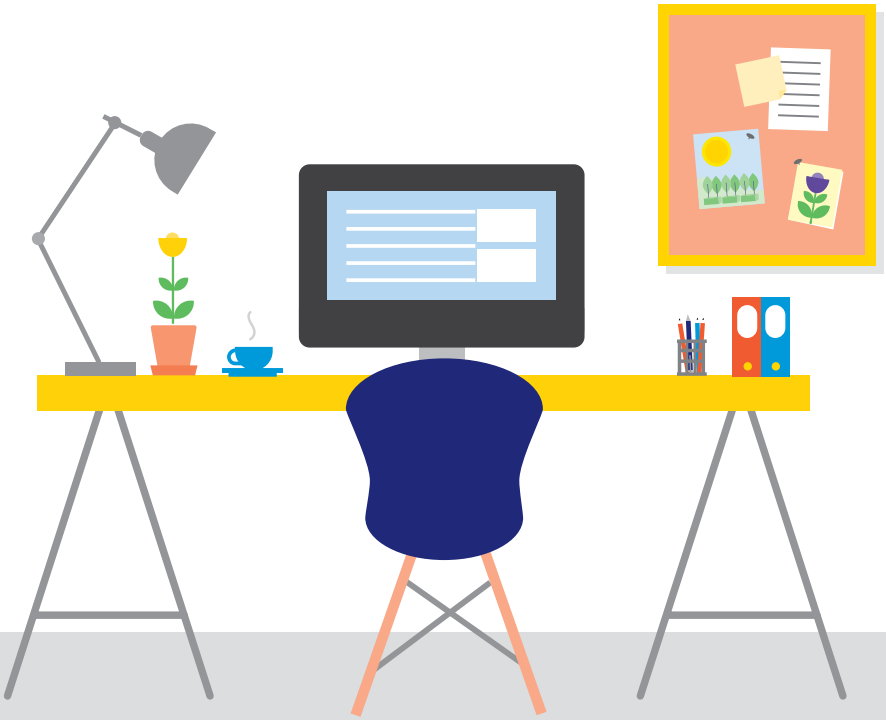
If you want to die in a residential aged care home, consider making an advance care document so that staff know your choices and preferences about care and treatment (see pages 41–49). Talk to your care providers about avoiding an unnecessary transfer to hospital at the end of life.

Key points about a residential aged care home

- It may provide a less clinical environment than some hospitals.
- Experienced staff are on hand to help manage symptoms and needs.
- It may be located close to carers, family and friends.
- It may provide 24-hour care.
- It can sometimes accommodate cultural rites and practices in care.
- Family and friends can go home to get some rest – although some carers may find this difficult.

Practical concerns

Getting your affairs in order can be an important task in the final stages of life. This chapter explains what advance care planning is and why it is important, as well as the medical, legal and other issues to consider at this time.



Planning for the end of life

Taking steps to plan for the end of life can be both rewarding and difficult. It may help you to feel more in control of the situation 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:

- social media logins and passwords (see page 45)
- birth, marriage or divorce certificates and passport
- bank, investment and credit card details
- Centrelink and Medicare details
- superannuation and insurance details
- house title/lease and loan details (e.g. house, car)
- will and funeral information (see pages 45 and 50–51)
- advance care planning documents (see pages 42–47).

Let someone close to you know who you have nominated as beneficiaries and how to contact your lawyer, if you have one.

Advance care planning

It is important to plan for your future health care, and to discuss your preferences and values with your family, friends and healthcare team in case there comes a time when you are not able to speak for yourself. This process is called advance care planning.

Advance care planning can be started at any time, whether you are healthy or ill. Many people find that advance care planning helps them feel more prepared for the future and gives them peace of mind.

Many people also find their attitudes and preferences for medical care change as they get closer to death, and they may need to revisit their decisions regularly.

For some people, quality of life is more important than length, but for others, it may be the reverse. Health professionals must give patients the best care they can. Sometimes, a treatment is unlikely to help and may even cause harm. In these cases, doctors are supported by the law and medical rules to not start treatment, or to stop treatment. This may happen even if a patient or their family wants the treatment to continue or begin. If this happens, it is important to talk with the senior doctor looking after you. You can also ask for a second opinion.

Discussing these issues will help others understand your goals, values and beliefs, and can reduce distress for family members. It makes disagreements about your care less likely, including whether to keep you alive using any means possible or to focus on your comfort.

▸ See our fact sheet *Advance Care Planning* for more information.

What advance care planning can involve

- Reflecting on and talking about what is important to your quality of life
- Discussing your wishes and preferences for your care
- Deciding what treatments you may or may not want, including where you want to receive care (e.g. in hospital or at home if possible)
- Preparing legal documents, including an advance care directive and appointing a substitute decision-maker (see pages 45-46)

▸ For more information about advance care planning, call Advance Care Planning Australia on 1300 208 582 or visit advancecareplanning.org.au.

You might like to use one of Palliative Care Australia's discussion starters at palliativecare.org.au/campaign/discussion-starters, or visit Advance Care Planning Australia's website at advancecareplanning.org.au and search "starting the conversation".

Preparing legal documents

If you haven't already, now is the time to think about what legal documents you may need, such as making a will, appointing a substitute decision-maker and preparing an advance care directive. These documents can have formal requirements such as authorised witnesses for signatures, so it's helpful to start sooner rather than later.

For these documents to be legally binding, you need to have decision-making capacity at the time of making them. In general, having capacity means you are able to understand the choices available and the consequences of your decisions, and that you are able to communicate these choices.

Each state and territory has different laws about what having capacity means and also about making an advance care directive and appointing a substitute decision-maker. For more information, talk to your doctor or a lawyer, or visit End of Life Law in Australia (end-of-life.qut.edu.au) for the law in your state or territory.

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, money, jewellery, clothes, furniture or investments. A will can record your wishes and guardianship plans for any children. It can also include arrangements for pets.

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's best to ask a lawyer to advise you, or contact the Public Trustee in your state or territory. Cancer Council may be able to connect you with a lawyer. Call Cancer Connect on 13 11 20.

If you die without a will, you are said to die intestate. Your assets are distributed to family according to a formula provided by law. Any will can be challenged in court, but having a valid will usually means your assets go to who you want, avoids costs, and simplifies things.

Appointing substitute decision-makers

You can organise for someone to make legal, financial and/or healthcare decisions on your behalf if you become too unwell (lose decision-making capacity) to make these decisions yourself. This person is called a substitute decision-maker. You can choose one person to make decisions about your finances and a different person to make decisions about your health care. Your substitute decision-maker/s should be someone you trust.

Managing social media

If you use social media, think about what happens to your accounts after your death (your digital legacy). Each social media platform has different rules for deactivating accounts, and some allow your account to be turned into a memorial page. Memorialising, locking or deactivating your accounts helps stop your information or that of your contacts being used by hackers.

Prepare a list of your social media accounts and directions for how they should be handled and leave it with someone you trust, so they can manage your ongoing digital presence in the way you want.

Financial and legal decisions – A person who can make financial and legal decisions on your behalf is appointed using a document called an enduring power of attorney.

Healthcare decisions – A substitute decision-maker for health care should be someone who understands your values and what you want for the future. They do not have to be a family member. You should talk to your chosen substitute decision-maker, and share any documents with them, to help them understand your wishes and preferences. Depending on your state or territory, the document used to appoint a substitute decision-maker, and the name of the role, may be different.

What happens if you don't appoint a substitute decision-maker for healthcare decisions – If you can't make decisions for yourself (have insufficient capacity) and you do not have an advance care directive (see below) or an appointed substitute decision-maker, the law in each state and territory outlines who may make medical treatment decisions for you. This is usually someone close to you, such as your spouse or partner, family member or close friend. For more information about who may make treatment decisions for you, visit end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws.

Making an advance care directive

You can record your wishes for your future health care in an advance care directive – what this is called varies depending on your state or territory. This will only come into effect if you can't make decisions for yourself (except in the Australian Capital Territory, where you can choose for a Health Direction to also apply while you still have decision-making capacity). It is legally binding. In some states and territories, you can appoint a substitute decision-maker in an advance care directive.

Keep a copy of your advance care planning documents for yourself and share copies with your GP, oncologist, substitute decision-maker/s, 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 online at My Health Record, a government website that stores your key health information – find out more at digitalhealth.gov.au. You can update your advance care directive when your preferences change.

As each state and territory has different laws about advance care directives, talk to a lawyer for specific advice about your situation. For information about the law on advance care directives, visit End of Life Law in Australia at end-of-life.qut.edu.au/advance-care-directives.

Voluntary assisted dying

Voluntary assisted dying (VAD) is when a person with an incurable condition or illness chooses to end their life using specially prescribed medicines from a doctor. "Voluntary" means that it is the choice of the person to end their life. VAD is different to palliative care. However, a person who accesses VAD can also access palliative care up until their death.

VAD is only available to people who meet strict conditions, including having decision-making capacity and being expected to die within a short period. They must follow certain steps as required by the laws in their state or territory. It is essential to check the latest updates and know the law and rules around this choice in the state or territory where you live.

As of August 2026, VAD is operating in all 6 Australian states and the ACT. In the Northern Territory, VAD laws have been passed and VAD is likely to begin in 2028. For current information on VAD, visit Queensland University of Technology's End of Life Law in Australia at end-of-life.qut.edu.au/assisteddying.

What to consider when getting your affairs in order

These questions can help you to work out the various things you need to consider or organise. Write a to-do list or use these pages as a checklist.

Financial/legal matters

- Have you made arrangements for your financial affairs?
- Do you want someone to make legal or financial decisions for you if you are not able to?
- Have you appointed a power of attorney?
- 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 binding beneficiary? This person must be your dependant. If it is a “lapsing” nomination, you must confirm it in writing every 3 years, so check when you did this last.

Relationships

- Who would you like to see before you become too sick? Are there people you want to see or speak to? Any family or friends you want to connect with?
- If you’d like to prepare letters or video messages 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? Do you need help or mediation to talk to estranged family or friends?
- Have you left the instructions and passwords for your social media accounts somewhere or given them to someone to safeguard?

Medical care

- Are there certain treatments that you don't want to have?
- Are there outcomes of specific medical situations (e.g. life support) that you would find unacceptable?
- 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?
- Have you 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?
- Is there a special place you would like to visit if possible? If you are Aboriginal or Torres Strait Islander, is it important to return to Country?
- Who do you need to ask to make sure that what you want will happen?
- Do you want a minister, priest, rabbi, imam or other spiritual practitioner present when you are dying?
- Do you want to be buried or cremated? Where do you want to be buried?
- Do you have a burial plot? Would you like to have your ashes scattered in a specific place?
- What are your preferences for a funeral or memorial service?
- Have you shared your wishes with family and friends?

Making funeral plans

Some people may find the idea of planning their own funeral too sad or upsetting. They may think that funerals are for the family, and should be organised by them. Others may feel comforted knowing that the funeral will be carried out according to their wishes and that family or friends won't have to guess what they would have wanted. Some people may prefer to have a memorial service or a living wake, while others don't want any kind of funeral at all, or are concerned about the cost.

It's a good idea to discuss the type of funeral you'd like to have with family and friends ahead of time. Even if you aren't concerned about it, a funeral or memorial service can be an important part of the grieving process and provide comfort for family and friends.

You may find satisfaction in leaving your mark on the occasion and 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, as well as any family or friends. Alternatively, you might simply discuss your preferences with your family and executor. Or you might write down your wishes or lodge a plan with a funeral director of your choice.

You can plan your funeral to meet any cultural or spiritual preferences that are important to you. You might have a few requests for music you want played or poems you'd like read, or you may have detailed plans for the full service. You can also choose to have a non-traditional event such as a celebration of life. If you change your mind, you can alter these arrangements at any time. To prearrange or prepay a funeral, talk to a funeral director. You can download a pre-planning information form from Funerals Australia at funeralsaustralia.org.au. It's important

to let your family know of any arrangements like this that you have made and to give copies of a prepaid funeral contract to your family or file it with your will.

Saying goodbye

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

Saying goodbye is a personal experience, so do what is right for you. When you feel you are ready, consider how you 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. In some cultures, having extended family or Mob with you near the end of life is important. Tell your healthcare team what you would prefer. While there may be limits on the number of visitors at a hospital or palliative care unit at times, your healthcare team will try to support your wishes.

If you have young children or grandchildren, you could ask that a letter or recording be given to them at a specific age or time in their life. You (or your friends) could also create a slideshow or book of special photos. A memory box (see next page) can be a special keepsake for your family. You may find it hard to think about a time when you won't be there for your family, but leaving behind mementos 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. A family member or friend may want to look after them, and you could

consider leaving money in your will to cover this care. You could also look on local online pet message boards or talk to your local RSPCA to see whether they have a program for rehoming pets.

Celebrating your life

Knowing you are going to die gives you a chance to reflect on your life and all that you have done, and to think about your legacy. You could talk with family and friends about the special times you have shared together.

You might like to share some of your belongings or a small keepsake with family members and friends as a permanent reminder. You could also write letters or stories of your life, record special memories, make a short film or video featuring you with your friends, review or arrange photo albums, document your family's history or family tree, make a playlist of favourite songs, gather treasured recipes into a cookbook, or create artwork or music. There are also paid and voluntary services that can help you make a record of your life.

Making a memory box

A memory box is a collection of keepsakes for your family. You can put in anything that is meaningful to you, but some suggestions include a:

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

Caring for someone who is dying

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 explains 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, learning what to expect can help you feel less frightened and confused, and allow you to manage the challenges ahead. If you have a complicated relationship with the person, end-of-life caring can be especially difficult.

- 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 personal care and practical support themselves with some guidance from a health professional, or occasional home help or respite. Other people find providing personal care awkward or overwhelming and prefer to have it given by someone else. The palliative care team (see pages 11–13) 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 that they receive specialist care in a hospital, palliative care unit or in a residential facility. Even then, you can still provide some personal care by helping them eat, shower and use the bathroom.

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 6 weeks and basically not move except hobble to bed and hobble to the toilet and hobble back to the chair. 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. Caring 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.

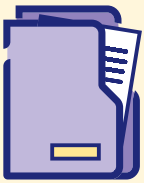
Practical ways to help

There are many things you can do to support someone at the end of life. Many people want to help, but might not know how. Let people know what the sick person

Prepare meals

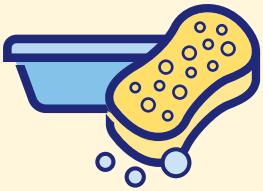
Cooking meals can become challenging. If possible, ask the person what they want to eat. Offer simple, small meals and mash food so it's easier to swallow. A dietitian can give advice on preparing food. If friends offer to cook, let them know what meals are suitable. As the disease progresses, the person may lose their appetite, taste and may not be able to eat or drink. Don't force them to eat or drink. Chips of ice can moisten the mouth.

Sort out the paperwork



Getting their affairs in order can give people closure to their life. Help gather important documents, discuss the person's choices for their future health care (e.g. substitute decision-maker), and arrange legal advice if needed.

Help with bathing and toileting



You may have to give the person a sponge bath, wash their hair over a basin, help them on and off the toilet or commode, help them use a urine bottle or bedpan, and help them to wipe themselves. An occupational therapist can help choose suitable equipment and teach you how to lift safely and correctly. You may need someone to physically help you with this.

Record social media details

People often have more of a social media presence than they realise. Help the person list their social media accounts, passwords and what they want to have happen to them after they die. See page 45 for more information.

may need, and what help you need as a carer. Perhaps one person can coordinate care or use an app such as Gather My Crew.

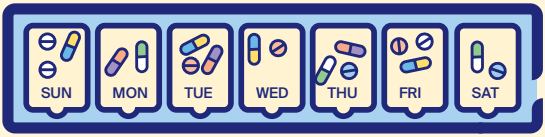
Do odd jobs and run errands

Friends may be able to 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. Some volunteer organisations may be able to help with suitable practical jobs too.

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. Talk to the palliative care team about borrowing a pressure-relieving mattress or hospital-style bed. Many people make space in the living room for a bed, particularly if bedrooms are located upstairs.

Manage medicines



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

Providing emotional support

The diagnosis of a terminal illness may be a crisis for family and friends. How everyone responds can depend on their relationship with the person dying and their own beliefs about death. Natural reactions are shock, anger, fear, sadness or relief, or a combination of these.

People who are dying often say they want to talk about what is happening but are afraid the topic will upset others. While starting the conversation can feel hard, sharing feelings is 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 them a book; look through old photos and talk about the pictures; sing a song; share some special memory or experiences you've had together; or tell them that you love them and that family and friends send their love.
▸ See *When you don't know what to say* on page 60 for more information.

When someone is ill for some time, it's common for their family and friends to start grieving their death before it happens. This is called anticipatory grief. You might find yourself wishing for the person's life to be over, or start thinking about how you'll cope, 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 how you're feeling, or to call Cancer Connect on 13 11 20.

Although all carers have the same rights, LGBTQI+ carers may worry about health professionals or the person's family or friends accepting them. Talk to your GP about local services that can help. You can also contact QLife, a national counselling and referral service for LGBTQI+ people. Call 1800 184 527, visit qlife.org.au or read Cancer Council's booklet *LGTBQI+ People and Cancer*.

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 they'd like a clergy member or other spiritual carer at the bedside, and what rituals or ceremonies should be performed.
Contact list	Have information on how to contact the doctor, nurse or support services easy for everyone to find.
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 the plan.
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 32). Some people have strong views about whether they want to be buried or cremated, what sort of ceremony they want, and what memorial they want.
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.

Saying goodbye

A life-limiting illness offers you time to say goodbye. You can encourage the person who is dying to discuss their feelings, and you can talk about 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 often find small, achievable, but very meaningful things to help the person (and you/those around them) say goodbye.

When you don't know what to say

People often wonder what they should say to a person who is dying. It is understandable that you might feel confused. What you feel might be so complex that it is hard to find the right words, or any words at all. It is natural to worry about saying the wrong thing. You may want to offer something that will help them cope but don't know what that is. It is usually better to say something than to pretend nothing is wrong.

Most times, someone who is dying will find comfort in you being there, and 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.

Ways to talk with someone who is dying

- 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, "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. You could 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.

Providing physical support

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

There will probably be gradual physical changes. Watching these 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 healthcare or palliative care team (see pages 11–13) can help you provide physical, emotional and practical comfort. You can call Cancer Connect on 13 11 20 to find out what support is available.

Signs that someone is dying

Some family and friends find that having information and knowing about the physical process of dying can help to ease their fear and anxiety when it happens. Other people prefer to take one day at a time and ask health professionals for explanations if and when the need arises.

If you would like to know what to expect when someone dies, this section describes some of the common physical changes that may happen in the last days and hours of life. These physical changes don't happen 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. They may still be conscious and able to hear, but have their eyes closed and not be moving.

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. They may resist or refuse food or drink. Giving the person fluids at this time does not help them, but you can offer slivers of ice or sips of water.

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 alertness.

Breathing changes – Breathing may become irregular, laboured, noisy and rattly. You may hear an irregular breathing pattern known as Cheyne-Stokes. This is a loud, deep breath followed by a long pause (which may last from 5 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, or playing music softly to distract from the sound. Listening to this change in breathing pattern can be upsetting, but many health professionals believe this is not painful for the person.

Bladder and bowel changes – As a person eats and drinks less, they produce less urine and faeces (pee and poo). As the body's systems slow down, the person may have trouble weeing. A catheter may be inserted into the bladder to drain urine. Medicines may be prescribed for constipation, a common side effect of some pain medicines. Loss of bladder and bowel control sometimes happens in the last stages of the dying process, but does not always happen. Speak with your healthcare or palliative care team to help you manage any incontinence.

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 and people that aren't actually there); delusions (false beliefs or ideas); 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. The person may drift in and out of consciousness and eventually become unresponsive.

Speak to the palliative care team if you notice any of these changes, so they can advise you on managing delirium.

Delirium may occur when waste chemicals (toxins) build up in the brain as vital organs begin to shut down. It can also have a range of other causes, such as fever or constipation, and these can be treated.

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

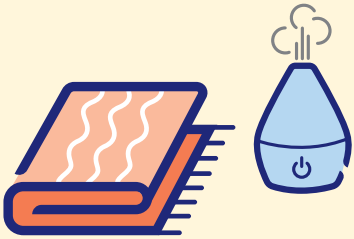
Dry mouth and dry or cracked lips – This can happen if the person is dehydrated or has been breathing through their mouth, or it may be due to some medicines. You can prevent this with regular mouth care, which your healthcare or palliative care team can teach you.

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

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 or healthcare team how you can help. In a palliative care unit, hospital or residential aged care home, ask the staff how you can be involved.

Offer comfort



Apply lip balm and keep the mouth moist with ice cubes or swabs. Use a vaporiser in the room to help with breathing. Put incontinence sheets or pads under the bedsheets. Keep the person warm with a blanket and use cushions so they are comfortable. Help them change positions often. 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 them 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.

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. 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. Taking breaks and sharing the time with others can help.

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.

How to keep a bedside vigil

- You can simply sit with the person and perhaps hold their hand.
- Hearing is said to be the last sense to go, so you may want to talk to the person or even have a conversation among the people in the room so that the person knows they are not alone.
- You could read aloud, sing or hum or play some of their favourite music.
- Plan to take breaks or organise shifts with other family and friends.
- Decide who you think is appropriate to have in the room at this stage and let other visitors know if you want just close family.
- Have food and drinks on hand and some cushions and blankets if you are at a hospital or palliative care unit where it may get cold.

"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

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 or for a time when there are few people around.

It can be very upsetting 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 how they wanted it to be.

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. You can ask a palliative care team member or nurse to talk you through it.

The person's breathing will stop, 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 and becomes pale.

Many carers say it was a profoundly moving experience and a privilege to be with someone at the moment of death. The memory of the final moments are likely to stay with you for a long time.

After someone dies

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 next depends on the circumstances.

What to do after the death

If the person was 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. You may want to call close family or friends who may have wanted to see the person or say goodbye. 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 action. There is no hurry to call or let someone know right away.

When you feel ready, call the person's GP or community nurse and a funeral home. The GP or nurse will examine the person to verify death and complete a medical certificate confirming the death. In some cases, the GP will also need to complete another form if the person is being cremated. This is needed to make funeral arrangements. Sometimes the person's GP may not be available at the time of death, so prepare for this possibility by discussing what to do in advance.

The funeral director can register the death with the registry of births, deaths and marriages in your state or territory; the registry will then organise a death certificate.

If the death occurs in a palliative care unit, hospital or residential aged care home, 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. Services Australia has a useful checklist of who may need to be notified. You can visit their website at servicesaustralia.gov.au and search for "death of a loved one".

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 service. Most people use a funeral director who can organise the service, coffin or casket, 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. Even if the person has prepaid their funeral plan, they may also have left 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.

You may choose not to have a funeral or to have an event such as a celebration of life. To find a funeral director, see page 74 for contact details.

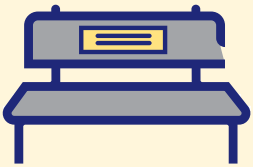
- See our fact sheet *Arranging funerals* for more information.

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.

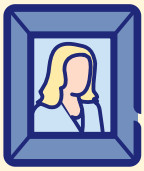
Cook their favourite meal or cake on their birthday.

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



Plant a special tree or flower.

Frame a photo or a cherished note or other memento.



Create an annual award or scholarship in their name.

Create an online memorial page with photos and stories.

Make a donation or volunteer at their chosen charity or community group.

Talk about the person with others who knew them.

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 *Caring for Someone with Cancer* booklet.

Financial matters

You usually won't be able to access the person's money from their bank accounts until after probate. You may be eligible for financial assistance after an immediate family member has died. Centrelink 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 servicesaustralia.gov.au.

- See our online legal and financial fact sheets about what happens to superannuation, income, assets or unpaid debts when someone dies.

Grief

The response you have to losing someone is called grief. This loss can impact many areas of your life – from the physical, mental and emotional, to the social and spiritual.

You may feel grief for people you loved very much, but you may also feel grief if you lose someone you had a complicated relationship with, or hadn't seen in a long time. You may feel sad, numb, disbelief, lonely, guilty, angry, relieved or accepting. It's common to have trouble sleeping, cry a lot or have difficulty crying, lose your appetite, or not be

interested in your usual activities. You may feel tired or lack energy, be forgetful or not able to concentrate, or not want to go out and do things you usually would.

Some people have a big emotional reaction right away, but other people may "get on with life" for a while before feelings of grief happen. 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 stages or timeline. 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 74). At any stage of grief, you can call Cancer Connect on 13 11 20 to talk about how you are feeling or connect with further support. Your specialist palliative care team may also offer support.

▸ See our *Understanding Grief* booklet.

Support and information

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

Useful contacts

Carer services

Carer Gateway 1800 422 737 **carergateway.gov.au**	Practical information, resources, links to respite care and counselling for carers.
Young Carers Network **youngcarersnetwork.com.au**	Support for people under 25 caring for a family member or friend.

Counselling and mentoring services

Australian Psychological Society **psychology.org.au**	Use the "Find a Psychologist" search to look for a practitioner in your area.
Beyond Blue 1300 22 4636 **beyondblue.org.au**	24-hour telephone counselling service; online and email counselling available 7 days a week.
Kids Helpline 1800 55 1800 **kidshelpline.com.au**	Telephone and online counselling service and crisis support for young people aged 5–25.
Lifeline 13 11 14 **lifeline.org.au**	24-hour telephone crisis support and suicide prevention service.
Suicide Call Back Service 1300 659 467 **suicidecallbackservice.org.au**	24-hour telephone and online counselling for people affected by suicide.

Funerals	
Funerals Australia (formerly Australian Funeral Directors Association) (03) 9859 9966 **funeralsaustralia.org.au**	Information about planning a funeral. Use the “Find a member” search to look for a funeral director in your area.
Funeral Celebrants Association Australia **funeralcelebrants.org.au**	Directory for finding a funeral celebrant in your local area.
Future planning	
Advance Care Planning Australia 1300 208 582 **advancecareplanning.org.au**	Information about planning for your future health care, including advance care directives.
Grief	
Grief Australia 1800 642 066 **grief.org.au**	Online telehealth counselling service for people experiencing grief.
Cancer Connect 13 11 20 **cancerconnect.org.au**	Information and support for people with cancer and their carers as well as telephone and support groups.
Griefline 1300 845 745 **griefline.org.au**	Telephone and online counselling service and support groups for all Australians who have experienced a loss.
GriefLink **grieflink.org.au**	Online information for the bereaved and grieving carers, friends and colleagues.
Palliative, respite and other care	
CareSearch **caresearch.com.au**	Australian Government website with palliative care information and links to services for patients and families.

Palliative, respite and other care (cont.)	
Healthdirect Australia **healthdirect.gov.au/respite-care**	Links to respite care at home, in a respite care centre or, in some cases, a hospital or palliative care unit.
My Aged Care 1800 200 422 **myagedcare.gov.au**	Information about the different types of aged care and respite services and eligibility.
Palliative Care Australia **palliativecare.org.au**	Information and resources; can link you to your local palliative care office.
Legal and financial information	
Cancer Connect 13 11 20 **cancerconnect.org.au**	Referral service for people affected by cancer needing professional advice about legal or financial issues; free for eligible clients.
Community Legal Centres Australia **clcs.org.au/legal-help**	Find organisations in each state and territory that may be able to assist you with a legal problem.
Services Australia 132 717 **servicesaustralia.gov.au**	Offers financial support for people with a long-term illness and for primary carers.
QUT End of Life Law in Australia **end-of-life.qut.edu.au**	Information about the law on end-of-life decision-making and voluntary assisted dying in each state and territory.
Public Trustee in your state or territory	Public and state trustees can help you prepare a will and manage your finances.
The social worker on the palliative care team	May be able to help you access legal or financial support.

Support from Cancer Council

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

Cancer Connect by Cancer Council

Call 13 11 20 to talk to a qualified professional. We can answer questions you have about your situation and link you to local services (see inside back cover).

Legal and financial support

If you need advice on legal or financial issues, we may be able to refer you to appropriate professionals. These services may be free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Connect on 13 11 20.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. We can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit cancercouncil.com.au/OC.

Information resources

Cancer Council produces booklets and fact sheets on more than 40 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit cancerconnect.org.au.

Practical help

Cancer Connect can help you find ways to manage the practical impacts of cancer. This can include connecting you with services, such as accommodation and transport services.

Glossary

advance care directive
A written document that records your preferences for future medical and personal care and/or appoints a substitute decision-maker to make decisions for you. May be called a Health Direction, an Advance Care Directive or an Advance Personal Plan.

advance care planning
When a person thinks about, discusses and records their future health care preferences with their family, friends and healthcare team.

advanced cancer
Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

allied health professional
A university-qualified professional who works with others in a healthcare team to support a person's medical care. Examples include psychologists, social workers, speech pathologists, diversional therapists, occupational therapists, physiotherapists and dietitians.

alternative therapy
Any of a range of therapies used instead of conventional treatment, often in the hope that it will provide a cure.

anticipatory grief
Grief that occurs before an expected loss. It affects the family members and friends of the person who is dying.

beneficiary
The person or entity (e.g. a charity) who you legally leave a benefit to (usually money, property or your estate) after you die.

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

cachexia
Loss of body weight and muscle mass, causing weakness.

capacity
Having the ability to make decisions and understand the impact of those decisions.

carer
A person providing unpaid care and support to someone who needs this assistance because of a medical condition, 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. Can help people cope with cancer symptoms and treatment side effects.

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 2 weeks. It can cause physical and emotional changes.

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

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

end-of-life doula
Works along with other professionals in a non-medical role providing emotional support, resources, education and companionship to a dying person and their family, friends and carers.

enduring power of attorney/guardianship
A legal document that lets you appoint someone you trust to act on your behalf if and when you become unable to make decisions for yourself. May cover financial, property, lifestyle, personal care, medical and treatment decisions.

executor
Person responsible for carrying out the terms of a will.

grief
The 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 years.

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

metastasis (plural: metastases)
Cancer that has spread from a primary cancer in another part of the body. Also known as secondary or advanced cancer.

morphine
An opioid. A strong and effective pain medicine that is commonly used to treat 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 addressing physical, emotional, cultural, social and spiritual needs. Also known as supportive care. It is not just for people who are about to die, although it does include end-of-life care.

palliative care nurse
A nurse who has specialised in the field of palliative care. Provides support to the 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 manage complex care, 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 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 may include inpatient medical care, respite care and end-of-life care for people who are unable to be cared for at home, or for people who don't wish to die at home. It may also offer day care facilities and home visits. Sometimes called a hospice.

power of attorney
See substitute decision-maker and enduring power of attorney/guardianship.

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).

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

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

Can't find a word here?

For more cancer-related words, visit connect.cancer.org.au/glossary.

References

1. Kodba-Čeh, H., et al. (2022) "How can advance care planning support hope in patients with advanced cancer and their families: A qualitative study as part of the international ACTION trial." *European Journal of Cancer Care*, 31(6).

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.

The right support.

cancer connect
Cancer Council

Cancer is never one story. Every diagnosis, every person, and every path is different. You don't have to figure it out alone.

Cancer Connect can help you find the information and support that are right for you.

You can explore trusted information on our Cancer Connect website at your own pace, or call 13 11 20 to talk to our qualified professionals. We will listen to your concerns, answer your questions, and connect you with support.

Wherever you are on your path, Cancer Connect can help make the next step feel clearer.

Right when you need it.

Call 13 11 20

Visit cancerconnect.org.au

TIS TRANSLATING AND INTERPRETING SERVICE

If you need information in a language other than English, an interpreting service is available. Call 131 450.

National Relay Service

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

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

cancer connect

Cancer Council

For information & support,
call **Cancer Connect 13 11 20**
or visit **cancerconnect.org.au**

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancer.org.au/tas

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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To support Cancer Council, call 13 11 20 or visit cancerconnect.org.au.

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