



# Living with Advanced Cancer

A guide for people with cancer,  
their families and friends

Practical  
and support  
information

For information & support, call

**13 11 20**



## **Living with Advanced Cancer**

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### **Note to reader**

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

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

### **Cancer Council**

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



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# Introduction

This booklet is for people who have advanced cancer. This means the cancer has spread from the original (primary) site or has come back (recurred).

Health professionals use several terms to describe cancer that has moved beyond early stages, including secondary, metastatic, advanced and progressive cancer. Sometimes health professionals don't use a particular name. In this booklet, we use the term 'advanced cancer'. Regardless of the words used, it's confronting to hear that the cancer has spread or come back.

This booklet offers general information about advanced cancer: what it is, how it is treated, what might happen and what support is available. There is also information for the family and friends of people who have advanced cancer. You may find reading about advanced cancer distressing – read what seems useful now and leave the rest until you're ready.

## How this booklet was developed

This information booklet was developed with help from medical and health professionals and people who have been diagnosed with advanced cancer.

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



**Cancer  
Council  
13 11 20**

# Contents

<b>What is advanced cancer? .....</b>	<b>4</b>
<b>Key questions .....</b>	<b>6</b>
What happens now? .....	6
What treatments are available? .....	6
Who will coordinate my treatment? .....	7
How will advanced cancer affect my day-to-day life? .....	7
Will palliative care help? .....	8
How long have I got? .....	9
How do I find hope? .....	10
<b>The emotional impact .....</b>	<b>12</b>
First reactions .....	12
Coping with advanced cancer .....	14
The effect on people close to you .....	18
<b>Talking with family and friends .....</b>	<b>20</b>
Partners .....	20
Parents .....	23
Friends .....	23
Children .....	24
How to talk to your children, family and friends .....	26
When you don't want to talk .....	28
<b>Making treatment decisions .....</b>	<b>29</b>
When treatment seems too much .....	30
Talking with doctors .....	31
A second opinion .....	31
Taking part in a clinical trial .....	32

<b>Treatment for advanced cancer .....</b>	<b>33</b>
Chemotherapy .....	35
Surgery .....	35
Radiotherapy .....	36
Hormone therapy .....	36
Targeted therapy.....	37
Immunotherapy .....	37
Palliative care .....	38
Rehabilitation.....	40
Complementary and alternative therapies .....	40
<b>Managing symptoms.....</b>	<b>44</b>
Pain .....	44
Feeling sick.....	47
Loss of appetite.....	50
Shortness of breath.....	51
Fatigue.....	52
<b>Planning ahead .....</b>	<b>54</b>
Advance care planning.....	55
Preparing legal documents .....	57
Dealing with bills and debts .....	59
Planning your funeral.....	60
<b>Information for carers .....</b>	<b>63</b>
Emotional concerns.....	64
Practical concerns.....	68
Physical concerns .....	70
<b>Support and information.....</b>	<b>71</b>
<b>Useful websites .....</b>	<b>75</b>
<b>Question checklist.....</b>	<b>76</b>
<b>Glossary .....</b>	<b>77</b>



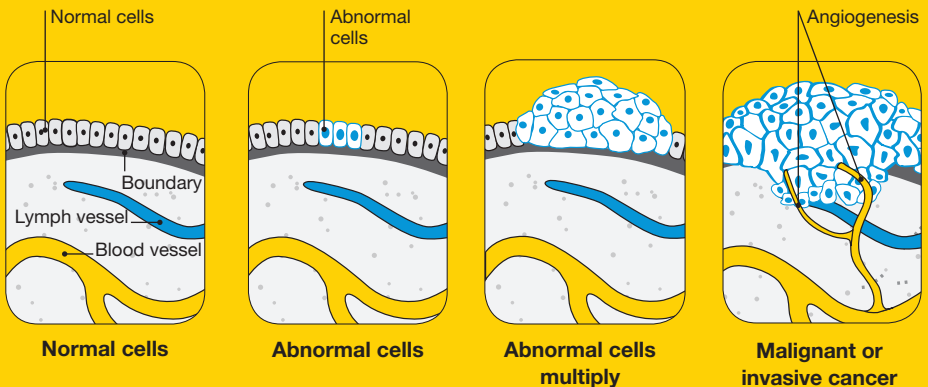
# What is advanced cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. It occurs when abnormal cells divide and multiply in an uncontrolled way. There are many types of cancer and each type develops differently. Some grow slowly, some advance rapidly, and others behave unpredictably. Some types of cancer respond well to treatment, while other types are more difficult to treat.

Advanced cancer is a term used to describe cancer that is unlikely to be cured. It may be primary or secondary cancer.

Primary cancer refers to the first mass of cancer cells (tumour) in an organ or tissue. The tumour is confined to its original site, such as the bowel. This is called cancer in situ, carcinoma in situ or localised cancer.

## How cancer starts



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

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

## How cancer spreads

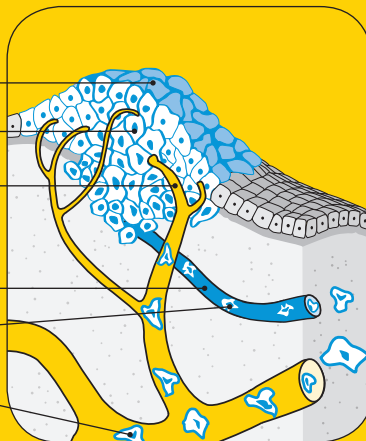
Primary cancer

Local invasion

Angiogenesis –  
tumours grow their  
own blood vessels

Lymph vessel

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





## Key questions

### **Q: What happens now?**

**A:** Some people's cancer may be advanced when they are first diagnosed. For others, the cancer may spread or come back (recur) after initial treatment.

Advanced cancer usually can't be cured, but it can often be controlled. For some people, improved treatments can help manage the cancer and relieve side effects, allowing people to live for a long time – sometimes for years – with a good quality of life. In this case, the cancer may be considered a chronic (long-lasting) disease.

### **Q: What treatments are available?**

**A:** This will depend on the aim of treatment – whether it's to try to cure the cancer, keep the cancer from spreading, or to control symptoms. Treatment will depend on where the cancer started, how far it has spread, your general health and preferences. The most common treatments include chemotherapy, radiotherapy, surgery, targeted therapy, hormone therapy, immunotherapy, or a combination of these. Sometimes, treatment is available through clinical trials.

Treatments can be used for different reasons, so talk to your doctor about the aim of each treatment. As the cancer progresses, the aim may change from trying to cure the cancer, to controlling the cancer, to relieving symptoms and improving quality of life. For further details, see the *Treatment for advanced cancer* chapter on pages 33–43.



## Q: Who will coordinate my treatment?

**A:** If you have many health professionals caring for you (also referred to as a multidisciplinary team), it can help to know who is coordinating your care. This may be your general practitioner (GP), your palliative care team, the oncologist, a care coordinator, or another member of the treatment team. See page 34 for more information.

## Q: How will advanced cancer affect my day-to-day life?

**A:** Cancer affects people's lives in different ways. You may be able to continue your usual routines for some time. If you work, you may need to take time off or stop work altogether.

Treatment or other services can be expensive and may affect your finances. This can add to concerns you may have, such as negotiating leave from work or getting financial assistance.

The cancer or treatment may cause various symptoms, such as nausea, fatigue or breathlessness. These may impact on what you can comfortably do and on your sense of independence. See the *Managing symptoms* chapter on pages 44–53.

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

There can be practical issues you may have to think about to make life more comfortable, such as medical equipment, alterations to your home, or home help. If the hospital is a long distance from your home, you may require transport or accommodation, especially if there are times when you are in and out of hospital.

You may also experience emotional changes from the cancer and its treatment – for example, some hormonal treatments affect people's emotions. Changes to your work, finances and health may also result in mood changes.

## **Q: Will palliative care help?**

**A:** Palliative care is an approach that allows people with advanced cancer to maintain their quality of life in a way that is meaningful to them. It treats physical, practical, emotional or spiritual symptoms. Palliative care involves a range of services offered by medical, nursing and allied health professionals, as well as volunteers and carers.

While some people delay or feel anxious about accessing palliative care because they believe it's only offered to people close to death, this type of care can improve quality of life from the time of diagnosis. It can be used for only a few weeks or months, but the number of people receiving palliative care for several years is increasing. Palliative care can also provide support for families and carers. For more information, see pages 38–39.

## Q: How long have I got?

**A:** After a diagnosis of advanced cancer, some people want to know how long they have left to live, while others prefer not to know. It's a very personal decision.

If you would like to know the expected outcome (prognosis) of the cancer, you will need to talk to your doctor. This is a difficult question for doctors to answer and you may find their response is vague. They may give you an estimate based on what usually happens to people in your situation, but can't say exactly what will happen to you. The actual time could be longer or shorter.

Not all people with advanced cancer die from it – for some people, improved treatments can keep the disease under control for months or years. For other people, different health issues become more serious than the cancer.

When faced with the possibility of dying, some people think about what they'd like to achieve in the time they have left. They may begin to live day by day, or take control of their life by completing practical tasks, such as preparing a will or the funeral. For further details, see the *Planning ahead* chapter on pages 54–62.

If you have questions about dying, call Cancer Council for a free copy of *Facing End of Life: A guide for people dying with cancer, their family and friends*, or download a digital version from your local Cancer Council website.

## Q: How do I find hope?

**A:** If you have been told you have advanced cancer and it is unlikely to be cured, you may find it hard to feel hopeful.

What you hope for may change with time. Sometimes, you may hope for good days with understanding company or the love of family and friends. You may find yourself hoping you will maintain your sense of independence or stay pain-free. Some people explore activities they've never tried before and find hope in this new aspect of their lives. Others find hope in small projects, such as completing a scrapbook of their life or planning a trip with their family.

“ If I think of myself as a person who is dying of cancer, then what lies ahead is a hopeless end. If I think of myself as a person who is living with cancer, then my daily life is an endless hope. ” *Roberta*

While the cancer and its treatment can limit your activities, some people discover new strengths in themselves, and this gives them hope.

For some people, faith or spiritual beliefs can help them get through tough times. People who find hope in these beliefs describe feelings of optimism that are hard to explain to others. Cancer can also test people's beliefs. Either way, you may find it helpful to talk to your spiritual or religious adviser, if you have one.



## Agnes's story

It was over 20 years ago after my first diagnosis, when the doctors discovered active cancer cells throughout my body, including my lymph nodes and lungs. I had an operation to try to remove cancer from my lungs, but it was too advanced and they couldn't get it all.

The doctors told me that the cancer was terminal and I had six months left to live. But that was more than 10 years ago, and I'm still here. I feel like I have had cancer for a lifetime: 29 years.

I only found out about palliative care a few years ago. For me, this made such a positive difference – I now have equipment such as a walking frame, wheelchair, shower seat and toilet seat.

My palliative care nurses visit me at home twice a week and also call a lot to check on me.

I have been in hospital many times, but I have been able to stay at home as much as my health has allowed. Being near my family is the most important thing to me.

The love I have for my children, and the desire to see them grow up, marry and have kids of their own, has kept me going. I credit them as the reason I've lived with advanced cancer for so long.

My advice for someone with advanced cancer is to be strong. Don't be afraid – what will be, will be. Have friends and family around to help provide the support you need. Get all the help you can from government and palliative care services.

You need the will, guts and knowledge to make the most of your time. To me, advanced cancer is just a sickness. I don't feel that I'm going to die today. I just take each day as it is, and try to maintain a strong will to live.



# The emotional impact


Being diagnosed with advanced cancer or finding out the cancer has returned or spread can feel overwhelming. It is often difficult to take in the news immediately.

## First reactions

When you are first told, or come to realise, that you have advanced cancer, you may feel a range of emotions.

If you didn't know you had cancer at all, a diagnosis of advanced cancer can sometimes feel like a double blow. And if you've already been treated for cancer, you may experience different, possibly stronger reactions than when you heard for the first time that you had cancer.

Sometimes people feel relieved; you may have suspected something was wrong and now you know what it is. A diagnosis of cancer can also lead people to question their values and priorities, as well as the meaning of their life. There is no right or wrong way to react when you are told your cancer is too advanced to cure. Everyone responds in their own way. Give yourself time to take in what is happening.

“When I heard the word cancer, my mind went completely blank. I was crying so hard I didn't hear a word the doctor said after that. After a few days I started to think more clearly again.”  *Roberta*

## Feelings you may experience

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<b>denial</b>	An advanced cancer diagnosis can be hard to accept. Denial can give you time to adjust, but it can also delay you from getting treatment or help.
<b>fear or anxiety</b>	It is frightening to hear the cancer has come back, has spread or is at an advanced stage to begin with. Fear or anxiety (a feeling of worry or unease) may occur from the shock of diagnosis or having thoughts about dying.
<b>anger</b>	You may feel angry because you've had to deal with cancer already or because you weren't diagnosed earlier. Sometimes it may even be difficult to pinpoint exactly what your anger is about.
<b>guilt</b>	It's common to blame yourself for the cancer, but the reason cancer spreads or doesn't respond to treatment is usually unknown. You may be worried about the impact cancer could have on your family or feel guilty that they may have to take care of you.
<b>uncertainty</b>	You may feel you have less control over your life. It can be hard to adjust to an uncertain future, although some people may also feel a sense of hope in the uncertainty.
<b>loneliness</b>	You may feel lonely at times even if you have people around you. It's natural to think nobody understands what you're going through. Your family and friends may have trouble dealing with the diagnosis and some may even distance themselves from you.
<b>sadness or depression</b>	Feeling sad after a cancer diagnosis is common. If you feel continually sad or down for two or more weeks and are not enjoying or interested in your usual activities, or are unmotivated, talk to your doctor – you may be experiencing depression.

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## Coping with advanced cancer

Having advanced cancer often means living with uncertainty. This can be challenging, and you may cycle through various emotions.

After the initial shock of the diagnosis, some people say they avoid thinking about what the future may hold by keeping busy or distracting themselves from their thoughts. Some people say distraction works during the day, but find it more difficult to silence worrying thoughts during the middle of the night.

### Grief, loss and change

Grief is the natural response to any loss or major change. An advanced cancer diagnosis can lead to physical, emotional, social, spiritual and financial changes. You may grieve for the loss of your hopes and plans for the future, how living with the illness could affect your life or independence, or the uncertainty it creates for what lies ahead.

Different people grieve in different ways. It can affect you physically and emotionally. Grief is not as simple as going through stages. It is a process, and the intensity can vary. Some people describe different 'waves' of grief, from mild to overwhelming. You may experience grief gradually and at different times – at diagnosis, if you start to feel unwell, or during treatment.

It is possible to find ways of accepting the loss. Some people refer to this as finding a 'new normal', a way to live life meaningfully while also experiencing grief. There could be more than one 'new normal', depending on how the disease progresses.



A social worker or counsellor can help you and your family find strategies to manage the grief and loss you may experience. Your palliative care team can also provide grief support, or refer you to someone who can help.

## Feeling down

Everyone reacts and adjusts to the diagnosis of advanced cancer in their own way and in their own time.

Feeling low or depressed following a cancer diagnosis is common. You may have continued feelings of sadness, or hopelessness, or you may have lost motivation to do things that previously gave you pleasure. Getting help with depression can allow you to deal with other problems more easily and quickly, and improve the quality of your life.

Talk to your GP, as counselling or medicine – even for a short time – may help. If necessary, they can prepare a GP Mental Health Treatment Plan and you can access the Medicare-funded Better Access initiative, which provides counselling with psychologists or social workers. Your local Cancer Council may also run a counselling program, or you may like to speak to somebody who has the same type of cancer as you through a peer support program.

The organisation [beyondblue](https://beyondblue.org.au) has information about coping with depression and anxiety. Go to [beyondblue.org.au](https://beyondblue.org.au) or call **1300 22 4636** to order a fact sheet.



## Being realistic

Some people believe that the attitude of the person with cancer can influence the outcome of the disease. While it can help to be positive, this doesn't mean you are denying the reality that cancer is often frightening and challenging. Trying to put on a brave face all the time and avoiding anything painful is hard work and can drain your energy.

“ I often think I will scream if one more well-meaning person says ‘Be positive!’ ” Carolyn

Pressure to be optimistic all the time can make it difficult to discuss any fears or sad feelings, which can make problems seem worse.

Try to be realistic about what is happening and talk to someone you trust about your fears and concerns so that you can better cope with them. Explaining your feelings to those around you may also help you get the support you need.

You might find that talking to a counsellor, social worker or psychologist allows you to discuss your worries more openly.

## Looking for meaning

Everyone has their own beliefs about the meaning of life, and it's quite common for people diagnosed with advanced cancer to re-examine this meaning. For some people, cancer may lead them to prioritise what they think is most important in their life.

The prospect of a shortened life span does not always stop people from trying to achieve long-held goals, but it may mean they adjust some of their goals. While the diagnosis may cause some to live life at a slower pace, others may feel an urgency to make the most of each day.

You may want to look for meaning in your life with someone close to you, or to talk to a spiritual or religious adviser, or to a professional counsellor or psychologist. If you'd prefer not to talk to someone else, you could write in a journal, meditate or pray.

## Celebrating your life

Having advanced cancer is often an opportunity for people to reflect on their life and all they have done, and to think about their legacy.

Some people like to prepare something to hand down to family and friends as a memory of themselves. If you'd like to do this, you could consider writing letters or stories of your life, making a recording of special memories, reviewing or arranging photo albums, documenting your family's history or family tree, making a playlist of favourite songs, gathering treasured recipes into a cookbook, or creating artwork.

Make a memory box to share elements of your life with family and friends. You can include items that reflect your life, shared experiences and personality, e.g. postcards, photos or a list of happy memories.



## The effect on people close to you

You may find that how your family and friends react to your diagnosis varies, and they may not react in the way you expect them to. They may need time to adjust to your diagnosis, and may experience similar fears and anxieties, and need as much information and advice as you. Sometimes family members may feel more distressed than the person with cancer. This seems to be more common when there is a lack of communication between the person diagnosed with cancer and the people close to them.

Cancer is often a reminder that life is fragile, and family and friends may behave in ways you find difficult or hurtful. Some may stay away or stop contacting you because they don't know how to respond or are afraid of losing you. Others may block out or ignore things that are too painful to contemplate. However, you may find that your friends respond with understanding and openness, and become even closer.

Your friends or family may need to take their lead from you. You can guide them on how much you want to talk about the illness and the different issues you want to think about or plan together.



There are many ways to keep friends and family updated when you don't have the time or energy to talk with people individually. Use text messages, email, blogs or social networking sites, or write one letter and have copies sent to loved ones. Ask for replies so you know what others are up to.

“ It is really important to ask for help when you need it – whether it be for practical, financial or spiritual needs. Volunteers, in particular, can offer lots of practical support, as well as friendship. ” Leon

## Getting help

People might be eager to offer help when they first hear about your diagnosis.

Some people will prefer doing practical things for you, such as cooking a meal, shopping for groceries or driving you to an appointment; others may be good at keeping you company.

People you know from your current or past workplaces may help by providing updates about what is happening at work, if you want to know or would like the distraction.

Even when your friends are genuinely willing to help, it can sometimes be hard to ask. It may be useful to delegate one friend or relative to coordinate offers of help and to update others of your progress if you're not able to contact everyone individually yourself. There are also online tools to help you organise volunteers, e.g. Lovlist or Meal Train. If you're keen to stay independent, it can be challenging if your friends want to do everything for you.

Home care services or Cancer Council may be able to provide assistance with domestic tasks such as cooking and cleaning. For more information, see *Support and information* on pages 71–74.



# Talking with family and friends

Talking about your feelings can be hard. However, people often cope better with a diagnosis of advanced cancer when they're open with family members and friends about their fears and concerns.

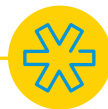
## Partners

The emotional support provided by a partner can affect how you cope with the diagnosis. How you communicate with your partner about cancer depends partly on how you've always communicated. Many relationships can be challenged by a cancer diagnosis. This may be because of several factors, including an uncertain future, financial worries after the diagnosis, and social isolation.

There may also be role changes for both of you. Your partner may try to protect you by doing everything for you, which can challenge your sense of independence. Or you may not be able to do things you used to do, which can lead to feelings of frustration and helplessness. These feelings are common for people diagnosed with advanced cancer.

Some studies suggest that partners experience levels of distress similar to or greater than those of the affected partner, and as a result may feel depressed and anxious. Share your feelings about how you're coping with the diagnosis, and give them the

““ The experience of having good communication with my partner was a blessing. It was the total difference in being able to cope. ”” *Kaye*



In this booklet, the term 'partner' means husband, wife, de facto, same-sex partner, boyfriend or girlfriend.

opportunity to do the same. Being open and honest can help you and your partner through any anxieties, sadness and uncertainty, and your relationship may become stronger.

At times, you and your partner may not share each other's feelings, attitudes or opinions, and this can lead to tension. It can help if you still feel involved at home and with the family, even if you can only do small tasks and need to pace yourself.

You may find it difficult if your partner doesn't want to talk about the diagnosis or your treatment options with you. They may unconsciously distance themselves as a way of coping, without meaning to be hurtful.

When things are tough, you could try telling your partner what you need most from them. Many people say that their biggest single need is for a sympathetic listener. Remind your partner that the important thing is not what they say – but to be there and to listen. Let them know you appreciate their support and that you understand that it's tough for them too.

Often the partner is the main carer, and will need support with emotional, practical and physical concerns. For more detailed information, see the *Information for carers* chapter on pages 63–70.

## Sexual intimacy

We are all sexual beings, and intimacy adds to the quality of our lives. During the initial shock of diagnosis, sex might be the furthest thing from your mind. Physical contact, such as hugging or holding hands, can provide comfort. Over time, you may have questions about your sexual and intimate life after cancer.

There may be times when it is difficult for you and your partner to have the kind of closeness you would like. Depending on where the cancer has spread, or the type of treatment you're having, you can feel sore and find even a gentle hug uncomfortable. Your partner may avoid contact for fear of hurting you or you may avoid physical contact for fear of rejection.

It takes time to adapt to physical and emotional changes. Most people find it is easier to re-establish contact by lying close together in bed. If this first step is hard, ask your doctor, nurse or therapist to suggest ways to help make sexual intercourse easier. If sexual intimacy is no longer possible or desired, you may find physical closeness in other ways, such as cuddling, stroking or massage. Talk with your partner about your feelings and concerns about the sexual changes in your relationship, and acknowledge the changes in intimacy.



Call Cancer Council **13 11 20** for a free copy of the *Sexuality, Intimacy and Cancer* booklet, or download a digital version from your local Cancer Council website.



## Physical and emotional intimacy

Physical and emotional intimacy can provide comfort at difficult times. A sense of closeness can come unexpectedly. A kiss from a child, a hug from a friend, or a caring touch from a nurse could make a difference to your day.

## Parents

Your parents are likely to feel overwhelmed and helpless when they first hear of your diagnosis. Regardless of the child's age, most parents have a strong desire to protect their son or daughter. It may take your parent a while to adjust. They will also have to deal with the emotions of other siblings or family members.

Parents of young children and adolescents play a big role in their care and may become their advocate during treatment. Parents of an adult child with cancer may not have a clear role, and they may feel excluded if others take precedence in caring for you.

## Friends

You may find your friends are invaluable in providing emotional and practical support. If you are not close to your family or if they don't live nearby, friends can be particularly helpful. Some friends can listen to whatever you say – complaints, hopes, fears, wishes – without judging you, and without trying to cheer you up or giving advice. Others may avoid you or seem reluctant to talk about the diagnosis. Let friends know that it's okay to talk about something other than cancer.

## Children

To help understand the diagnosis, children need age-appropriate explanations. If you've explained cancer and its treatment before, it might be easier to start the discussion. However, you might find it harder to talk about the cancer spreading and being difficult to treat. The conversation may be easier if you think about the questions children may ask and work out a response beforehand.

Once children know the cancer is advanced, they will need to be given some idea of the prognosis.

## Young children

Even if they are young, your children will probably suspect that something is wrong. They may notice changes at home, such as your distress or an increase in visitors. Assure children that the disease is no-one's fault. Children may think they, or their behaviour, caused the cancer. They might also fear the same thing happening to them or someone else they know.

Children will want to know in advance when you will be staying in hospital or needing rest at home. They will want to know that there will always be someone to care for them.



If you are a sole parent, finding someone to look after your children may be harder. It may help to talk to a social worker about what's available in your local area.



To read more suggestions about discussing cancer with children, call Cancer Council **13 11 20** for a free copy of *Talking to Kids About Cancer*, or download a digital version from your local website.

## Teenage children

Teenagers react in different ways, ranging from withdrawal to offers of help and assurances of love. Like younger children, teenagers can feel abandoned as the family concentrates on the sick person. Instead of focusing on themselves, teenagers may be required to deal with the needs of the family. Because of these pressures, there may be outbursts over trivial things. Teenage children may feel upset by how unfair the situation seems and also react to feelings that they are not really aware of, or cannot acknowledge, like anger, guilt or grief.

## Adult children

Adult children may feel overwhelmed when they find out you have advanced cancer. They can become aware of their own desire to have a parent around forever. They may feel guilty because they have to juggle other responsibilities (e.g. a job or caring for children of their own) or they live far away.

You might feel you have to, or want to, carry on as the head of the family, reassuring everyone that things are the same as always. Having to rely on your adult children may make you feel uncomfortable, particularly if you need help with feeding or bathing. However, your adult children may see it as their opportunity to look after you and show their love.

## How to talk to your children, family and friends

### Young children



- ✓ Listen and be alert to their feelings, this gives you an idea of what they can handle.
- ✓ Communicate feelings as well as facts.
- ✓ Give simple, honest answers, and clarify any confusion.
- ✓ Explain what will happen next and give children realistic hope, e.g. that the family can still enjoy time together.
- ✓ Don't make promises you may be unable to keep.
- ✓ Reassure them that they didn't cause the cancer.
- ✓ Try to keep family routines and boundaries as normal as possible.
- ✓ Provide extra physical and verbal expressions of love. Children may become clingy, angry or withdrawn – all are natural reactions.

### Teenage children



- ✓ Encourage them to talk about their feelings, but understand they may find it easier to confide in friends, teachers or other trusted people.
- ✓ Help them find ways to express their feelings in different ways, e.g. listening to music, playing sports, writing in a journal.
- ✓ Negotiate role changes in the family.
- ✓ Keep their routine as normal as possible – school, homework, activities and social outings.
- ✓ Provide resources for learning more about cancer and getting support and counselling, such as Canteen's website at [canteen.org.au](http://canteen.org.au).

## Adult children



- ✓ Provide information about your condition to your grown-up children to help them cope with their feelings.
- ✓ Involve them in decision-making about treatment or activities you want to continue. They may have valuable input.
- ✓ Discuss ways your children might be able to help you, while still managing their other responsibilities.
- ✓ Organise or make time to spend with your children so you can create meaningful memories together.

## Parents



- ✓ Explain current treatments. This may lessen any fears and misconceptions from their past experiences with cancer.
- ✓ Talk openly about your feelings. You may avoid discussing your worries with your parents to avoid upsetting them. It's also an opportunity for them to express their emotions.
- ✓ Let them know what help you need, and be honest if you want independence to make your own decisions.

## Friends



- ✓ Set boundaries around how much you want to share – you can simply say you'd like to talk about something else.
- ✓ Ask friends how they feel about the diagnosis – this gives them permission to discuss the situation.
- ✓ Be as specific as possible when friends ask how they can help.
- ✓ Change the topic if friends volunteer information you're not comfortable with, e.g. alternative therapies, a friend or celebrity who has had a miraculous recovery.

## When you don't want to talk

You may find that you don't want to talk about your fears and concerns with family and friends. This may be because you feel uncomfortable discussing private matters, you don't have the words to describe how you feel, or you fear becoming upset or overwhelmed. Sometimes putting things into words makes it seem more real, and you may not feel ready to address some of these concerns. Everyone handles a cancer diagnosis in their own way. If you don't want to talk, your wishes should be respected.

### Ways to share how you're feeling

If you are having trouble talking to others about personal issues, you can share the experience in the following ways:



#### Let others help

Try to allow others to provide support, as this can help you adjust to your situation and cope better with your own emotions.



#### Join a support group

Talking about your fears and concerns with people who are going through a similar experience can often be easier. Join a support group, talk to a health professional or call Cancer Council **13 11 20**.



#### Express your feelings creatively

Explore your feelings by writing in a journal or making something creative like an artwork or a song. This can help you to release your emotions if you find it difficult to talk to others.



# Making treatment decisions

Sometimes it is difficult to decide on whether to have treatment for advanced cancer. Some people choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the expected benefits outweigh the side effects so that they have the best quality of life.

Some people decide not to have active treatment for the cancer, but to treat symptoms to reduce pain and discomfort. You may want to consider what quality of life means to you. Perhaps you would choose chemotherapy if it meant you could have two good weeks each month. Or you might value being able to spend as much time as possible with family and friends, without the disruption of treatment.

Understanding the disease, available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You can also discuss the options with your family and friends or with your doctor, or call Cancer Council 13 11 20.

## Talking about future care

Discussing the kind of care you might want in the future can be difficult. However, talking to your family about this can help them if you are so sick that you can't make decisions, and they need to make decisions about your health care for you.

Palliative Care Australia has developed a discussion starter that can help you reflect on your preferences for care and talk about them to your family. See [dyingtotalk.org.au/discussion-starter/](http://dyingtotalk.org.au/discussion-starter/).

## When treatment seems too much

To cure a primary cancer, it can seem worthwhile having treatment with side effects. But when a cure is unlikely, it may seem less reasonable to choose treatments that leave you feeling exhausted or sick, even if they will help you to live longer.

- Before you start or stop treatment, think about the benefits and drawbacks. Rarely do decisions have to be made quickly.
- Ask yourself if you are feeling unwell from the side effects of the treatment, from the advancing disease or from emotional overload. Some or all of these may be able to be treated.
- Talk with others, particularly your doctor and those close to you. Their input and support may help clarify your thoughts.
- Speak to professionals, such as a counsellor or social worker, who can help you decide what is important to you.

## Refusal of medical treatment

You have the right to accept or refuse any treatment offered. For your refusal to be accepted, you must understand the nature of the treatment proposed and the consequences of not having it. You can refuse each treatment separately – you do not have to accept treatment on an all-or-nothing basis.

In some states and territories, you will need to complete a refusal of treatment certificate, which your treating doctors must follow. See *Advance care planning*, page 55.



## Talking with doctors

When your doctor first tells you that you have advanced cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask for further explanation – see page 76 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You may decide you would prefer to be treated by the doctor who provided the second opinion.

🗨️ Always, always get a second opinion. Second opinions will either confirm what you've already been told or present different options to weigh up. 🗨️ *Peter*

## Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer. For some people with advanced cancer, participation in a clinical trial may be a way to access new therapies.

It may be helpful to talk to your specialist or a clinical trials nurse, or to get a second opinion about participating in a clinical trial. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



## Treatment for advanced cancer

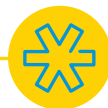
The aim of treatment for advanced cancer is to control the cancer for as long as possible. Controlling the cancer might mean shrinking the size of the cancer or stopping it growing for a while. In some cases, this may be months or years. If treatment is no longer controlling the cancer, the aim of treatment is to relieve symptoms.

New drugs are constantly becoming available, so if your current treatment stops working or you are finding it hard to cope with the side effects, ask your doctor about other options. Also, ask if you are eligible to join a clinical trial (see opposite page).

Treatment choices for advanced cancer will depend on where the cancer started and how much it has spread. Usually cancer that has spread needs systemic treatment. This means treatment is taken by mouth or injected into the blood to reach cancer cells throughout the body. Examples include chemotherapy, immunotherapy or hormone therapy. Treatment that affects only a certain part of the body might also be used to relieve some symptoms. Examples include surgery or radiotherapy. Palliative treatment can also help to maintain or improve quality of life.

A range of health professionals will work as a multidisciplinary team to treat you. See the table on the next page.

To find out more about the treatments available for advanced cancer, call Cancer Council **13 11 20** and ask for free booklets on chemotherapy, surgery, radiotherapy or palliative care, or download digital versions from your local Cancer Council website.



Health professional	Role
<b>GP</b>	continues to see you for day-to-day health care issues
<b>medical oncologist*</b>	prescribes and coordinates the course of chemotherapy
<b>radiation oncologist*</b>	prescribes and coordinates the course of radiotherapy
<b>nurses</b>	give the course of treatment, and support and assist you through all stages of your treatment
<b>cancer care coordinator</b>	supports patients and families throughout treatment and liaises with other staff
<b>dietitian</b>	recommends an eating plan for you and helps with digestive issues, such as nausea
<b>palliative care team</b>	specialise in pain and symptom control to maximise wellbeing and improve quality of life
<b>social worker</b>	links you to support services and helps you with emotional and practical issues
<b>counsellor, psychologist, clinical psychiatrist*</b>	provide emotional support and help manage any feelings of depression and anxiety
<b>spiritual adviser, chaplain, pastoral carer</b>	talk about spiritual matters and help you reflect on your life and search for meaning

\*Specialist doctor

## Chemotherapy

Chemotherapy is the most commonly used treatment when cancer has spread. The drugs kill cancer cells or slow their growth. There are many types of chemotherapy drugs, which are often used in different combinations and strengths. Treatment is usually given over a few hours or days, followed by a rest period of 2–3 weeks. Most people have several cycles of treatment.

The chemotherapy drugs are usually given by injecting the drugs into a vein (intravenously), but can also be taken as tablets or capsules (orally). Ask your doctor which combination of drugs is best for you, and how long your treatment will last.

**Side effects** – Some chemotherapy drugs cause nausea, depression, tiredness and hair loss. Many of these are temporary and can be prevented or reduced. Different types of chemotherapy have different side effects – for instance, not all of them cause hair loss.

## Surgery

Surgery can remove tumours from affected areas, such as the bowel or lymph nodes. It can also relieve discomfort caused by tumours that obstruct organs or cause bleeding, such as unblocking the bile duct to relieve jaundice in pancreatic cancer.

Some organs release hormones that stimulate tumour growth, so your doctor might suggest surgery on these – for example, removing the testicles will reduce testosterone levels and can slow the growth of prostate cancer.

## Radiotherapy

Also known as radiation therapy, radiotherapy uses radiation, such as x-rays, to kill cancer cells or injure them so they cannot multiply. Radiotherapy can be precisely targeted at cancer sites in your body. Treatment is carefully planned to have the greatest effect on the cancer cells and to limit damage to the surrounding healthy body tissues.

Radiotherapy can shrink tumours or stop them from spreading further. It can also relieve some symptoms, such as pain from secondary cancer in the bones. External beam radiotherapy or internal radiotherapy (brachytherapy) may be offered.

**Side effects** – Common side effects from radiotherapy include fatigue, skin problems or loss of appetite. These may be temporary or longer-lasting.

## Hormone therapy

Cancer that grows in response to hormones can often be slowed by taking drugs to suppress the body's production of the hormone. If you have prostate, breast or uterine cancer, you may be offered hormone therapy. This treatment may cause some side effects.

**Side effects** – For women, certain hormone drugs will cause menopausal symptoms, regardless of age. If you have been through menopause, hormone drugs called aromatase inhibitors may be used and these may cause thinning of the bones (osteoporosis) and vaginal dryness. For men, hormone drugs can produce hot flushes.

## Targeted therapy

Targeted therapy may be used instead of, or together with, chemotherapy. This treatment uses drugs that work in a different way to chemotherapy drugs. While chemotherapy affects all rapidly dividing cells and works by killing cancerous cells (cytotoxic), targeted therapy affects specific molecules within cells and often works by blocking cell growth (cytostatic).

Not all cancers respond to targeted therapy, and the drugs are sometimes hard to access because they are expensive, not yet developed for all types of cancers, and sometimes available only in clinical trials (see page 32).

**Side effects** – These vary depending on the targeted therapy used, but may include fevers, allergic reactions, rashes, diarrhoea, blood-clotting problems, and blood pressure changes.

## Immunotherapy

This is the use of drugs to alter the immune system's response. New immunotherapy drugs are being rapidly developed, and several of these are approved for the treatment of some cancers. These new drugs work by permitting the immune system to bypass 'checkpoints' set up by the cancer that block the immune system.

**Side effects** – The side effects of immunotherapy drugs are different to chemotherapy. If the drugs inflame organs, it may cause symptoms, for example, in the lungs (shortness of breath), bowel (diarrhoea) or thyroid gland (abnormal thyroid hormone levels).

## Palliative care


Palliative care allows people with advanced cancer to maintain their quality of life. It also provides support to families and carers.

Many people think that palliative care is just for people who are dying, but it is appropriate at any stage of advanced cancer. Some people live comfortably for months or years after their diagnosis of advanced cancer, and they can be supported by palliative care services throughout this time.

The role of palliative care is to:

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

Your palliative care may be coordinated by your GP or community nurse or by the specialist palliative care team in your area. These different professionals work together to give you relief from pain and other symptoms of cancer. They will also try to help you live your life as fully as possible.

“ I’ve been having palliative treatment for five years. I’m not trying to get rid of the disease, just keeping it under control. My quality of life is excellent. ”  *Kate*

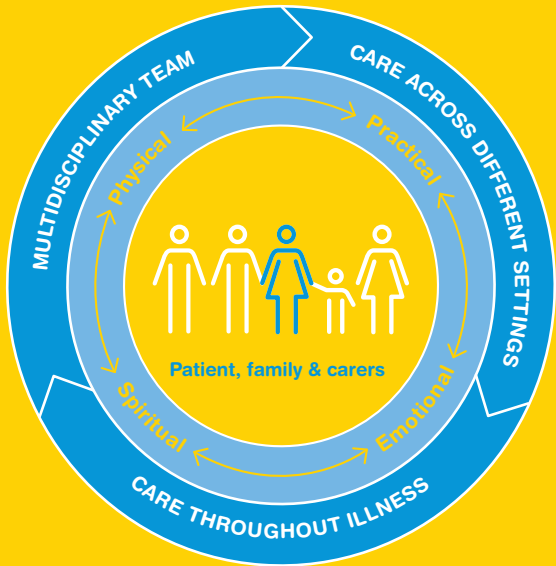


Contacting the palliative care team early in your illness means that you can find out what the different team members do and see which services might be useful now or in the future. This will vary according to how you feel, what problems you have, and how your carers are managing. If you are not linked in with a palliative care service and would like to be, speak to your doctor or nurse.

For more information about what palliative care is and how it helps, visit the Palliative Care Australia website, [palliativecare.org.au](http://palliativecare.org.au). You can also use the directory on this website to find a palliative care service in your local area.

### Working together: holistic care

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



## Rehabilitation

It is frustrating to find that cancer can limit your activities. Rehabilitation is a way of improving your quality of life between or after treatments. It may involve restoring physical functioning with the use of physiotherapy, occupational therapy, speech therapy or artificial body parts (prostheses). It can also include emotional support, such as counselling.

Returning to work is another form of rehabilitation. You may find you need to start back at work with reduced hours. If you can no longer work, or choose not to, you may need something to do that helps you feel involved in life and connected with people.

For most people, rehabilitation is organised through their treatment centre. If you have been treated in a private hospital, ask your doctor about the availability of these services. Your GP can also organise rehabilitation for you.

For more information on the availability of rehabilitation services in your area, contact Cancer Council 13 11 20.

## Complementary and alternative therapies

You may wonder whether there are any complementary and alternative therapies you could try. You may want help managing different symptoms and side effects, or a treatment for the cancer. You may want to feel that you've tried every available option and have some control over your treatment.

## Complementary therapies

Complementary therapies can be used in combination with conventional medicine, such as chemotherapy or radiotherapy. Therapies include acupuncture, massage, hypnotherapy, nutrition and relaxation. These may help you cope better with side effects and feel as well as possible.

In clinical trials, some therapies have been shown to be helpful for managing the various emotional and physical effects of cancer and its treatment. Examples include:

- **anxiety** – meditation, relaxation, counselling, support groups, art therapy, music therapy, massage, hypnotherapy
- **fatigue** – meditation, relaxation
- **pain** – hypnotherapy
- **stress** – meditation, relaxation, counselling, support groups, spiritual practices
- **nausea and vomiting** – acupuncture, hypnotherapy.

While some cancer treatment centres and palliative care units offer complementary therapies as part of their services (e.g. art therapy, massage or meditation), you may have to see a private practitioner. If you go to a private practitioner and have private health insurance, check if your health fund provides a rebate.

Most complementary therapies cost money, but some community centres offer group therapies, such as tai chi or yoga, for free or a small charge. Call 13 11 20 for a copy of *Understanding Complementary Therapies*, or download a digital version from your local Cancer Council website.



Let your doctor know if you plan to use any other therapies. This is important, as some therapies may not be appropriate, depending on your conventional treatment or what is happening in your body. For example, some herbs and nutritional supplements may interact with your medication, resulting in harmful side effects.

## Alternative therapies

Alternative therapies are commonly defined as those treatments used instead of conventional medicine. Many alternative therapies claim to stop cancer growing and to cure the disease, but they are not scientifically tested or proven to be effective.

When cancer has spread and treatment options are limited, some people consider alternative therapies. However, alternative therapies can be harmful – for example, taking high-dose vitamins can have side effects, and eliminating food groups could mean that your diet no longer provides all the nutrients you need. Some therapies may also be costly. Be wary if any treatment:

- claims to cure all cancers
- requires you to travel overseas
- claims the medical/pharmaceutical industry wants to stop its use
- claims to have positive results with few or no side effects.

Information on alternative therapies may be misleading. It can come from many sources, such as the internet. Friends and family may also tell you about alternative treatments. Look for information from reliable sources such as Cancer Council or government websites, ask questions, and check a practitioner's qualifications.



## Key points

- Improved treatments mean that some advanced cancers can be kept under control for months or years, like a chronic disease.
  - If your current treatment is no longer working or the side effects are hard to cope with, ask your doctor about other options. New drugs are constantly becoming available.
  - There are different types of treatment for advanced cancer that may be used separately or in combination.
  - Chemotherapy is the most commonly used treatment when cancer has spread.
  - Surgery can be used to remove tumours that might be causing pain.
  - Radiotherapy is used to kill cancer cells or injure them so that they cannot multiply.
- It is also used to relieve symptoms such as pain.
- Hormone therapy is used for cancer that grows in response to hormones. It can slow tumour growth.
  - Palliative care helps you manage the symptoms of cancer or its treatment, and can help maintain your quality of life.
  - Contacting a palliative care team early in your illness means that you can find out what may help now and in the future.
  - Rehabilitation is another way of improving your quality of life between or after treatments.
  - Let your doctor know if you plan to use any other therapies to make sure they do not result in harmful side effects.



# Managing symptoms

People experience many different symptoms when they have advanced cancer. Common symptoms include pain, nausea, loss of appetite, tiredness and breathlessness. While it may not be possible to control all symptoms, the suggestions in this chapter can help make you as comfortable as possible. As the disease progresses, these symptoms can vary in intensity and frequency, placing different limitations on your body.

The relief of symptoms is one of the aims of the palliative care team. Contact them to work out what you need and discuss suitable options.

## Pain

Many people with advanced cancer worry they will be in pain, but not everyone with cancer has pain and many find the pain comes and goes. Whether you have pain depends on the location of the cancer and its size.

If you do experience pain, it can usually be controlled. Pain management is a specialised field for doctors and nurses, and palliative care services are specifically trained in pain management.

There are many ways to relieve pain, including:

- pain medicines (see opposite page)
- pain-relieving procedures for nerve pain (see page 46)
- complementary therapies such as massage, meditation, yoga, hypnotherapy or cognitive behavioural therapy (see page 41)
- chemotherapy, radiotherapy or surgery.

Everyone experiences pain differently, so it may take time to find the most effective pain relief or combination of treatments for you. To work out the best pain control method, your pain specialists will ask you to use a variety of tools, such as a pain scale or pain diary, to describe your pain.

How and where the pain is felt and how it affects your life can change. Regular reviews by pain management experts can help keep the pain under control. It's better to take medicine regularly, rather than waiting for the pain to build up. This is called staying on top of the pain. Controlling the pain may allow you to continue with activities you enjoy for some time and offer a better quality of life.

## Pain medicines

Medicines that relieve pain are called analgesics. Depending on the type of pain and how intense it is, you may be offered:

- mild pain medicines, such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs)
- moderate pain medicine, such as codeine
- strong pain medicine known as opioids, such as morphine, oxycodone and fentanyl.

Some people worry about becoming addicted to pain medicine, but this is unlikely when medicines are taken to relieve pain. Any side effects, such as constipation or drowsiness, can usually be managed. For more information about managing pain and answers to common concerns, call Cancer Council 13 11 20 for a free copy of the *Overcoming Cancer Pain* booklet, or download a digital version from your local Cancer Council website.

## Other pain relief methods

You may also be given other types of medicine to take with the main pain medicine. These could include 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. The type of nerve block you are offered will vary depending on the type of cancer you have. Delivering the pain medicine directly into the nerves in the spine via a tube (epidural) can cause fewer side effects, however this is usually temporary.

### Cancer treatments for pain relief

Chemotherapy, radiotherapy and surgery may also be used to control pain.

**Chemotherapy** – This drug treatment can shrink cancer that is causing pain because of its size or location. It can also slow the growth of the cancer and help control symptoms, including pain, loss of appetite and weight loss.

**Radiotherapy** – This uses radiation such as x-rays, to

shrink a tumour and reduce discomfort. For example, it may relieve headaches by shrinking cancer that has spread to the brain from another part of the body (brain metastasis).

**Surgery** – An operation can remove a single tumour in the soft organs; treat a bowel obstruction that is causing pain; or improve outcomes from chemotherapy and radiotherapy by reducing the size of a tumour.



## Feeling sick

People with advanced cancer often have problems with feeling sick (nausea) or being sick (vomiting). These can be caused by treatment with chemotherapy or radiotherapy, cancer growth, blockage of the bowel or the location of the cancer. Nausea can usually be managed with medicines. You may need to try different types until you find one that works for you.

Many people talk about anticipatory nausea, the response your body learns when you know it is chemotherapy time again. Even if you are no longer having chemotherapy, you may still feel a surge of nausea if you're going past the place where you were treated.

**Blockage in the bowel** – Sometimes cancer in the abdominal area can cause the bowel to become blocked. This is called bowel obstruction. Because waste matter (faeces) cannot pass through the bowel easily, symptoms may include feeling sick or vomiting. To relieve these symptoms, you may have a small tube (stent) put in to keep the bowel open. The stent is inserted through the rectum using a flexible tube called an endoscope.

**High levels of calcium in the blood** – Feeling nauseous may be a symptom of high levels of calcium in your blood (hypercalcaemia). If the cancer spreads to the bones, the cancer cells make the bone break down and release calcium into the blood, causing you to feel tired and drowsy. Hypercalcaemia is more common in some types of advanced cancer. You may be given drugs to lower high calcium levels. These are called bisphosphonates, and are usually given through a drip into a vein.

## Tips on managing symptoms

### Nausea and vomiting

- Eat small meals or snacks 5–6 times during the day. Going without food for long periods can make nausea worse.
- Choose cold foods or foods at room temperature, such as sandwiches, salads, stewed fruit or jelly.
- Have food or drink with ginger, e.g. ginger ale, ginger tea or ginger biscuits.
- Take anti-nausea medicines as prescribed. Let the doctor know if the medicines don't seem to be working.
- Avoid fried, greasy or spicy foods or those that have strong smells.
- Use stress reduction techniques, such as meditation.

### Loss of appetite

- Eat what you feel like, when you feel like it, e.g. have cereal for dinner or a main meal at lunch.
- Use a smaller plate – a big plate full of food may put you off eating.
- Relax dietary restrictions. During treatment, maintaining your weight is more important than avoiding full-fat foods.
- Add flavour to foods with lemon juice, herbs and spices.
- Add ice-cream or cream to fruit or a smoothie to increase kilojoules and nutrients.
- Sip on juice, cordials, soft drinks and sports drinks during the day to keep hydrated.
- Make meals as enjoyable as possible, e.g. play music, light candles or eat with friends.
- Gentle physical activity can stimulate appetite, e.g. take a short walk around the block.



## Breathlessness

- Use a fan or open a window to increase airflow near your face.
- Sit up or lean forward on a table with an arm crossed over a pillow to allow your breathing muscles to relax.
- Wear loose-fitting clothing around your waist and chest.
- Drink plenty of fluids. Being dehydrated can increase breathlessness.
- Place chairs around the house so that you can sit down between activities or when moving from room to room.
- Try to relax or practise breathing techniques.
- Use a walking frame or lean on the shopping trolley when at the supermarket, as the position or pace can ease your breathing.
- Spread out activities during the day or break them up into smaller tasks.

## Fatigue

- Plan activities for the time of day when you feel less tired, and include rest times.
- Do regular gentle activities, such as walking to the letterbox, doing stretches or getting out of bed for meals.
- Avoid stress where possible – relaxation techniques or meditation can help.
- Have several short naps rather than one long rest period.
- Limit visitors if you find they are tiring you.
- Limit the amount of alcohol you drink. Alcohol can cause tiredness and energy loss.
- Use Meals on Wheels or other home delivery meal companies that bring prepared food to you.

## Loss of appetite

People with advanced cancer often notice changes in their appetite. This may be because of the cancer itself, treatment, or other side effects such as tiredness, nausea or vomiting, change in sense of taste, pain, lack of activity, or depression.

A loss of appetite often leads to weight loss and malnutrition. By controlling appetite, your strength, function and quality of life can be maintained. However, it's not necessary to force yourself to eat; this may only make you feel uncomfortable and cause vomiting and stomach pain. See page 48 for suggestions.

Food-type nutritional supplements can increase nutrient intake. These are used as snacks between meals. Many pharmacies and supermarkets sell these specially formulated nutritional supplements. You do not need a prescription from your doctor or dietitian to buy them.

Many people with advanced cancer develop wasting syndrome (cachexia). This means the body isn't using protein, carbohydrates and fats properly. Your doctor or dietitian will discuss ways to control cachexia, which may include nutritional supplements.



Read Cancer Council's *Nutrition and Cancer* booklet for more details on malnutrition and wasting syndrome (cachexia). Call **13 11 20** for a copy, or download a digital version from your local Cancer Council website.

## Shortness of breath

People with advanced cancer often experience shortness of breath (breathlessness). This is also called dyspnoea.

Breathlessness can occur for different reasons, including:

- fluid surrounding the lungs
- having an infection
- the cancer itself
- scarring from radiotherapy
- pressure from a swollen abdomen
- anaemia (low red blood cell levels)
- underlying chronic breathing disorders, such as asthma or emphysema.

Symptoms of breathlessness include difficulty catching your breath, noisy breathing or very fast, shallow breaths. Although breathlessness can make you feel distressed and anxious, there are surgical and non-surgical ways to prevent or reduce its impact on your quality of life.

Treatment will depend on the cause of the breathlessness. You may need your lungs drained or medicine prescribed to treat an infection or other lung problem. If breathlessness is caused by the lungs not supplying enough oxygen to your blood, your doctor can arrange a portable oxygen cylinder.

See page 49 for ways to improve breathlessness without surgery. Ask your doctor or nurse about medicines, such as a low dose of morphine, to manage feelings of distress.

## Fatigue

For many people, extreme or constant tiredness (fatigue) can be a major problem, particularly as the cancer advances. You may find feeling fatigued distressing and frustrating. Some people say the fatigue is worse than any pain or nausea they've experienced.

Fatigue can be caused by a range of things, such as:

- anxiety or depression
- poor sleep
- infection
- progression of the cancer
- anaemia (low red blood cell levels)
- cancer treatment such as chemotherapy or radiotherapy
- loss of weight and muscle tone
- drugs such as analgesics, antidepressants and sedatives.

Tell the doctor or nurse if you think you are becoming weaker or more fatigued. If anaemia is making the fatigue worse, it can be managed. You may be referred to an occupational therapist who can teach you techniques for conserving your energy.



## Key points

- People with advanced cancer tend to experience a range of symptoms, which may change over time.
- You may experience pain, but it will depend on the size and location of the cancer and it can usually be controlled.
- Pain-relieving medicines (analgesics) can be mild, like paracetamol, moderate like codeine, or strong like morphine.
- Palliative care services are specifically trained in pain management. They can assess your needs to work out the most effective drug, dose and mode of delivery.
- It is better to treat the pain early than wait to treat the pain when it builds up.
- Chemotherapy, radiotherapy and surgery can be used to control pain.
- A nerve block can relieve pain if cancer is affecting the nerves, but the pain relief from this is usually only temporary.
- Cancer treatments, cancer growth or the location of the cancer can make you feel sick (nauseated). This can usually be controlled with medicines.
- You may also experience a loss of appetite. Eat what you feel like when you feel like it, and relax dietary restrictions.
- If you experience trouble breathing or breathlessness, let your doctor know, as there may be treatment that helps.
- Constant tiredness can be distressing. If you feel it is getting worse, tell your doctor. It may be caused by something that can be treated.



# Planning ahead

It can be daunting to organise your personal, financial and legal affairs, collect all the paperwork and make decisions, such as writing your will or choosing the type of funeral you would like. However, getting your affairs in order can bring a sense of relief and can allow you to focus on treatment and living.

This chapter explains the practical, medical and legal issues to consider at this time.

## 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 and divorce certificates
- bank and credit card information, passwords
- investment details (e.g. shares, funds)
- Centrelink and Medicare details
- superannuation and insurance information
- house title/lease documents
- loan details (e.g. house, car)
- passport
- will (see page 57)
- advance care directive (see page 58)
- document appointing a substitute decision-maker (see page 58)
- funeral information (see pages 60–61).

Discuss your legal arrangements with your family, and let someone know how to contact your lawyer.



## Advance care planning

It can be a good idea to plan for your future medical care, and to discuss your wishes with your family, friends and health care team. This process is called advance care planning, and it can be started at any stage. It enables you to outline your future wishes for health care if you become unable to communicate later.

Advance care planning doesn't mean that you have given up or will die soon – many people review their wishes from time to time.

Studies conducted in a range of health care settings suggest that advance care planning can improve individual and family satisfaction with care, reduce the number of people transferred from nursing homes to hospitals, and reduce stress, anxiety and depression in surviving relatives.

As part of your advance care planning, you may appoint a substitute decision-maker (see page 58) or record your wishes in an advance care directive (see page 58). You can make the advance care documents as simple or as detailed as you like. If you have religious, spiritual or cultural beliefs that may affect your health care decisions, you can record these in your advance care documents. You need to be an adult and have capacity (see page 57) to complete advance care documents.

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

## Steps to advance care planning

### Talk to others



Talk to your family, close friends and carers about what you want or don't want if you are unable to make your own medical decisions.

- Use Palliative Care Australia's discussion starter to reflect on your preferences and discuss these with family and friends. Visit [dyingtotalk.org.au/discussion-starter](http://dyingtotalk.org.au/discussion-starter).

### Record your wishes



Record your wishes in an advance care planning document. Include the following details:

- The names and contact details of people who can speak on your behalf if you are unable to. This person is known as your substitute decision-maker (see page 58).
- A description of the care that would and would not be acceptable to you.
- An outline of treatments or services that you do or do not want.
- A signature and date. Have the document witnessed.

### Make copies



Make copies of your advance care documents and share them with your GP, oncologist, substitute decision-maker, solicitor and a family member or friend.

- Ask your doctor or hospital to place the plan on your medical record. You can save it online at [myhealthrecord.gov.au](http://myhealthrecord.gov.au).
- Review the documents regularly and update them whenever your wishes change.

## Preparing legal documents

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

For any of these documents to be legally binding, you need to have capacity at the time of signing the document. Having capacity means you are able to understand the choices that are available and the consequences of your decisions, and are able to communicate your choices. For more information, talk to your doctor and lawyer.

### Making a will

A will is a document that records who you would like to receive your assets (estate) after you die. It can also record your wishes regarding guardianship plans for any children.

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

When you die without a will, you are said to die intestate. Your assets are distributed to family members according to a formula provided by the law. Although any will can be challenged in court, having a valid will usually means your assets will go to the people of your choice, avoids extra expenses, and simplifies the process for your family.

## 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. These can include decisions about your finances, property, medical care and lifestyle. This person, called a substitute decision-maker, should be someone you trust or who understands 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 may be known as an enduring power of attorney, enduring power of guardianship, or appointment of enduring guardian.

## Advance care directive

You can record your wishes for your future medical care in an advance care directive, commonly known as a 'living will'. In some states and territories, the advance care directive has a different name, such as health direction, advanced personal plan, advance health directive, or refusal of treatment certificate. This document may not always be legally binding, but it does provide a record of your wishes for doctors, family and carers to consider.

For more information, read Cancer Council's *Getting your affairs in order* fact sheet – call 13 11 20 to check whether a printed version is available in your state or territory, or view it online on your local Cancer Council website.

Legal advice is also recommended. You can start by contacting Cancer Council's Legal and Financial Referral Service on 13 11 20.

## Dealing with bills and debts

Depending on your circumstances, you may need to consider ways to manage the financial impact of advanced cancer. If you are having difficulty paying your utility bills, such as electricity, gas, water, phone or internet, contact your provider. You may be able to access flexible payment arrangements, discounts, rebates or concessions. Check with the hospital social worker whether other options are available in your state or territory.

## Accessing superannuation early

In Australia, you need to be at least 55 years old and retired before you are allowed to access your superannuation (super). However, you can apply to access your superannuation early under particular circumstances, such as if you need to pay for medical treatment, are facing severe financial hardship, or are diagnosed with a terminal illness.

To access super early, you will need to apply to the Department of Human Services, [humanservices.gov.au](http://humanservices.gov.au), or directly with your super fund. You may need to provide supporting documentation. Call 13 11 20 to speak to Cancer Council's Legal and Financial Referral Service for more information.

This is only an introduction to these topics. Cancer Council's booklet *Cancer and Your Finances* has more detailed information, and there are also fact sheets on superannuation, insurance, debts and funerals available in many states and territories. Call **13 11 20** for these free resources, or download digital versions from your local website.



## Insurance

People often don't realise that they have insurance attached to their superannuation. Many funds offer insurance by default. Common types of insurance provided through superannuation funds can include income protection, total and permanent disability and life insurance (may be called death cover).

To find out whether you're eligible to access cover through superannuation insurance or how accessing your super early will affect your insurance entitlements, talk to your insurer or to a financial planner.

## Planning your funeral

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

Planning your funeral can be as simple as discussing your wishes with your family and friends, or you can lodge a plan with a funeral director of your choice or record them in your will. The executor should follow the directions in your will, but is not bound to do so. You can personalise your funeral to suit your cultural or spiritual

“ I'm planning my funeral to have the music that has been a special part of my life. ” *John*

beliefs. You may have just a few simple requests for music you want played or poems you'd like read, or you may have ideas for the full service. You can also choose not to have a funeral at all or to have a non-traditional event such as a celebration of life. If you change your mind, you can alter these arrangements at any time.

If you feel you need to make preparations but you can't do all the work, or prefer not to, talk to a social worker or pastoral carer, who can help you work out the options.

To prearrange or prepay a funeral, talk to a funeral director. You can download a pre-planning information form from the Australian Funeral Directors Association website at [afda.org.au](http://afda.org.au) or Funeral Directors Australia at [funeraldirectorsaustralia.com.au](http://funeraldirectorsaustralia.com.au). It's important to let your family know of any arrangements you have made. Copies of a prepaid funeral contract should be provided to members of the family or filed with your will.

If you would like to know more about the practical and emotional aspects of dying, call Cancer Council 13 11 20 for a free copy of *Facing End of Life: A guide for people dying with cancer, their family and friends*.



## Key points

- Organising your personal, financial and legal affairs can be hard, but it may also bring a sense of relief and allow you to focus on treatment and living.
- It's helpful to update all your important documents and to keep them in one place. This will make it easier if a family member has to help you with financial and legal matters.
- You may want to think about your wishes for future health care and discuss these with others. This is called advance care planning. Use Palliative Care Australia's discussion starter to plan ahead, [dyingtotalk.org.au/discussion-starter](https://dyingtotalk.org.au/discussion-starter).
- A will is a document setting out whom you would like to receive your assets after you die.
- 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 records your wishes for your future health care. You can ask your doctor or the hospital to place a copy of the directive on your medical record. You can also save it online at [myhealthrecord.gov.au](https://myhealthrecord.gov.au).
- If cancer causes financial issues, you may consider accessing your superannuation or claiming on insurance policies that are attached to your superannuation account.
- If you are having trouble paying your utility bills or are struggling with other debts, talk to your service provider or lender about your situation.
- Planning your funeral may be difficult, but is an opportunity to personalise the occasion.





# Information for carers

Caring for a person with advanced cancer can feel overwhelming at first. The future may be uncertain and you may feel that everything is out of control. You may both be trying to come to terms with the diagnosis and experiencing a range of strong emotions, such as fear, anger, sadness and grief.

Some people live with advanced cancer for years, and their needs will change as the disease progresses. The demands on you as a carer might increase, and will include physical, emotional and financial changes. You may have many questions and concerns – for example, will they be in pain, will they become depressed, or will they die.

As well as having to manage your emotions, you may also have to tell other family and friends. This can be time-consuming and difficult. If you need advice or support, contact your GP, hospital social worker, a palliative care service, a support group, hospital nurses, your oncologist or Cancer Council 13 11 20.

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

“ At first, I didn't ask for help, because I didn't want to bother anyone. I see caring as my duty; I have to do it. I now realise people genuinely want to help. They need my help to show them how. ” Judy

## Emotional concerns

### Feelings of loss

You may grieve about how things used to be with the person you are caring for, or for your loss of time and ability to enjoy life as you used to. You may be starting to grieve the expected death of the person you are caring for. This is called anticipatory grief. Your emotions can cycle from feeling very caring and protective to feelings of anger and resentment about what you have lost or may lose.

Everyone deals with loss in their own way, but there are ways to feel more in control.

- Acknowledge your grief. It is alright to cry or feel angry at times.
- Ask family and friends for practical and emotional support.
- Call Cancer Council 13 11 20 for information about coping with loss and grief.

### Depression

Providing ongoing care and support can be challenging, and some carers become depressed. If you find that you are not feeling any pleasure, that you are stressed, irritable or emotional almost all the time, or that you cannot sleep or have lost your appetite, talk to your doctor. You may be referred to counselling or prescribed medicines, if appropriate for your situation.

People with advanced cancer can also become depressed. If you notice any of the symptoms mentioned above, suggest they see a counsellor or doctor. The *beyondblue guide for carers* includes information for carers of people living with depression – [beyondblue.org.au/supporting-someone](http://beyondblue.org.au/supporting-someone).

## Managing uncertainty

Many carers, and people with cancer, struggle with uncertainty after the diagnosis. Your plans may change or have to be put on hold if the future is unknown. You may want to delay making any major changes or big decisions for a while. The anxiety will come and go, but it can help to learn ways of dealing with it.

### Focus on what you can do

Think about what has helped you cope with previous difficult times.



### Try relaxation strategies

Your local community health centre or council may run relaxation, yoga or tai chi classes. Regular exercise, adequate sleep and a healthy diet can also help.



### Read about what to expect

Information can help you understand what to expect, and plan for any changes. This may make you feel more in control.



### Speak to your doctor or health professional

If at any stage you feel that you are not coping, they can refer you to a counsellor and prescribe short-term medicine if needed.



### Join a support group

Face-to-face, internet and telephone support groups are available. These are groups of people in a similar situation that meet regularly to share their experiences. There are groups for people with cancer and their carer/s or groups just for carers. See page 74 for details on how to access the different types of support groups.

## Talking about death and dying

When cancer is advanced, family and friends may wonder if the person will die. This can be a frightening thought, and one that is often mixed with other feelings, such as anger, sadness or guilt.

Although most people are not comfortable talking openly about death and dying, it's an important topic and an opportunity to discuss practical issues such as place of death. Sometimes, knowing the person's wishes can help you avoid regret or feelings of guilt later on. Palliative Care Australia's *Dying to Talk* discussion starter can help you start a conversation.

## Changes to relationships

For many carers, a diagnosis of advanced cancer can affect the established roles within a family, friendship or relationship. These changes may last for only a short time or be longer-lasting.

Cancer can strengthen a relationship or strain it. Try to be open and honest about your concerns. Before beginning a conversation, work out if it is a good time to talk. If you find it difficult to start this discussion or feel the person with cancer is avoiding the conversation, you could suggest you both talk with a counsellor.

You may find yourself thinking about how you will manage if the person with cancer dies. This is natural, but try not to exclude them from everyday events and decisions. If people with cancer are physically able, they often prefer, or even need, to take on daily activities to help maintain their sense of independence. They don't have to, and often don't wish to, feel helpless.

## How to find a counsellor

- Ask your GP for a referral to a counsellor, social worker or psychologist. The Better Access initiative allows GPs to refer people to psychologists or social workers for several free sessions. You could also see a private counsellor or psychologist for a fee.
- Call the National Carer Counselling Program on 1800 242 636. This offers short-term counselling and is run by your local Carers Association. You can also call Cancer Council 13 11 20 – our oncology nurses can put you in touch with a counsellor who has oncology-related experience.



### Isabella's story

My husband, Louis, and I were very anxious when he was diagnosed with cancer.

I took on the tasks at home that Louis was unable to do – such as lawn mowing and feeding the animals. I also arranged appointments and checked details with the treating team. I was grateful I could contact the cancer care coordinator at the radiotherapy centre when I had questions or when I was finding it difficult to cope.

I joined a tai chi class organised through the Carers Association and also attended their support workshops and relaxation sessions. I found the encouragement from other carers gave me the confidence boost I needed.

The support of the hospital social worker was invaluable and reduced many of the day-to-day tasks and concerns I had, and allowed Louis and I to spend more quality time together.

## Practical concerns

### Work and income

You may need time off work to attend medical appointments or to care for the person with cancer. Explain your situation to your employer. Most employers appreciate honesty and will try to accommodate your needs. Check your entitlements because you may be eligible for time off. Some employers will let you take annual leave, long service leave or leave without pay.

You may be eligible for a carer payment from the government if you provide constant care for the person with cancer (whether or not you work outside the home). To find out more, visit [humanservices.gov.au](http://humanservices.gov.au).

Speak to your hospital social worker about other sources of financial assistance. You may be eligible to access Cancer Council's Legal and Financial Referral Service. Cancer Council also has free resources about your rights in regard to care and work.

### Accepting help

Not all your family and friends will know how to respond and provide support – some may not know what to do or even avoid contacting you at first. They may want to avoid thinking about their own death or be afraid of saying the wrong thing, so instead say nothing. This doesn't necessarily mean family and friends don't care; they may be having trouble coping with the diagnosis.

The box opposite lists various ways that family, friends, work colleagues and neighbours can help.



## Practical ideas for carers

- Use group text messages, email, and other social media platforms or record a message on an answering machine to let people know what is happening. This avoids having to repeat information.
- Ask someone to take on the role of information provider. Make sure this person has the latest information.
- Place a message on the door when it is a good time for visitors.
- Turn off the phone and have a rest when the person with cancer is resting.
- Take time out. There will be times when you feel exhausted or overwhelmed. This is normal. Sit outside, or go for a walk or a drive.
- Chat to people you trust about what is happening. It helps them understand what you are going through and helps you release any concerns or stresses you have.
- Involve friends and family – try not to do everything yourself. Sometimes people need to be told specifically what they can do, for example, providing a meal or picking up the kids from school.
- Keep all information about the person you're caring for in one place. This could include emergency contacts, details of advance care planning documents and a list of medicines.
- Be realistic about how much you can do, as doing too much may affect how well you cope. Do more of what is important and less of what isn't.
- Use Carer Gateway's 'Find a service' search function to locate home help, transport, counselling and support groups near you. See [carergateway.gov.au](https://www.carergateway.gov.au).
- Connect with someone who has had a similar experience. Call Cancer Council **13 11 20** for more information.

## Physical concerns

Providing physical care is a challenge for many carers. For example, if the person you're looking after needs help to get out of bed, you will need to learn how to move them safely. Ask the palliative care nurse, doctor or physiotherapist to show you the safest way to do this, as it's easy to injure your back.

If you need extra help and support providing care, talk to your doctor about services you can access. Home nursing services and a palliative care team can provide professional help at home. The My Aged Care website lists available services and explains how to arrange access. Visit [myagedcare.gov.au](http://myagedcare.gov.au) or call 1800 200 422.

You may want to consider accessing respite care to give you a break. This may be for a few hours or days or for longer periods, depending on your needs, the needs of the person with cancer, and what services are available in your area. Respite care can happen in your home or at facilities such as an overnight respite cottage, a day centre or residential care facility. You may be able to access respite through the Commonwealth Home Support Programme. Start by contacting My Aged Care or speak to your doctor.

For a listing of available support services, see pages 71–74.





# Support and information

Help and support can help make life easier. This chapter provides an overview of different organisations and services that can provide information and help for you and your family. The availability of services may vary depending on where you live. Talk to the social worker at the hospital or call Cancer Council 13 11 20 to find out what services are available.

## Accommodation

### Cancer Council

13 11 20

Contact the hospital social worker.

Cancer patients and carers who travel a long way for treatment can often get accommodation at or near the treatment centre. Facilities may be self-contained or shared, and the cost is sometimes subsidised.

### National Rural Health Alliance

[ruralhealth.org.au](http://ruralhealth.org.au)

and search for 'PATs'

Every state and territory has a government scheme that provides financial help to people who need to travel long distances to access specialist medical treatment that is not available in their local area.

## Carer services

### Carers Australia

1800 242 636

[carersaustralia.com.au](http://carersaustralia.com.au)

National body representing Australia's carers; can direct you to local counselling and support services. Carers Associations are available in each state and territory.

### Carer Gateway

1800 422 737

[carergateway.gov.au](http://carergateway.gov.au)

Provides practical information and resources for carers, and helps them connect to local support services.

### National Carer Counselling Program (NCCP)

1800 242 636

Offers short-term counselling for carers. The NCCP service is run by your local Carers Association.

## Counselling and mentoring services

<p><b>Australian Psychological Society</b> psychology.org.au</p>	<p>Use the 'Find a Psychologist' search to look for a practitioner in your area.</p>
<p><b>Better Access initiative</b> health.gov.au/mentalhealth-betteraccess</p>	<p>Medicare-subsidised referral to counselling through your GP.</p>
<p><b>beyondblue</b> 1300 22 4636 beyondblue.org.au</p>	<p>Offers 24-hour telephone counselling service. Online and email counselling are available 7 days a week.</p>
<p><b>Cancer Council's Peer Support Programs</b> 13 11 20</p>	<p>Community of people affected by cancer that you can connect with online, by phone or in person.</p>
<p><b>Canteen</b> 1800 835 932 canteen.org.au</p>	<p>Online, phone and face-to-face counselling for young people aged 12–25.</p>
<p><b>Kids Helpline</b> 1800 55 1800 kidshelpline.com.au</p>	<p>Phone, email and webchat counselling for young people aged 5–25.</p>
<p><b>Lifeline</b> 13 11 14 lifeline.org.au</p>	<p>A 24-hour telephone crisis support and suicide prevention service.</p>
<p><b>MensLine Australia</b> 1300 78 99 78 mensline.org.au</p>	<p>A 24-hour telephone and online support and referral service for men with family and relationship issues.</p>
<h2>Equipment and aids</h2>	
<p><b>Independent Living Centres Australia</b> 1300 885 886 ilcaustralia.org.au</p>	<p>Offers advice on a range of products and services to help with aspects of day-to-day living, including mobility, sleeping, eating and transport.</p>

## Financial assistance

**Centrelink**  
132 717  
humanservices.gov.au

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

**Financial Counselling Australia**  
1800 007 007  
financialcounselling  
australia.org.au

Information about financial counselling and help to find a qualified counsellor.

## Funerals

**Australian Funeral Directors Association**  
1300 888 188  
afda.org.au

Provides a listing of funeral directors and estimates of funeral costs. It also has information on prepaying or planning a funeral.

**Funeral Directors Australia**  
funeraldirectorsaustralia.com.au

Includes a listing of independent funeral directors in your local area.

**Funeral Celebrants Association Australia**  
funeralcelebrants.org.au

Includes a directory for finding a funeral celebrant in your local area.

## Home help

**Ask your local council or your palliative care team.**

Some local councils provide a range of community and in-home services, such as Meals on Wheels or respite care.

**My Aged Care**  
1800 200 422  
myagedcare.gov.au

Provides information about different types of aged care services and eligibility.

## Home nursing

**Talk to your palliative care team and/or health fund.**

Home nursing can be organised as part of your palliative care. Private services are also available.

## Legal advice and information

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

Supports people affected by cancer needing legal advice. This service is free for eligible clients.

## Palliative care

**CareSearch**  
[caresearch.com.au](http://caresearch.com.au)

Online palliative care information, services and evidence for patients, carers and families.

**Palliative Care Australia**  
[palliativecare.org.au](http://palliativecare.org.au)

Provides information and resources, and can link you to your local palliative care office.

## Spiritual or pastoral care

**Contact your hospital.**

Most large hospitals have a pastoral carer who can talk to you about spiritual concerns (from religious and non-religious viewpoints).

## Respite care

**Commonwealth Respite and Carelink Centres**  
1800 052 222  
1800 059 059 (emergency)

Available at home, in a respite care centre or, in some cases, a hospital or hospice.

## Support groups

**Face-to-face groups**  
Call Cancer Council 13 11 20 for details of local support groups.

Meet with others who understand what it's like to have cancer. Many people find they benefit from the close bonds formed at these groups.

**Telephone support groups**  
Cancer Council 13 11 20

There are groups for people with advanced cancer and for carers.

**Online discussion forum**  
[cancercouncil.com.au/oc](http://cancercouncil.com.au/oc)

People can connect with each other at any time, ask or answer questions, or write a blog about their experiences.



# Useful websites

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

## Australian

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Cancer Council Australia.....	<b>cancer.org.au</b>
Cancer Australia.....	<b>canceraustralia.gov.au</b>
Department of Health.....	<b>health.gov.au</b>
Department of Human Services.....	<b>humanservices.gov.au</b>
Department of Social Services.....	<b>dss.gov.au</b>
My Aged Care.....	<b>myagedcare.gov.au</b>
ehospice.....	<b>ehospice.com</b>
Healthdirect Australia.....	<b>healthdirect.gov.au</b>
NPS MedicineWise.....	<b>nps.org.au</b>
Palliative Care Australia.....	<b>palliativecare.org.au</b>
Therapeutic Goods Administration.....	<b>tga.gov.au</b>

## International

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American Cancer Society.....	<b>cancer.org</b>
Macmillan Cancer Support (UK).....	<b>macmillan.org.uk</b>
Memorial Sloan Kettering Cancer Center (US).....	<b>mskcc.org</b>
National Cancer Institute (US).....	<b>cancer.gov</b>
National Center for Complementary and Integrative Health (US).....	<b>nccih.nih.gov</b>



# Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What is my prognosis? How long am I likely to live?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- Are there any clinical trials I can join?
- Are there any complementary therapies that might help?
- What treatment do you suggest for any pain or discomfort?
- What are the risks and possible side effects of each treatment?
- What will happen if I don't have treatment?
- Can I access palliative care?
- Can I call the palliative care team at any time?
- Does the palliative care team inform my GP and other specialists about my care?
- Do I have to pay for any palliative care services?
- Can you help me talk to my family about what is happening?

## More question suggestions

Visit [palliativecare.org.au](http://palliativecare.org.au) to download *Asking Questions Can Help: An aid for people seeing the palliative care team.*



# Glossary

## **advance care directive**

A written document intended to apply at 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. Known by various names such as advance care plan or living will.

## **advance care planning**

When an individual thinks about their future health care and discusses their wishes with their family, friends and health care team.

## **advanced cancer**

Cancer that has spread into surrounding tissues or to other parts of the body (secondary or metastatic cancer), and is less likely to be cured.

## **alternative therapies**

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

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

## **analgesic**

A medicine used to relieve pain.

## **cachexia**

Loss of body weight and muscle mass, and weakness.

## **capacity**

Having the ability to understand and think things through.

## **carer**

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

## **cells**

The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.

## **chemotherapy**

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth. May be given alone or in combination with other treatments.

## **chronic disease**

An illness or disease that is long-lasting and may change the way a person lives their life.

## **complementary therapies**

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

## **cytotoxic drug**

A substance (e.g. chemotherapy) that is toxic to cells, so it can kill or slow the growth of cancer cells.

## **depression**

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

## **dyspnoea**

The medical term for difficulty breathing. Also called breathlessness.

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

See substitute decision-maker.

**hospice**

See palliative care unit.

**hypercalcaemia**

Higher than normal levels of calcium in the blood.

**immunotherapy**

The prevention or treatment of disease using substances that stimulate your immune system to attack certain cells.

**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.

**lymphatic system**

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells.

**malignant**

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

**metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body.

Also called secondary cancer.

**morphine**

A strong and effective pain reliever that is commonly used to treat people with cancer who have pain.

**multidisciplinary care**

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

**oncologist**

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

**osteoporosis**

Thinning and weakening of the bones that can lead to bone pain and fractures.

**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, practical, emotional and spiritual needs.

**palliative care unit**

A place that provides comprehensive care for people with a life-limiting illness. This includes inpatient medical care, respite care and end-of-life care for people who are unable to or don't wish to die at home. It may also offer day care facilities and home visiting teams. Also called a hospice.

**palliative treatment**

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



**power of attorney**

The ability of a person to act on behalf of another on financial and legal matters.

**primary cancer**

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

**prognosis**

The predicted outcome of a person's disease.

**quality of life**

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

**radiotherapy**

The use of radiation, such as x-rays, gamma rays, electron beams or protons, to kill cancer cells or injure them so that they cannot grow and multiply. Also called radiation therapy.

**recurrence**

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

**relapse**

See recurrence.

**respite care**

Alternative care arrangements that allow the carer and person with cancer a break from their usual arrangements. Respite care can be given in the home, at hospital or in a palliative care unit.

**secondary cancer**

See metastasis.

**second opinion**

Talking to another specialist to consider other treatment options or to confirm a recommended course of treatment.

**substitute decision-maker**

A person who makes decisions on your behalf if you become incapable of making them yourself. The documents for appointing this person may be called an enduring power of attorney, an enduring guardian or a power of guardianship.

**targeted therapy**

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread. The two main types of targeted therapy at present are monoclonal antibodies and small molecule inhibitors.

**tumour**

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

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

For more cancer-related words, visit:

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



# How you can help

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

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

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

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

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

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

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



# Cancer Council 13 11 20

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

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

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

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

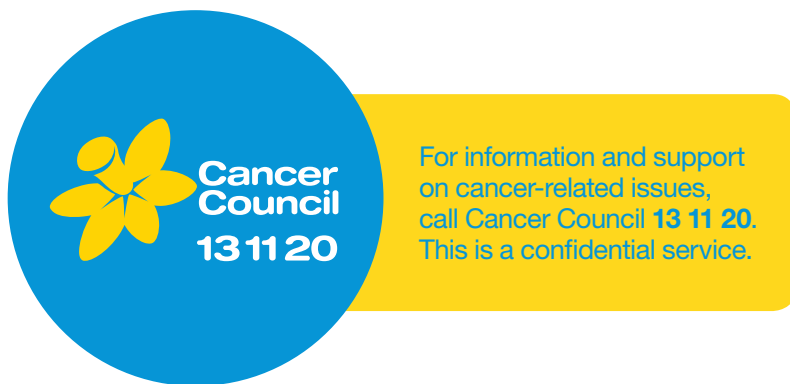
Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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



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



Produced in collaboration with:



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**Cancer Council ACT**  
actcancer.org

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cancercouncil.com.au

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