Facing End of Life
A guide for people dying with cancer, their families and friends
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First published February 2014.
© Cancer Council Australia 2014. ISBN 978 1 921619 93 9

Facing End of Life is reviewed approximately every three years. Check the publication date above to ensure this copy is up to date.

Acknowledgements
This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Publications Working Group initiative.

We thank the reviewers of this booklet: Dr Melanie Price, Executive Director, Psycho-oncology Co-operative Research Group, Senior Research Fellow, School of Psychology, University of Sydney; Dr Erica Cameron-Taylor, Staff Specialist, Department of Palliative Medicine, Mercy Hospital and Calvary Mater Newcastle, NSW; Gabrielle Gawne-Kelnar, Telephone Support Group Facilitator, Cancer Council NSW; Helpline and Cancer Counselling Service staff, Cancer Council QLD; Judith Quinlivan, Consumer; Linda Wolfe, Consumer; and Dr Mary Brooksbank, Philip Plummer and Claire Maskell Gibson on behalf of Palliative Care Australia.

Thank you to The Guardian for giving permission to reprint quotes from their newspaper.

Writer and Editor: Jenny Mothoneos. Designer: Eleonora Pelosi. Printer: SOS Print + Media Group

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 appropriate independent professional advice relevant to your specific situation and you may wish to discuss issues raised in this book with them.

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

Cancer Council NSW
Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council’s website at www.cancercouncil.com.au or phone 1300 780 113.

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Introduction

Sometimes cancer treatments stop working and a cure or remission is no longer possible. You may be told the cancer is end stage, and it’s expected that you have a limited time to live.

This booklet is for people who have terminal cancer. There is also information for family and friends of someone who is dying. It outlines what might happen physically, the emotional impact of knowing you are dying and how you can prepare for death. We hope it will provide support and direction during this period.

Everyone copes with the news that they’re dying in their own way. How you cope may depend on your age, family situation, cultural background and spiritual beliefs.

You may find reading about dying difficult and distressing. Each chapter begins with a summary to help you quickly see if it is relevant for you. Read what seems useful now and leave the rest until you’re ready. You may also like to pass this booklet on to your family and friends for their information.

How this booklet was developed

The information in this booklet was developed with help from health professionals and patients, and from the findings of research studies.

Cancer Council Helpline 13 11 20 can arrange telephone support in different languages for non-English speakers. You can also call the Translating and Interpreting Service (TIS) on 13 14 50.
Contents

Coping with the news that you’re dying ......................... 5
Your feelings ........................................................................................................ 6
Telling others ........................................................................................................ 8

Emotional concerns .................................................................................................. 9
Talking about dying .................................................................................................. 10
The effect on people close to you .......................................................................... 11
Coping with change and loss .................................................................................. 13
Living with dying ...................................................................................................... 14

Common questions about dying ............................................................................. 15
How long have I got? ................................................................................................. 16
What is it going to be like? ......................................................................................... 17
How will I know that the end is near? .................................................................... 18

Spiritual concerns .................................................................................................... 19

Symptom control ..................................................................................................... 21
Palliative care ............................................................................................................ 22
Pain ............................................................................................................................ 23
Tiredness and fatigue ................................................................................................. 24
Loss of appetite .......................................................................................................... 25
Feeling sick ................................................................................................................ 26
Shortness of breath .................................................................................................... 26
Other symptoms ........................................................................................................ 27
Using complementary therapies ............................................................................... 28
Where to die ................................................................. 29
What is a ‘good death’? .................................................. 31
In your own home .......................................................... 32
In a hospice ................................................................. 34
In hospital ................................................................. 35
In a nursing or residential home .................................... 37

Practical concerns .......................................................... 39
Organising your paperwork ............................................. 40
Making care choices ..................................................... 42
Making a will ............................................................... 43
Appointing a substitute decision maker ......................... 43
Advance care directive .................................................. 44
Planning your funeral .................................................. 45
Organ donation ........................................................... 47
Saying goodbye ........................................................... 47

Caring for someone nearing the end of life ..................... 49
Providing practical support .......................................... 50
Providing emotional support ....................................... 53
Providing physical support .......................................... 57
After the death ......................................................... 63

Services and information ............................................... 68
Glossary ................................................................. 74
How we can help .......................................................... 76
“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.

When I have been up to it, my family has been filming a video of our time together, especially the special moments with my grandchild. This has been very important to me, and will be a treasured keepsake for my family.

I would encourage others to set a goal to work towards. My goal is to stay with my children in my home until the end.” — Agnes
Coping with the news that you’re dying

This chapter discusses the different ways you may cope with the news that you’re approaching the end of life and how your family and friends may cope.

- People may feel shocked, frightened, angry, helpless, anxious or even relieved when told that they are approaching the end of life. These feelings are likely to change often.

- Depression is understandably common.

- Telling friends or family about your prognosis can be difficult. You may find it helps to prepare what you want to say.

- People may react in a variety of ways. Some people may not know what to say.

- Finding someone to talk to may help you cope with these feelings. It can be a family member, a friend or a professional, such as a counsellor, psychologist or psychiatrist.
Coping with the news that you’re dying

Learning that you may not have long to live is shocking news. Even if you are aware that the cancer is progressing, hearing that you are dying is likely to be devastating.

We all know that death is a natural part of life and that it will happen to us all one day, however most of us hope that we won’t die anytime soon. Realising that death is close can be frightening and hard to believe. However, for some people, it may be a relief.

You may have questions straightaway or you might need time to absorb the news and come to terms with the prognosis.

Your feelings

After the initial shock, feelings of fear, anger, despair, helplessness and anxiety are common. You may also worry about being a burden to family and friends; emotionally, physically, socially and financially.

You probably will have more than one emotion at a time. These feelings are likely to change, sometimes from day-to-day or even from hour-to-hour. This is often part of the process of making sense of what is happening. You may find it hard to think clearly. It’s natural to cry at this time, don’t feel like you have to put on a brave face.

Many people compare these feelings to waves at the beach. Sometimes waves knock you off your feet, other times your footing is a little stronger. But, at anytime, a large wave can suddenly come back and knock you off your feet again.
The waves of your emotions don’t hit in any particular order or strength. However, people often say that their fears, thoughts and feelings are stronger at night, when they’re lying in bed, and that they don’t often share them with family and friends.

You may feel unsure of how to cope with your feelings and emotions. Find someone you can talk to; perhaps a family member or friend. You could also consider professional help through a general practitioner (GP), counsellor, psychologist, psychiatrist or spiritual adviser. Other people nearing the end of life offer a unique perspective and you may want to consider joining a support group; see page 73 for details.

These feelings probably won’t go away altogether, but they may change over time and you may learn strategies to help you live as well as you are able for as long as you can.

“The worst is at night when I am in bed. Lying there on my own I start thinking about funerals and I get the horrors. I’ll be sitting there watching telly and suddenly remember that I’m dying. There are moments when my brain swirls and I think of things I’ve done and people I’ve hurt in the past. It’s a suffocating feeling, all jumbled thoughts – it’s 60 years of memories at once. I’ve found a cure though: I just get in the bath. That’s the only thing that relaxes me now.”

Victor Fournere, Living with death, The Observer, Sunday 19 June 2011
Telling others

People share the news in different ways. There’s no easy way to start this conversation but you may find it helps to prepare.

• 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.
• Be prepared for people being uncomfortable and perhaps not knowing what to say.
• Accept that the person you are telling may get upset. You may find yourself comforting them, even though you are the one dying.
• Call Cancer Council Helpline 13 11 20 if you need help telling people. They can help you find the words that feel right for you.

For ways to talk to people (including children) about dying, see the Emotional concerns chapter on page 9.

When family decides

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

Often people who are dying know what is happening. Keeping it a secret from them may mean they feel isolated and lonely at a time when they most need support. Although it may be difficult, it is best to be honest and truthful.
Many people are not comfortable talking about the end of life. This chapter covers common reactions and how to cope with them.

- Talking about death and the dying process can help support you and your family and friends through sadness, anxiety and uncertainty.

- It’s common to feel like nobody understands what you’re going through. If you want your family and friends to acknowledge that facing the end of life is a challenge, let them know.

- Your family and friends may react in different ways. Responses range from not wanting to leave you alone to withdrawing and not talking about the terminal nature of the cancer.

- Telling children that the cancer diagnosis is terminal is difficult but it can help to prepare them.
Emotional concerns

Talking about dying
Most people are not used to talking openly about death and dying, and it’s common to avoid this conversation.

Why it helps to talk
There may be days when you feel like talking about approaching the end of life, and days when you don’t. It may even change from minute to minute.

In general, it can help to talk about 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 often help support all of you through sadness, anxiety and uncertainty.

Some people dying with cancer have said that the process can feel isolating and lonely. This is particularly true if family and friends avoid talking about what is happening. If you want people to acknowledge that dying from cancer is a difficult experience, let them know.

When you don’t want to talk
You may find that you don’t want to talk about dying. Or you want to discuss it with some people but not others. You may be the type of person who would prefer to focus on making the most of the time you have left, rather than talking about death. If you don’t want to talk about facing the end of life, don’t force yourself.

In some cultures people think it’s disrespectful to talk about dying. Or they may feel that talking about death makes it happen sooner.
The effect on people close to you
You may sometimes feel that the hardest part about dying is the effect it will have on your family and friends.

People who are living with terminal cancer often say family and friends react in different ways when they find out the disease is at the end stage. You may experience the following responses:

• They may be overprotective, not wanting to leave you alone.
• They may offer to help in any way they can.
• They may 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.
• They may volunteer the story of a friend or celebrity who had a miraculous recovery from something everyone had deemed hopeless and fatal.
• They may pull away and withdraw from your life.
• Some people may start to regard you as already gone.

These reactions can be hurtful and frustrating but they don’t mean that your family and friends don’t care. They need time to adjust to the news and come to terms with how they’re feeling.

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

Catherine
Children
Telling children that you are dying is confronting and difficult. There is no easy way to approach this conversation, but it is important to let them know what is happening. While you might avoid telling them for as long as possible, children may sense that something has changed, and not sharing can add to their anxiety.

It may be helpful to have your partner or a support person with you when you have this discussion. How you tell your children will depend on their age, but these suggestions may help:

• Be honest with them and explain the situation using words they could understand. Children may benefit from seeing a counsellor, or depending on their age, a play therapist.

• Keep your explanations as simple as possible, and be guided by their questions so you don’t offer more information than they may want or can handle.

• For more information, call 13 11 20 for a free copy of Talking to Kids About Cancer.

If you live alone
You may live on your own and not be able to receive care from a family member or friend in your own home. If you don’t have family or don’t have contact with them, other services can help – the palliative care team or your local community health service, local council or church group. You may also need to organise practical care from support services, see page 68.
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, and your cultural or spiritual beliefs.

Everyone will find their own way at their own pace. There is no right or wrong way. For some, learning more about the physical dying process can make it easier to cope. Others find it helps to think ahead within a specific time period.

Finding hope

You may find it hard to feel hopeful when you’ve been told that you’re dying with cancer. While it may be unrealistic to hope for a cure, you can find hope in other things. For example, sharing some special times with those you love.

Studies of people dying with cancer show that people’s hope can be maintained when their health professionals involve them in decision-making, especially about palliative care treatment options and where they’d like to die, and reassuring them that their pain will be well controlled.

“If I didn’t wake up every morning hopeful, then I wouldn’t get out of bed, get dressed, eat or breathe. What’s anyone without hope?”

Holly Webber, Living with death, The Observer, Sunday 19 June 2011
Maintaining a sense of control
For many people, learning that they are approaching the end of life may make them feel like they’ve lost control. If you want to regain control over some areas of your life, you can plan future medical decisions and tidy up unfinished business (see page 42).

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

People often grieve for events they won’t be around for, such as marriages, graduations and having babies. People without children or a partner may mourn the lost opportunity to have these relationships or experiences.

You may also gradually feel less able to do things or you may lose interest in activities you previously enjoyed. Although this process can be helpful in allowing you to get used to the idea of death, it can also make you feel sad and very low.

Living with dying
You may have heard the term ‘living with dying’ and wondered what it means. For many people, it’s the balance between knowing you are dying and still trying to live as fully as possible. This may mean focusing more on the present. You may find that some days it’s easier to achieve this than others.
Knowing that you’re approaching the end of life raises many questions. This chapter answers some of the questions you may have.

- Some people want to know how long they’ve got, others prefer not to hear the answer.

- A doctor can only give a general idea about how much time you have left, not exactly what will happen to you.

- You may want to decide what you value most: quality of life or amount of time.

- Knowing about the physical process of dying may make it easier to cope and alleviate any fears you may have.

- You may wonder how you’ll know the end is near. As the body shuts down, sleeping more and more is common. Slowly you let go of your attachment to living.
Common questions about dying

Often people who are dying have lots of questions. Sometimes they’re not sure if they want to know the answers. Here are some questions you may want to ask when you are ready.

**How long have I got?**

Some people want to know how long they have left to live while others prefer not to know. It’s a very personal decision. This question can be hard for your doctor to answer and you may find their response is vague. As everyone is different, a doctor can only give you an estimate (prognosis) based on what usually happens to people in your situation, not exactly what will happen to you. Sometimes doctors are hesitant to predict your prognosis because they’re concerned about over- or under-estimating a person’s remaining life span. But if it is important for you to have an estimate, ask your doctor for one.

You may want to think about whether quality of life or the amount of time left to live is important to you. Some people prefer to have less time if it means feeling relatively well, while others want as much time as possible, regardless of how they feel. Sometimes people find that near the end they change their minds and want to do everything possible to postpone death, if only by days. This is a natural reaction.

It is likely to be very difficult if you are told that the time you have left to live will probably be short. Even if it is only a matter of weeks, though, having a sense of remaining time can give you an opportunity to prioritise what you’d like to do.
If you live past the estimated time, you may feel unsettled and not quite know what you should do next. Or you might feel lucky to be living beyond that time. It may help to talk about your feelings with your family, the palliative care team, your doctor or a counsellor.

“It was like appearing in court expecting a death sentence and discovering the judge didn’t want to commit himself.”  

Richard

What is it going to be like?

It’s common to have misconceptions or fears about what dying is like. Many people say they don’t fear death as much as the unknowns of dying. Knowing what you might expect makes things easier – not being told what might happen can be distressing for you as well as for your family and friends.

If you’ve been with a person who has died, this experience may have left you reassured, sad, angry or scared. You may be worried by some of the physical changes that happened to them. For example, perhaps it appeared they were having trouble breathing, or they seemed to be in pain or uncomfortable.

It will help to talk to your doctor, the palliative care staff, or if you’re staying in a hospice, the staff there. They can explain the physical dying process and reassure you that you will be cared for. Modern health care means that people should not die in pain or distress. The following question also describes the physical dying process in more detail.
How will I know that the end is near?
For many, dying is a gradual shutting down of the body’s systems. Energy levels fluctuate and there are good days and days you can’t do much at all. Appetite reduces and sips of water or a teaspoon of food here and there may be enough.

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

Near the end, many people slip into unconsciousness before dying, although some remain alert almost until the end. Others may have phases where they are awake and can talk, and then slip back into unconsciousness.

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

“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
As you approach the end of life, you may consider your spirituality. This chapter covers what that means to different people.

- Spirituality means different things to different people. To some it may mean being part of organised religious beliefs, to others spirituality is expressed as a personal philosophy.

- For many people, spirituality is important at the end of life, and provides comfort. It can be expressed through prayer or meditation.

- It is also natural for people to question their beliefs.

- If you have specific cultural or spiritual practices that you would like to follow near the end of life, talk to the hospital or hospice staff who can help this happen.
Spirituality is an individual concept. For some people, it may mean being part of organised religious beliefs and practices, such as Christianity, Judaism, Islam or Buddhism. For others, spirituality is expressed as a personal philosophy or a world view.

Spiritual care is important for many people at the end of life. Often people find comfort and strength in their spirituality, and talking to their priest, minister, rabbi, imam or equivalent is an important source of support. For others, their beliefs are challenged by their situation. It may help to talk about your thoughts and feelings with a pastoral care worker. They are part of the palliative care team and have the expertise to discuss spiritual issues, whatever your religion or whether you are atheist or agnostic. You may wish to discuss life’s meaning or your beliefs about death. A pastoral care worker can also provide encouragement and companionship.

Some people say that knowing they’re dying makes them feel more spiritual and they need to think about and discuss these issues. Others may embrace a belief system that they have never been interested in before or abandoned many years ago.

Some people find comfort in prayer or meditation. Many people gain a lot of support from knowing that other people are praying for them or sending positive thoughts their way.

Some religions have specific practices for when people are dying. If you want to follow certain rites in a hospital or hospice, it’s best to discuss this with the staff. They will be able to help find the space and time for you to do this.
People experience many different symptoms as cancer progresses. This chapter describes the common symptoms and how they can be managed.

- Managing symptoms near the end of life is a common concern.

- Many people worry that they could spend their last days in pain. Medication can be used to control pain.

- Loss of appetite occurs as the end of life approaches.

- Nausea caused by the cancer or other side effects can usually be managed with medications.

- While shortness of breath is common, it can make you and those around you feel anxious. Talk to your doctor about ways to ease anxiety.

- Other symptoms include restlessness, feeling confused or experiencing hallucinations. There are ways to cope with these symptoms.
Symptom control

Managing symptoms is a common concern for people who are dying and their family. Near the end of life, the focus of care is usually about maintaining quality of life and remaining pain-free.

Health professionals will do all they can to provide you with the highest possible level of comfort and care during your last days. Ask them any questions you have so you have a good understanding of what to expect.

Palliative care

Palliative care offers relief, support and comfort to people who are dying and their family and friends. It involves caring for your physical, emotional, psychological and spiritual needs.

Your GP and community nurses may be able to provide all the care you need, but they may also call on your local specialist palliative care team (see next page). These different professionals work together to give you relief from pain and other symptoms of cancer. They will try to help you live your life as fully as possible until you die. They will also support your family and friends to help them cope during the illness, and after the death.

For more information about what palliative care is, how it helps and how to access it, call Cancer Council Helpline 13 11 20 for a free copy of Understanding Palliative Care or visit the Cancer Council website for your state or territory (see the inside back cover for details).
Pain

Many people with end-stage cancer worry they could spend their final days in pain, but not everyone with cancer has pain. If you do, the health professionals caring for you will help you control the pain as much as possible.

Everyone experiences pain differently so it might take time to find the right pain relief or combination of treatments for you. Controlling the pain may allow you to continue with activities you enjoy for some time and offer a better quality of life. Even if you have experienced pain from cancer, it will not necessarily get worse as you get closer to dying.
The right pain relief for you depends on the type of pain you have and how bad it is. You might be offered:

- mild pain medications, such as paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs)
- moderate pain medication, such as codeine
- strong pain medication, such as morphine, oxycodone, hydromorphone and fentanyl.

You may also be given other types of medication to take with the main pain medication. For example: antidepressants and anticonvulsants for nerve pain; anti-anxiety drugs for muscle spasms; or local anaesthetics for nerve pain. If the pain is hard to manage, a pain specialist may consider a nerve block or epidurals.

Some people worry about becoming addicted to pain medication, but this is not a concern when being treated for symptom control for end-stage cancer. For more information, read Cancer Council’s pain booklet online or call the Helpline for a copy.

**Tiredness and fatigue**

Having a terminal illness will almost certainly leave you feeling fatigued. Try to pace yourself and save your energy for the activities that are most important to you. The fatigue may also affect your ability to think clearly and make decisions. This can be frustrating, particularly when you are dealing with the practical concerns outlined on pages 40–48. If you are trying to put your affairs in order for family members, you may want to do this at a time of day when you have more energy.
Loss of appetite

Many people find they lose their appetite as they near the end of life. This may be because of other symptoms, such as pain, nausea or breathlessness, or because the body’s energy needs have slowed down and it’s no longer necessary to eat as much.

It’s not necessary to force yourself to eat; this may only make you feel uncomfortable and can cause vomiting and stomach pain. Try having small meals or eat your favourite foods more frequently. Another option is liquid meals. Ask your doctor, nurse or dietitian to recommend something suitable.

It’s common for others to want to encourage you to eat, as preparing food for you is how they show they care. You may need to let them know that you don’t feel like eating, and suggest other ways they can show their love, such as a hand or foot massage.

As the disease progresses, the body reaches a point where it can no longer absorb or get nutrients from food. Clear fluids such as water or weak tea may be all you can handle. There will come a time when even this isn’t tolerated, and family or friends can help keep your mouth moist. See the carers section for suggestions.
Feeling sick
You may feel sick or have trouble keeping food down either from the cancer or from some of the side effects from the medication you’re taking. Nausea can usually be managed with medications. They can be taken as tablets, or if swallowing is difficult, as injections under the skin or suppositories, which are inserted into the bottom and absorbed through the lining of the rectum.

Shortness of breath
Breathlessness, also called dyspnoea, is common at the end of life. Breathing may become uneven, change rhythm, and become noisy. There may also be excessive secretions, creating loud, gurgling sounds. Your health care team will assess if something is causing the dyspnoea and manage it with medication or practical measures, such as being placed near an open window, having a fan in the room or trying relaxation exercises.

Feeling breathless may make you feel distressed and anxious, and this is likely to make the breathlessness worse. Talk to your doctor about medications that can ease your anxiety.

As you spend more and more time in bed, your breathing may change again and you may lose the ability to cough effectively or to swallow and clear secretions from your mouth. Adjusting your position in bed or sitting up slightly can improve this.
Other symptoms

As you approach the final days or hours of life, other symptoms can be managed to help you feel more comfortable.

- **Trouble emptying bladder** – The palliative care nurse or doctor may need to insert a catheter into the bladder to drain the urine and avoid a blockage.

- **Restlessness, calling out or twitching** – At this stage you will probably be unconscious or asleep and unaware of what is happening. While these symptoms are common, your family may find your restlessness upsetting. It may help for them to talk to a doctor or other health professional.

- **Feeling confused or experiencing hallucinations or visions** – This is referred to medically as delirium. Your doctor can give you medications to help you relax and sleep. Your family and friends are likely to find this symptom distressing, and will need support and reassurance.

- **Noisy or moist breathing** – This often occurs when saliva and other fluids collect in the airways. Although the sound is often distressing for family and friends at the bedside, it is thought that the breathing is not painful. Various medications can help dry up new production of secretions but not what is already there.

- **Cool skin** – Although the skin can be cool, particularly the hands and feet, it’s thought that you will be unaware of feeling cold.
Using complementary therapies

Many people use complementary therapies to help them feel better and cope with cancer and its treatment. This is also true for people who are dying with cancer. Complementary therapies may help you relax and reduce anxiety. They can also help calm your emotions, and improve symptoms such as pain and nausea.

Some people find having gentle therapies, such as massage and aromatherapy, helpful. People who find it uncomfortable or painful to be touched may find reiki, meditation or visualisation useful.

Your local Cancer Council website has more details on individual complementary therapies.
There are several choices for end-of-life care. This chapter outlines these options and lists some of the benefits to consider.

- While choosing where to die is a personal decision, it can still be difficult to make.

- Options include: dying in your own home, at a hospice, in hospital or in a nursing home. Each setting has pros and cons.

- Many people express the wish to ‘die with dignity’. Talking about what you want will help ensure that the way you want to die is respected.

- Having some control over where death occurs is often cited as a factor that contributes to a ‘good death’.

- Other factors include having some understanding of what to expect, having some control over pain relief, maintaining a sense of dignity and being able to have a say in end-of-life care.
Where to die

Choosing where to die is a personal decision. The options covered in this chapter all have pros and cons.

You’ll need to evaluate your physical needs and the support that can be provided by family and friends. In some cases, you may feel like your choice is limited, and that the practicalities help decide the setting. This may be because you have medical needs that only a hospital, hospice 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.

Discuss with your family or friends where you’d like to have end-of-life care and what is important to you. Ask them about their views and preferences.

You may be concerned about dying with dignity. This means different things to different people, but for many it means dying with respect for your wishes and the way you want to die. For help working out the best option for you and your family, talk to the palliative care team.

As you approach the end of life, you may wonder how you will know the end is near. See pages 17–18 for more information.

Where people would like to die may change over time and as their circumstances change.
What is a ‘good death’?

People often talk about wanting to have a ‘good death’. What this means is unique for everyone, shaped by his or her attitudes, cultural and spiritual backgrounds, as well as medical treatments.

Although there is no right way to die, research has identified some common factors that can help a death seem good, including:

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

With planning, you can achieve a good death.

Dying at home may be seen as a marker of a good death, but there is more than one way to die well. The important thing is that you are able to decide and have your physical and emotional symptoms well controlled.

Achieving a dignified and peaceful death can help family cope better with bereavement.
In your own home
If asked, many people say they want to die at home around familiar surroundings and people. While it may not be the option everyone might choose, if you do want to be at home, then help and support may be available for you and your carers. Even if you live alone, with planning, you can stay as long as possible in your own home.

Who can help you stay at home?

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your GP</td>
<td>overall responsibility for your care</td>
</tr>
<tr>
<td>Palliative care team</td>
<td>helps you and your family maintain quality of life</td>
</tr>
<tr>
<td>Community-based nurse</td>
<td>provides ongoing care</td>
</tr>
<tr>
<td>Volunteers</td>
<td>provide a range of support services – can help with home or personal care</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>helps make the physical aspects of your life easier</td>
</tr>
<tr>
<td>Social workers</td>
<td>organise help with housework, shopping and cooking or personal care</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>assesses your home and suggests equipment, such as hospital beds, wheelchairs and bedside commodes</td>
</tr>
<tr>
<td>Counsellor, psychologist or psychiatrist</td>
<td>helps you work through your feelings</td>
</tr>
<tr>
<td>Pastoral care worker</td>
<td>talks about any spiritual matters</td>
</tr>
</tbody>
</table>
It’s a good idea to check how your family and friends feel about home care. Some carers may appreciate having you nearby and not having to fit in with the hospital routines. Other carers may be frightened and worried that they don’t know what to do. Although dying is a natural process, few people have experience or knowledge of looking after someone who is dying. If you find your family isn’t supportive of you staying at home, talk to your doctor, nurse or palliative care team. They can advise your family of what assistance is available, and reassure them that they don’t have to cope alone.

Although you may wish to die at home, you may change your mind as you get closer to the end of life. Sometimes people go into a hospice or hospital to have their symptoms managed or to give their carers a break, and then return home. Talk to your palliative care team about ways of dealing with unplanned events. Have the contact details of professionals you can call if you need advice and support.

For more information on how they can cope, suggest your carers read *Caring for someone nearing the end of life*, page 49.

**Home: what are the benefits?**

- Maintain emotional wellbeing by being in a familiar environment surrounded by family and friends
- Sometimes offers better opportunities to maximise the quality of life
- Retain a greater sense of control over your life
**In a hospice**

You may decide that you’d be more comfortable in a setting with staff who have the expertise to help your family and friends look after you.

A hospice focuses on end-of-life care centred on quality of life. Staff specialise in providing physical and emotional comfort to the patient, and supporting the family before and after the death.

Hospices are different from hospitals. They are often quieter and calmer, and have a more homely environment. You can stay for a short period of time, and sometimes you can go back and forth during your final weeks. Many hospices now have a maximum length of stay, so you may want to check this when booking in.

Hospices are valued for their relaxed surroundings, skilled staff and symptom management. The hospice may offer a break from mainstream health care and respite from people wanting to visit you. You may choose this option if you want to relieve your family from caring for you while dying, although they can still be involved. They can help in many ways, such as feeding, bathing and offering comfort by reading, sharing music, or simply being present.

Some people and their family and friends are unsure of when to contact a hospice. They may wait to call the hospice until the final days, possibly missing out on the support that this environment has to offer. Talk to your palliative care team or doctor about when it’s a suitable time to call the hospice.
Hospice: what are the benefits?

- A warm and comfortable physical environment
- 24-hour care
- Focus on quality not length of life
- A team of professionals and volunteers trained to meet the needs of the dying patient and their caregivers. This can involve doctors, nurses, social workers, chaplains and other trained hospice staff and volunteers
- Pain and symptom control
- Treats the patient, not the disease
- Allows the patient and family and friends to focus on being together
- Carers can leave at the end of the day and get some rest
- Some carers may not want their family member to die at home as it could be a constant reminder of their dying

In hospital

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

If you have spent a lot of time in hospital during your illness, you may want to stay on the same ward where you are familiar with staff and surroundings, and they know you and understand your specific needs. You’ll need to check if this is possible as sometimes people are moved to a different ward as their medical needs change.
To help create a more homely environment, ask if you or your carers can bring in familiar items from home, such as a favourite blanket or photos.

Hospitals can provide medical interventions, such as resuscitation and intravenous lines, that some people may think are unnecessary as a person nears death. If you are concerned, talk to the hospital staff. You can request that you don’t receive them.

The quality of end-of-life care in a hospital can be managed with communication and advance care directives. Preparing an advance care directive can help give you control over the type of medical treatment and interventions you receive. See page 44 for further details on what this is and how it can help ensure your wishes are followed.

**Hospital: what are the benefits?**

- Experienced staff to manage physical symptoms (i.e. pain, fatigue, breathlessness) and emotional needs (i.e. anxiety and delirium)
- Access to medical technology
- Carers can leave at the end of the day and get some rest
- 24-hour care
- A hospital can offer a sense of closure to family and friends, as they don’t have to return to the hospital after someone dies
In a nursing or residential home
A nursing or residential home is a place where people stay who need continual care and help with daily living. They are available to people who have different conditions, and nurses and aides are available 24-hours to provide care.

Some people fear that dying in a residential home will be unpleasant and perhaps frightening. Yet dying in a nursing home can be comforting, particularly if it has been your home for a period of time and you are familiar with the staff, who will try to create the right environment to make you comfortable.

The hospital staff took care to ensure we had a private space to gather as a family, and we could come and go to my husband’s bedside. Maria

Nursing/residential home: what are the benefits?
- Possible choice of a facility close to carers or loved ones
- Less clinical environment than some hospitals
- Experienced staff to manage physical symptoms and emotional needs
- Carers can leave at the end of the day and get some rest
- After you have died, families and friends don’t have to return to the nursing home
Thoughts about euthanasia

If an illness is prolonged or very debilitating, some people think about speeding things up. Euthanasia is when somebody’s life is deliberately ended to relieve them of their suffering from an incurable condition or illness.

Voluntary euthanasia is illegal in every state in Australia. Nevertheless, it is something that some people consider when they are seriously ill.

Sometimes a person with cancer may decide that they want their death hastened, but later decide that they don’t. They may have thought that way because they were feeling particularly ill, scared, or worried about the strain they were putting on others.

If this is how you feel, discuss your concerns with your doctor, a counsellor or social worker. Sometimes these feelings are due to depression, feeling helpless or because pain is not being well controlled.

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

If you urgently need somebody to talk to because you are thinking about ending your life, call Lifeline on 13 11 14 for free, confidential telephone counselling at any time of the day or night.
Getting your affairs in order can be an important task in the final stages of life. This chapter covers the medical and legal issues to consider.

- A will is a legally binding document outlining who receives your assets after your death.
- A substitute decision maker is someone you appoint to make decisions for you, if at some point in the future you are unable to make them for yourself.
- An advance care directive is a legal document that details your wishes for the medical treatment you do or don’t want to have.
- The rules that surround these documents vary from each state and territory. Check what is relevant to your local area.
Planning for the end of life can be both rewarding and difficult. For many people, preparing for death helps them feel more in control of their situation. Some may wish to ease the burden on family members or friends.

Most people like to get their affairs in order before they die. See the *What to consider* box on the next page.

**Organising your paperwork**

It’s helpful to have all of your paperwork up to date and in one place. This will make it easier if a family member has to help you with financial and legal matters.

Important documents to get together might include:
- birth, marriage, divorce and citizenship certificates
- bank and credit card information
- investment details (e.g. shares, funds)
- Centrelink and Medicare details
- superannuation and insurance information
- house title/lease documents
- loan details (e.g. house, car, etc)
- will
- passport
- funeral information.

It’s a good idea to check or update who you’ve nominated as beneficiaries on your retirement plans and life insurance policies. Let someone close know how to contact your lawyer.
Getting your affairs in order – what to consider

- Are your financial affairs in order?
- Do you want someone to make legal or financial decisions for you if you are not able to?
- Does someone know where to find important papers?
- Do you have a current will?
- If you have life insurance, is the beneficiary information up to date?
- If you have superannuation, have you nominated a beneficiary?
- Have you prepared a letter, gifts or heirlooms for family or friends, if you’d like to do so?
- Are there certain treatments that you don’t want to have?
- Have you discussed your wishes for end-of-life care with your loved ones and treating health professionals?
- Have you considered who can make decisions about your end-of-life care if you’re not able to make them yourself?
- Have you recorded these decisions in an advance care directive or appointed a substitute decision maker?
- Who would you like to have around you as you get closer to death? Are there people you don’t want around?
- Are there unresolved issues that you would like to sort out with particular people?
- Are there any cultural, spiritual or religious practices that you would like carried out before or at the time of your death, or once you have died? Who do you need to ask to make sure this happens?
- Do you want a minister, priest, rabbi or spiritual advisor present at the end?
- Do you want to be buried or cremated? Do you have a burial plot? Would you like your ashes scattered in a particular place?
- What are your preferences for a memorial service? Have you shared your wishes?
Making care choices
As you approach the end of life, you may want to think about your ongoing medical care.

As it is hard to know what medical care you’re going to want until the situation arises, uncertainty is common. Many people find their attitudes and preferences for medical care change as they get closer to death and they need to revisit their decision regularly. To help you decide, think about what is important to you and talk with your health professionals, over several appointments if necessary.

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

Having capacity to sign a legal document
When you make a will, appoint a substitute decision maker or write an advance care directive, you need to be an adult and have capacity at the time of signing the document. This means you are able to understand the choices that are available, the consequences of your decisions and are able to communicate your choices. If there could be any doubt about your capacity, it’s a good idea to get a doctor’s certificate to verify this.
Making a will

A will is a binding document that records who should receive your assets (estate) after you die. A will also covers guardianship plans for your children. Many people want to make a will or update the one they have. Having a will usually makes it easier for family and friends to carry out legal and financial arrangements after you die. Without a will, these arrangements can be complicated, lengthy and expensive.

Making a will is not difficult but it’s a legal document that must be prepared and written in the right way. It is best to ask a lawyer to help you or contact the Public Trustee in your state or territory. Cancer Council has more information on preparing a will – visit your local website or call the Helpline on 13 11 20.

Appointing a substitute decision maker

You can appoint someone to make decisions for you if at some point in the future you’re not able to make them yourself. This can include decisions about your finances, property, medical care and lifestyle. This person, called a substitute decision maker, should be someone you trust, who will listen and understand your values and wishes for future care.

Depending on which state or territory you live in, the documents used to appoint a substitute decision maker have different names. These can include an enduring power of attorney, enduring power of guardianship or appointment of enduring guardian.
Advance care directive

Your doctor or another health professional may recommend that you consider making an advance care directive. In some states and territories the advance care directive is referred to as an advance health directive, advance care plan or living will. This document outlines the medical treatment you do or don’t want to have.

An advance care directive can provide you, your family and carers with the opportunity to take control of decisions that affect your care, if at some point in the future you no longer have the capacity to make them yourself.

You can make the advance care directive as simple or as detailed as you like. You can also record any religious or spiritual beliefs that may affect your health care decisions. You need to be an adult and have capacity to make an advance care directive, see box on page 42.

You can make an advance care directive in every state and territory in Australia but the responsibility of representatives can vary from state to state. Keep a copy of your advance care directive for yourself and also give copies to your GP, oncologist, substitute decision maker and solicitor. You can ask your doctor or the hospital to place the directive on your medical record.

For more information read Cancer Council’s *Getting your affairs in order* fact sheet. Legal advice is also recommended. You can start by calling Cancer Council’s legal referral service. This fact sheet or service may not be available in all states and territories, call the Helpline to check.
Planning your funeral

Some people may find planning their own funeral difficult or morbid. However, others may be comforted that it will be carried out according to their wishes and that their family or friends won’t have to guess what they would have wanted. Others think that funerals are for the family, and should be organised by them.

You can lodge a plan with a funeral director of your choice well before it is needed. It may be difficult to do, but you can record in writing your wishes or discuss them with your family. It is probably not easy for most of us to hear or think about the

What to consider

It is a good idea to let others know of your preferences for medical care and that you have prepared an advance care directive.

This document can relieve your family or a friend from the stress of trying to guess what you’d want done.

Without written instructions, family members may feel guilty and confused. In this situation, it’s not uncommon for distressed family members to have disagreements about whether to keep you alive with any means possible or whether to focus on your quality of life.

While you may find it difficult, it is important to talk about the various aspects of your care with your family, for example, dying in comfortable surroundings, and whether you’d like to be resuscitated or put on life support.

Practical concerns
reality of what is involved in funerals. However, there can be a satisfaction in leaving your mark on the occasion, and also involving your family in the planning.

There are no rules so you’re able to personalise your funeral to meet your cultural or spiritual preferences. You may just have a few simple requests for music you want played or poems you’d like to be read, or you may have ideas for the full service.

If you feel you need to make preparations but you can’t do the work, or prefer not to, you may like to talk to a social worker or pastoral care worker who can help you work out what you can do.

To prearrange or prepay a funeral, talk to a funeral director. You can download an online pre-planning information form from the Australian Funeral Directors Association website, www.afda.org.au. It’s important to let your family know of any arrangements you have made. Copies of a pre-paid funeral contract should be provided to members of the family or filed with your will. Payment of the funeral is made once the service is conducted.

I’m planning my funeral to have the music I want. It is the music that has been a special part of my life. I also intend to leave a tape to be played at the service – they haven’t heard the last of me. My two closest friends are going to have something to say about my life – warts and all. I hope my funeral will be a celebration of life. John
Organ donation
Some people with cancer may be able to donate their organs after they’ve died. This will depend on the type and spread of the cancer. After someone dies, a doctor considers the person’s medical history. They then make a decision about whether or not some or all of the person’s organs or tissue are suitable for transplant. Each case needs to be assessed individually, as there are usually restrictions. Even if other organs and tissues can’t be used, almost all people with cancer (except those with certain blood or eye cancers) can donate part of their eyes (corneas).

To donate organs, you need to register with the Australian Organ Donor Register at www.donatelife.gov.au. Share your decision with family as they will be asked to confirm your wishes. Driver’s licences no longer include an organ donation question.

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

Saying goodbye is a personal experience and you need to do what is right for you. When you feel you are ready, consider how you will say goodbye. You might set aside a time to talk to each person individually. Or, if you are physically up to it, you might have a gathering for friends and family. Other ways to say goodbye include writing letters, creating a recording on CD or DVD and
passing along keepsakes. Dying to Know: bringing death to life by Andrew Anastasios lists many suggestions.

If you have children, you may want to write them a letter or make them a recording on a CD, DVD or a camera. You could specify that this is opened at a specific age or time in their life. You (or friends) could also create a slideshow or scrapbook of special photographs. Memory boxes can also be special keepsakes for family. You may find this hard to do but it can be helpful and comforting for children. If your children are very young, they’ll understand your words and sentiments when they’re older.

Making arrangements for the important parts of your life can help you talk about death with family and friends. It can also give you a sense of control and relief that things that mean something to you will be looked after in the future.
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 what you can do to provide comfort and support.

- You may need to provide support with physical, emotional and practical issues. Services are available to help.

- It’s natural to feel like you don’t know what to say. Often all that is required is sitting with the person who is dying, and letting them talk, if they’d like to.

- After the death you may need to deal with practical matters, such as organising the funeral and administering the will.
Caring for someone nearing the end of life

Looking after a person who is dying can be stressful, and you will need help and support. It is common to feel like you don’t know what to do, what to say and how to cope.

As a person nears the end of life, you may not know what to expect. It’s common for people to have little practical experience of death and dying. If you’ve never seen anyone die before, you may be afraid of what will happen. For many family members and friends, often called carers, anticipating what is going to happen helps them feel less frightened and confused, and allows them to prepare for the emotional and physical changes ahead. This chapter covers ways to deal with the dying process.

Caring can be physically and emotionally hard work. Cancer Council’s *Caring for Someone with Cancer* booklet has many suggestions on how you can look after yourself during this time. Call 13 11 20 for a copy or download it from your local website.

Providing practical support

Many people worry about how they’ll manage with the day-to-day tasks of looking after someone. This might include showering, toileting and getting them safely in and out of bed. Some of these tasks can be performed by someone else and can help reduce your stress and free you up to spend quality time with the person you’re caring for (see table opposite). You may find providing personal care awkward or embarrassing, especially at first, but most carers say they get used to it. Some carers find their loved one prefers receiving personal care from somebody they don’t know well.
Who can help

<table>
<thead>
<tr>
<th>Who can help</th>
<th>Description</th>
</tr>
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<tr>
<td>Community nurses</td>
<td>provide hands-on nursing care and practical assistance</td>
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<tr>
<td>Occupational therapist or</td>
<td>help make the physical aspects of daily activities easier for the carer by</td>
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<tr>
<td>physiotherapist</td>
<td>organising equipment</td>
</tr>
<tr>
<td>Palliative care team</td>
<td>help the carer maintain quality of life for person they’re looking after</td>
</tr>
<tr>
<td>Social worker</td>
<td>connect you with support services which can help with shopping and cooking</td>
</tr>
<tr>
<td></td>
<td>or personal care</td>
</tr>
<tr>
<td>Pastoral carer</td>
<td>supports you in talking about any spiritual matters</td>
</tr>
<tr>
<td>Home nursing services</td>
<td>provide nursing care and support</td>
</tr>
<tr>
<td>GP</td>
<td>advises on the person’s day-to-day care</td>
</tr>
</tbody>
</table>

How you can help

There are many things that family and friends can do to help support their loved one. For many people who are dying, it is important for them to get their affairs in order, such as organising paperwork or a will. This can help them express their choices and feel like they’ve given closure to their life. Family and friends can often help their loved one gather together important documents or consider choices about their future health care. Assistance can also be offered for the tasks on the next page.
Meal preparation
Preparing meals for someone who is sick can be stressful. Try cooking simple foods or mashing food up so it’s easier to swallow. As the disease progresses, the person may lose their appetite and not be able to eat or drink. At this time, it’s important to not force them to eat.

Managing medications
If you need to give medications and feel overwhelmed, ask your doctor for some suggestions. The *Caring for Someone with Cancer* booklet also provides answers to key questions carers have about medications. You can also ask a pharmacist or community or palliative care nurses for more information.

Bathing and washing
If the person you are caring for can’t move around easily, you may have to sponge bathe them or wash their hair over a basin.

Toileting
You may have to help them get on and off the toilet or commode, help them use toileting equipment in bed such as urine bottles or bed pans, and sometimes help them to wipe themselves. Lifting someone is hard work and you may need help with this, either from another person or mobility aids or equipment.

Getting in and out of bed
It’s common for a person to spend more time in bed. You may need to help them get in and out of bed, roll them over regularly so they don’t get bedsores or lift them to change the sheets. You can use equipment to help with lifting. Many people create space in the living room for the bed; particularly if bedrooms are located upstairs. The palliative care team can help with providing this care.
Providing emotional support

The diagnosis of a terminal illness may create a crisis situation for family and friends. How everyone responds may depend on the relationship with the person dying, whether they are your partner, parent, child or friend, and everyone’s beliefs about death. At first, it’s natural to feel shocked, angry, scared, sad or relieved.

You may be scared of talking about the end of life with your loved one because you think you’ll upset them. It may help to know that often people who are dying want to talk about what is happening but are afraid the topic will upset you – their carer, family member or friend. Starting the conversation can be difficult but the opportunity to share feelings can be valuable for both of you.

As the person you are caring for nears the final days of life, there are still many ways to share time together: you can read a book; sing a song; talk about what you’ve been doing or about the weather; share some special memory or experiences you’ve shared together; or tell them that you love them and that family send their love. Conversation may feel difficult sometimes because it may be hard to keep going when there is no visible response. You may find it challenging to keep talking but don’t want to leave the person alone. See the I don’t know what to say table on the next page for suggestions.

You may find yourself wishing for their life to be over. You may find yourself thinking about yourself – other events in your life, the funeral, etc. All these responses are natural and okay.
I don’t know what to say

People often wonder what they should say. It’s understandable to feel tongue-tied – what you feel might be so complex that it’s hard to find the right words, or any words at all. It is common to worry about saying the wrong thing.

You may want to say something that would help them cope but don’t know what that is. It’s usually better to say something than pretend that nothing is wrong. Someone who is dying probably appreciates knowing that family and friends are thinking of them. Even if you feel you’re not doing anything, your presence sends the message that you care.

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

- Listen to what the person 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 pastoral care worker, offer to put them in touch.

- 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 alive and still a part of your life. Tell them what’s happening at work or at home, talk about films you’ve seen, programmes you’ve watched on TV, or books you’ve read.

- Avoid talking with an overly optimistic attitude, i.e. “You’ll be up in no time”. Such comments block the possibility of discussing how they’re really feeling – about their anger, their fears, faith, etc.
• 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 that you don’t know what to say.

• Ask questions. Depending how comfortable you feel asking direct questions and their willingness to talk, you may ask, “Are you frightened of dying?” or you may prefer a softer approach, “I wonder whether there’s something you want to talk about?”

• Just be there. You don’t need to talk all the time, sometimes it’s the companionship that is most appreciated – sit together and watch television or read.

• 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.

• Try not to be embarrassed if you or the person dying cries. This is a natural response to a distressing situation.

• Even if they’ve shown no religious interest in the past, that could change as death approaches, so you could offer to pray together.

• Try to be with the person during the final days or hours, if that is what you both want. Dying can be a lonely experience, and even though you might find it hard to cope with, the experience may be harder for them to face alone.
Saying goodbye

A life-limiting illness offers you time to say goodbye. You can encourage your loved one to share their feelings, as you share your own. Sharing how you both feel can start important conversations, which 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 documenting their life or writing letters to loved ones. They may want to visit a special place or contact someone with whom they’ve lost touch. These tasks are all things you can help them do. These are all part of the process of saying goodbye, for all of you.

Keeping vigil

For many people, staying with the dying person is a way to show support and love. This is called keeping a vigil. It also ensures the dying person doesn’t die alone.

You may find it comforting to spend time sitting with your loved one, perhaps holding hands. Hearing is said to be the last sense to go, so you may want to talk, read aloud, sing or play music.

“When my dad was dying, I sat beside his bed for hours and held his hand. I didn’t know what to say so sometimes I read the newspaper to him and at other times I talked about the things we did together when I was a kid.” — Chloe
Your cultural or spiritual traditions may require someone to be present, and this may also be a good time to perform any rituals.

Some people find keeping vigil exhausting. It’s easy to forget about your needs while in this situation. Plan to take breaks or, if you want to keep close by, organise shifts with other family members and friends. This is a good time to eat a nutritious meal, have a nap or even go for a walk. You can use a baby monitor so you can hear from another room, if you feel it necessary.

Sometimes people worry that leaving the room could mean missing the moment of death, and they would carry a sense of guilt or regret about this. However, many times people seem to wait to be alone before they die.

Providing physical support
When a person is dying, carers often have lots of questions: Can they hear me? Are they in pain? What can I do to make this easier?

There will probably be gradual changes. The not-so-good days will become more common. Some people are able to continue with their activities, others find they have to pace themselves or spend more time at home.

You do not need to deal with these changes alone. Palliative care professionals specialise in helping people with cancer and their families with end-of-life care. They can help with providing physical, emotional, and practical comfort. To find out more, call 13 11 20.
Changes that occur before death

Some family and friends may prefer more detailed information about the physical process of dying. If this is the case, you may want to keep reading about the changes that occur.

Each death is unique, but as a person nears the final weeks of life they often show common signs. In medical terms the dying process is viewed as the body’s systems closing down.

**Loss of appetite** – The body needs less energy to keep going and appetite decreases. The person may begin to resist or refuse meals or liquids, and weight loss can occur.

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

**Disorientation and confusion** – The person may not be aware of where they are or who else is in the room, may speak or reply less often, may respond to people who can’t be seen in the room by others. The person may be drifting in and out of consciousness and possibly entering a coma.

**Breathing changes** – Breath intakes and exhalations become rattly, irregular and laboured. You may hear a pattern of breathing known as Cheyne-Stokes: a loud, deep inhalation followed by a pause of not breathing for between five seconds to as long as a minute, before a loud, deep breath resumes and again slowly fades out. Sometimes excessive secretions create loud, gurgling inhalations and exhalations, which some people call a ‘death rattle’.
**Little interest in the outside world** – The dying person may gradually lose interest in those nearby. They may find it hard to concentrate and stop talking. Withdrawing is an aspect of letting go. Near the end, some people can, however, have an unexpected burst of alert behaviour.

**Changes in urination** – As the person eats and drinks less, they will produce less urine. Loss of bladder and bowel control may happen in the last stages of the dying process.

**Restless moving, groaning, calling out, twitching or jerking of the body** – These symptoms are often known as terminal restlessness. They occur as waste chemicals (toxins) build up in the brain, and can often be controlled with medications.

**Cool skin, especially the hands and feet** – As circulation slows down the hands, feet, fingers, toes (the extremities) become cooler and turn a bluish colour.

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

It can be upsetting to watch someone go through these physical changes. It may help to know that they are part of the dying process, and don’t mean that the person is distressed or uncomfortable.
What you can do

If you are providing care at home, ask for help from the palliative care team, district nursing service or other organisations (see page 72). If you’re using hospice care, the staff will show you how to provide general care and comfort. If the person is in a hospital, nursing home or other facility, ask the staff how family members or friends can be involved.

- Use soft lighting.
- Don’t force-feed even though you may be distressed by their loss of interest in eating.
- Make the bed and chairs more comfortable with cushions.
- Help the person change positions frequently.
- Apply lip balm to dry lips.
- Keep the mouth moist with ice cubes.
- Use a vaporizer in the room.
- Speak gently and occasionally remind the person of the time, place and who is there with them.
- Gently massage their hands or feet with a non alcohol-based lotion.
- Sit with the person and talk or hold their hand. Often just being with a loved one is all that is needed so that they don’t feel alone.
- Play their favourite music in the background to create a gentle and peaceful atmosphere.
- Quietly read a favourite poem, passage from a book or spiritual or religious text.
- Add bed pads under sheets.
- Keep the person warm with a blanket. If they complain about the weight of the covers on their legs, keep the blankets loose.
As death approaches you may want to consider the following.

- Ask your doctor or other health professionals who to contact if complications arise at home. Your first reaction might be to call an ambulance, but keep in mind that an ambulance officer’s duty of care means they have to resuscitate. If this is something the person you are caring for would prefer didn’t happen, it’s worth thinking about other options.

- Find out what the person would like done with their body after they die. Some people have strong views about whether they want to be buried or cremated, what sort of ceremony they want, and what type of memorial they would like.

- Make a list of people that the person you are caring for would like to have visit in the final weeks.

- Notify the chosen funeral home that a death is expected soon.

- Speak to health professionals or palliative care staff about what to expect as death gets closer.

- Think about who should be present at the time of death.

- Decide whether a clergy member or other spiritual leader should be at the bedside and what rituals or ceremonies are important to perform.

- Ask a friend or relative to help let people know after death occurs.

- Look into closing any social media accounts, such as Facebook and Twitter. Contact them directly for more details.
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, before passing away. Others appear to wait until their family or friends have left the room – even for a short period – before they die.

It can be difficult if you’ve been sitting with your loved one 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’s a fairly common occurrence.

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. I believe he didn’t want to die with everyone in the room with him, it was nearly like he was looking after us. — Judith

What happens at death

No one really knows what death feels like, but we know what death looks like from those who have nursed a dying relative or friend. The moment of death is commonly described as being peaceful. Many carers say it was a profoundly moving experience and it felt like a privilege to be there. The memory of the final moments of your loved one are likely to stay with you for a long time. Knowing the wishes of your loved one, and working with the health professionals to help achieve them, can mean that the death is described as a ‘good death’. See page 31 for more information.
After the death

Even when death is expected, it’s common to feel shocked. A natural death is not an emergency, and what you need to do depends on the circumstances.

What to do after the death

If death occurs at home, your instinct might be to call an ambulance or the police, but there is no need to do anything straightaway. You can take some time to sit with your loved one. Some people may not want to be alone, so you may want to call a friend or family member. If the person dies during the night, many people wait until the morning to take further action.

When you feel ready, call the person’s doctor and a funeral home. The doctor will sign a certificate confirming the death. This is needed to make funeral arrangements, and the funeral director can lodge the death certificate with the Registrar of Births, Deaths and Marriages. There is no need to call an ambulance or the police.

If the death occurs in a hospice (or a hospital or aged care facility), there’s usually no need to rush. You can have time alone with your loved one 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.

A number of organisations will need to be told of the death. The Department of Human Services has a useful checklist of people and organisations that may need to be notified. Download this from their website, www.humanservices.gov.au.
**Funeral and religious services**

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

The executor of the will or a family member usually arranges the funeral. If the person has a pre-paid funeral plan, it will usually include details of what they wanted and also which funeral director to use, otherwise you will need to choose. Funeral directors can organise the service, newspaper notices and flowers, and help with many of the legal responsibilities such as registering the death.

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

> Judith

You may know the person's wishes for their funeral or you may need to decide this. One important decision is what the person wanted to happen with their body after death. Knowing what someone would like done with their body after they die can be helpful during the stressful time after their death. Try and have this conversation early on, as some people have strong views about whether they want to be buried or cremated, what sort of ceremony they want, and what type of memorial they would like.
It can be difficult and stressful to make these decisions, especially as other family members may have different ideas about what should happen.

To select a funeral director who is an accredited member of the Australian Funeral Directors Association, visit www.afda.org.au or call 1300 888 188.

**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.

**Financial matters**

You may be eligible for financial assistance after a loved one has died. The Department of Human Services provides a number of payments and services to the spouse, partner or children. Check to see if you’re eligible for a bereavement allowance or payment, double orphan pension, widow allowance or pension bonus bereavement payment at www.humanservices.gov.au.

Cancer Council has several online fact sheets that cover questions about what happens to the superannuation, income, assets or unpaid debts of someone who has died. They are not available in all states and territories, call the Helpine on 13 11 20 to enquire.
Grief

Grief is a natural response to losing someone you love. It can be both a physical and emotional response. The feelings you may experience include sadness, numbness, disbelief, loneliness, and even guilt, anger, relief and acceptance. You might have trouble sleeping, cry a lot or have difficulty crying, lose your appetite, or not be interested in your usual activities.

Many people say grief comes in waves. There’s no right or wrong way to grieve. Everyone mourns in different ways. Sometimes it’s according to religious or spiritual practices but it can also be more personal. Sometimes there is a feeling of relief that your family member or friend is no longer suffering.

How long you experience grief is different for each person. There is no set time, though you might feel pressure from yourself or others to get over it and get on with life. It has been said that time heals all wounds. Many who have lost a family member or friend might disagree. Sometimes you might feel yourself ‘coming good’ and then swiftly go downhill again for a while. Time may help you adapt to the loss, but it may never be completely gone.

For others, feelings of grief don’t seem to improve over time. If you’re concerned that your grief is stopping you from living your life, you may want to talk to a professional. There are several professionals and services available to help people come to terms with their loss and move at their own pace towards a sense of acceptance, see page 71. Call 13 11 20 for printed information on coping with grief.
Remembering your loved one

You may want to do something special to acknowledge and honour the life of your family member or friend after they’ve died. This can help some people cope with the loss.

There are many ways you can remember your loved one, the following are some suggestions to consider:

- plant a special tree or flower
- place a memorial plaque in a favourite place
- create an online memorial page with photos and stories
- make a contribution to their preferred charity or community group
- display a photo of your loved one
- light a candle
- frame a cherished note or other memento
- cook their favourite meal on their birthday
Support services and organisations are available to help throughout the process of dying.

**Carer services**

<table>
<thead>
<tr>
<th>Service</th>
<th>Contact Information</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td><strong>Carers Australia</strong></td>
<td>1800 242 636, <a href="http://www.carersaustralia.com.au">www.carersaustralia.com.au</a></td>
<td>National body representing Australia’s carers, which can direct you to your state or territory carer association.</td>
</tr>
<tr>
<td><strong>National Carer Counselling Program (NCCP)</strong></td>
<td>1800 242 636</td>
<td>Offers short-term counselling for carers. The NCCP service is run by your local carers association.</td>
</tr>
<tr>
<td><strong>Young Carers</strong></td>
<td>1800 242 636, <a href="http://www.youngcarers.net.au">www.youngcarers.net.au</a></td>
<td>Supports young people who are caring for a parent who is physically or mentally ill. They run support programs and provide information. You can access the Young Carers association in your state from this site.</td>
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</table>

**Counselling and mentoring**

<table>
<thead>
<tr>
<th>Service</th>
<th>Contact Information</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>beyondblue</strong></td>
<td>1300 22 4636, <a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a></td>
<td>Offers 24-hour telephone counselling service. Online and email counselling available 7 days a week.</td>
</tr>
</tbody>
</table>
| **Dying Matters**  
www.dyingmatters.org | UK coalition that aims to raise awareness of dying, death and bereavement. |
| **The GroundSwell Project**  
www.thegroundswellproject.com | Community organisation using creativity to promote resilience and wellbeing through all phases of life. |
| **Kids Helpline**  
1800 55 1800  
| **Lifeline**  
13 11 14  
www.lifeline.org.au | A 24-hour telephone crisis support and suicide prevention service. |
| **LifeCircle***  
www.lifecircle.org.au | Provides support, guidance and information by matching you to a trained volunteer mentor. |
| *not available in all states and territories |
| **MensLine Australia**  
1300 78 99 78  
www.mensline.org.au | Telephone and online support and referral service for men with family and relationship concerns. |
| **Cancer Council’s Peer Support Programs**  
13 11 20 | Community of people affected by cancer that you can connect with online, by phone or in person. |
### Equipment and aids

**Independent Living Centres Australia**  
1300 885 886  
www.ilcaustralia.org.au  
Offers advice on a range of products and services to help with aspects of day-to-day living, including mobility, sleeping, eating and transport.

### Financial assistance

**Centrelink**  
13 27 17  
www.humanservices.gov.au  
Offers financial support for people with a long-term illness and for primary carers.

**Financial Counselling Australia**  
1800 007 007  
www.financialcounsellingaustralia.org.au  
Information about financial counselling and help to find a qualified counsellor.

### Funerals

**Australian Funeral Directors Association**  
1300 888 188 or 03 9859 9966  
www.afda.org.au  
Provides a listing of funeral directors and estimates of funeral costs. It also has information on pre-paying or planning a funeral.

**Professional Funeral Celebrants Association of Australia**  
www.funeralcelebrants.org.au  
Includes a directory for finding a funeral celebrant in your local area.
## Future planning

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td><strong>Advance Care Planning</strong></td>
<td>Includes documents you can use to prepare advance care directives and plans.</td>
</tr>
<tr>
<td><a href="http://www.advancecareplanning.org.au">www.advancecareplanning.org.au</a></td>
<td></td>
</tr>
<tr>
<td><strong>Public Trustees Australia</strong></td>
<td>Gateway for all public and state trustees in Australia.</td>
</tr>
<tr>
<td><a href="http://www.publictrusteesaustralia.com">www.publictrusteesaustralia.com</a></td>
<td></td>
</tr>
<tr>
<td><strong>WrappingUp.com</strong></td>
<td>Social networking website for people seeking support for bereavement, grief and estate planning.</td>
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<tr>
<td><a href="http://www.wrappingup.com">www.wrappingup.com</a></td>
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## Grief

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Australian Centre for Grief and Bereavement</strong> 1300 664 786 <a href="http://www.grief.org.au">www.grief.org.au</a></td>
<td>Information and referral service for people experiencing grief.</td>
</tr>
<tr>
<td><strong>GriefLink</strong></td>
<td>Web-based information for the bereaved and grieving, their carers, friends, colleagues.</td>
</tr>
<tr>
<td><a href="http://grieflink.org.au">http://grieflink.org.au</a></td>
<td></td>
</tr>
<tr>
<td><strong>GriefLine</strong></td>
<td>Provides community and family services to support all Australians who have encountered a loss.</td>
</tr>
<tr>
<td>1300 845 745 <a href="http://www.griefline.org.au">www.griefline.org.au</a></td>
<td></td>
</tr>
<tr>
<td><strong>National Association for Loss and Grief</strong> <a href="http://www.nalag.org.au">www.nalag.org.au</a></td>
<td>24-hour telephone support service to help those dealing with loss.</td>
</tr>
</tbody>
</table>
### Home help

| Call your local council or speak to your palliative care team | Some local councils provide a range of community and in-home services, such as Meals on Wheels or respite care. If you have a palliative care team, they can organise home help for you. |

### Home nursing

| Talk to your palliative care team and/or your private health fund | Home nursing can be organised as part of your palliative care. Private services are also available. |

### Legal advice and information

| Cancer Council Legal Referral Service*  
13 11 20 | Supports people affected by cancer needing legal advice. Available in some states and territories.  
*not available in all states and territories |

### Pastoral care

| Contact your hospital | Most large hospitals have a pastoral worker who can talk to you about practical and spiritual concerns (from all religious and non-religious viewpoints). |
### Palliative care

<table>
<thead>
<tr>
<th>Palliative Care Australia</th>
<th>Provides information and resources and can link you to your local palliative care office.</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.palliativecare.org.au">www.palliativecare.org.au</a></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>CareSearch</th>
<th>Online palliative care information, services and evidence for patients and families provided as part of the National Palliative Care Program.</th>
</tr>
</thead>
</table>

### Support groups

<table>
<thead>
<tr>
<th>Face-to-face groups</th>
<th>Meeting with others who understand what it is like to have cancer can be helpful. You may be reluctant to share your story or listen to other people’s, but many people find that they benefit from the close bonds with others.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Council Helpline 13 11 20</td>
<td>Contact your hospital social worker to see if they run any support groups.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Telephone support groups</th>
<th>There are groups for advanced cancer and carers.</th>
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</thead>
<tbody>
<tr>
<td>Cancer Council Helpline 13 11 20</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Online discussion forums</th>
<th>People can connect with each other at any time, ask or answer questions or write a blog of their experiences.</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.talkbloodcancer.com">www.talkbloodcancer.com</a></td>
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</tbody>
</table>
advance care directive
A written document intended to apply to a point in the future when you don’t have the capacity to make decisions. It provides a legal means for a competent adult to appoint a substitute decision maker and/or record their choices for future medical and personal care.

advanced cancer
Cancer that has spread deeply into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured.

capacity
Having the ability to understand and think things through.

carer
A person who provides physical and/or emotional support to someone who is ill or living with a disability such as cancer.

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

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

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

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

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

hospice
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 die at home.

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

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

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

morphine
A strong and effective pain reliever 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, spiritual, social and practical needs.

**palliative care nurse**
A nurse who specialises in the field of palliative care and is experienced in helping patients, families and carers with end-of-life care.

**palliative care specialist (physician)**
A doctor who has specialised in the field of palliative medicine, prescribing medical treatment for pain and other symptoms, as well as supporting and advising the other members of the palliative care team, the patient, family and carers.

**palliative treatment**
Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms of cancer.

**power of attorney**
The ability for a person to act on behalf of another on financial and legal matters.

**prognosis**
The likely outcome of someone'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 illness.

**relapse**
The return of a disease after a period of improvement.

**resuscitation**
The process of reviving someone who appears to be dead, for example by heart massage or artificial respiration.

**secondary cancer**
Cancer that has spread from the original site to another part of the body. Also called a metastasis.

**secretion**
The release of a substance.

**substitute decision maker**
A person who makes decisions on your behalf if you become incapable of making them yourself. Documents used to make a substitute decision maker may be called enduring power of attorney, enduring power of guardianship or appointment of enduring guardian.

**terminal illness**
An illness that is unlikely to be cured and will result in a person's death some time in the future. It may also be called a life-limiting illness.
How you can help

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

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

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

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

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

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

To find out more about how you, your family and friends can help, please call your local Cancer Council.
Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk about any concerns confidentially with oncology health professionals. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

Regional offices

<table>
<thead>
<tr>
<th>Central and Southern Sydney</th>
<th>North Sydney</th>
<th>Western</th>
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<tbody>
<tr>
<td>Woolloomooloo</td>
<td>Crows Nest</td>
<td>Wagga Wagga</td>
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<tr>
<td>02 9334 1900</td>
<td>02 9334 1600</td>
<td>02 6937 2600</td>
</tr>
<tr>
<td>Hunter and Central Coast</td>
<td>Northern</td>
<td>Western Sydney</td>
</tr>
<tr>
<td>Charlestown</td>
<td>Byron Bay</td>
<td>Parramatta</td>
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<tr>
<td>02 4923 0700</td>
<td>02 6639 1300</td>
<td>02 9354 2000</td>
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<tr>
<td>Southern</td>
<td>Southen</td>
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<td>North Wollongong</td>
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<td>02 4223 0200</td>
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</tbody>
</table>

References


Halpern, SP 2004, *The etiquette of illness: what to say when you can’t find the words*, Bloomsbury, New York.
For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancercouncil.com.au