



Caring for Someone with Cancer

Coping with cancer

For information & support, call

13 11 20



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

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

Cancer Council

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



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Introduction

This booklet is for people who are looking after someone with cancer.

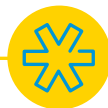
You may still be adjusting to the news that someone you know has cancer and that you will need to be their carer. You may be wondering what this will mean. It's natural to be worried about the demands of being a carer, the impact this might have on your life and how caring might affect your relationships.

This booklet aims to support you so that you can manage your emotional and physical needs and those of the person you are caring for. You may relate to some of the emotions and feelings described here, and you might learn practical tips on how to balance the demands of caring, family, work and your own needs.

Your role as a carer is valuable. Although caring for someone with cancer can be difficult and stressful at times, many carers have said they are better people for the experience of caring. While some people find that caring can be rewarding and life-changing, this is not always the case.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you.

If you're reading this booklet for someone who doesn't understand English, let them know that Cancer Council **13 11 20** can arrange telephone support in different languages. They can also call the Translating and Interpreting Service (TIS National) direct on **131 450**.



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Who is a carer?

A carer provides unpaid personal care, assistance and support to a person who needs this help because of a disability or disease such as cancer.

You may be a relative, friend or neighbour. Anyone can be a carer – it doesn't matter what your age, sex, sexuality, profession or cultural background is.

You may not see yourself as a carer, rather that you are simply helping out a person in need or that you are providing care as a natural extension of your relationship. Some carers accept the increased responsibilities, while others may feel they have no choice or the role is something they 'should' do.

Every carer is different

For some, becoming a carer can be sudden; for others, it's a gradual process. However it happens, it may take some time to adjust. You may have to balance caring with other demands such as work, family or study. You may provide care for a short time or over months or years. Care may be needed for a few hours once a week or on a 24-hour basis. You may be providing care alone or sharing the responsibility with others. Sometimes a carer lives a long way from the person they are helping and coordinates care by phone, email or the internet.

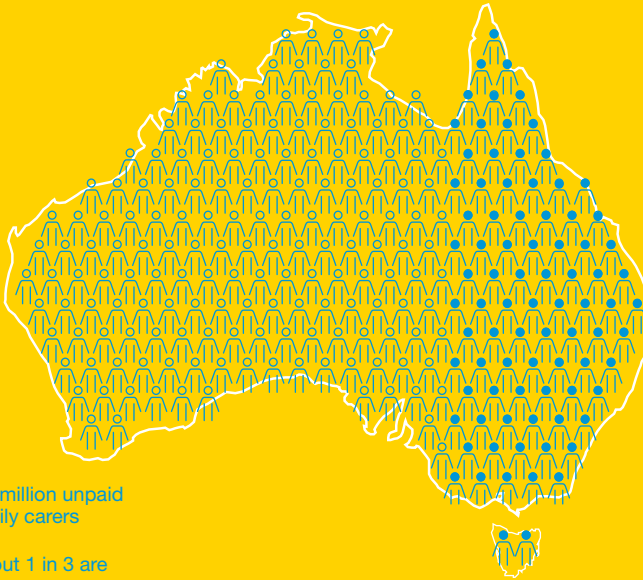
The level of care you provide depends on the needs of the person you are caring for, and what you are able to do. See the chapter *What carers do* on page 14 for more details.

How many carers are there?

According to the Australian Bureau of Statistics¹, there are almost 2.7 million unpaid family carers in Australia.

About one-third of these people are primary carers, meaning they provide most of the care for the person they are looking after. Two in five of these primary carers spend 40 hours or more per week providing care. Over 40% of primary carers are balancing paid work with caring responsibilities.

Women are more likely than men to be carers, and most care for a close relative such as a partner, parent or child. Almost 75,000 carers are under 15.





Isabella's story

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

Initially I took on the tasks at home that Louis was unable to do – such as lawn mowing and feeding the animals.

He had previously done the grocery shopping, because I don't drive. 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. She referred me to the hospital social worker, who organised domestic assistance and transport to treatment.

Louis joined a support group at the Cancer Support Centre. He enjoyed meeting new people and didn't feel so alone. While Louis was at the support centre, 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. After the exercise class I felt recharged and like I had more energy.

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.



How will I feel?

It's common for carers to experience a range of feelings about their role and responsibilities. Many feel as if they are on an emotional roller-coaster, and have many questions. Often these feelings are similar to those experienced by the person with cancer.

This chapter outlines the common emotions experienced, and outlines strategies to manage these feelings.

Common reactions

Although everyone is different, the following feelings are common to most carers at some point.

Worry

Caring for someone with cancer can be frightening. You may feel worried about:

- the health of the person you're caring for
- not knowing enough about the treatment and the health professionals involved in their care
- being responsible for giving medications
- having so many things out of your control
- not knowing what the future holds
- the possibility that the person you're caring for will die.

Many carers say that learning more about the cancer helps them feel more in control, while others feel overwhelmed by the information available. You need to do what feels comfortable for you. If you are anxious about managing medications, see page 20.

Anger and frustration

You may feel angry or frustrated for many reasons, including:

- having to be the carer
- managing the extra responsibilities
- believing that family and friends could do more to help
- having future plans disrupted
- having little or no time for activities you used to enjoy
- trying to juggle caring with family responsibilities and/or paid work
- feeling the person you're caring for does not seem to appreciate the hard work and the sacrifices you're making.

Stress

The demands, difficulties and limitations of looking after someone with cancer are often stressful. Symptoms of stress include physical signs, such as trouble sleeping, headaches, high blood pressure, changes in appetite and heart palpitations. Emotional signs may include feeling tired, unwell, overly sensitive or physically and emotionally drained.

It's common for carers to say they feel continually out of control or under extreme pressure. If stress is ongoing, it could lead to exhaustion and burnout.

“ I feel a huge burden of responsibility and my workload has increased. I have to care for someone who needs a great deal of attention, do all the chores around the house and make all the big decisions on my own. ” *Angela*

Loneliness

It is easy to become isolated or feel lonely as a carer. You may feel too busy or guilty to socialise or contact friends and family. People may visit you less often because they think you have too much to do or they don't know what to say. Some people are uncomfortable being around someone who is ill. Maybe you did a lot with the person who has cancer and you miss this special time together.

Even if you have many helpers, you can still feel alone and isolated. You may feel as though the main caring responsibility has fallen to you, and no-one quite understands what you are going through and how you feel.

Satisfaction

While caring can be challenging at times, many carers say it can also be a rewarding experience. Providing support for someone can bring a sense of satisfaction, achievement and personal growth.

Knowing that you are supporting someone during a time of need can help you feel good about yourself. Being there for them and helping even in small ways can strengthen

your relationship and create lasting memories.

You may not always feel this sense of satisfaction when you're caring for someone on a day-to-day basis. However, some people find that when their caring role ends, they are able to reflect on the positive and gratifying parts of their caring experience.

Depression

The word depression is used to describe a range of emotional states, from feeling low to not being able to get out of bed. Feeling down or sad is common in difficult situations and usually lasts a short time without severely affecting your life. However, clinical depression is different from feeling down or sad and is more than a mood you can snap out of.

Research shows that depression is common among carers. About one in four female carers and one in five male carers experience clinical depression². Some of the symptoms of clinical depression include:

- feeling sad or empty
- losing interest and pleasure in activities you used to enjoy
- experiencing a change in appetite or weight
- having problems sleeping
- feeling tired all the time
- having trouble concentrating
- feeling restless, agitated, worthless or guilty
- relying on alcohol and sedatives
- feeling that life isn't worth living.

There are a number of ways to manage depression. Talk to your doctor about your options.

“ I felt so much for my husband. And looking ahead, knowing he was going to die, I wondered how I was going to manage on my own. ” Vicki

Guilt

Guilt is one of the most common emotions that carers experience.

Some carers have said they feel guilty about:

- feeling angry and resentful
- wanting a break from caring
- being well, while the person they are caring for is sick
- not being able to make the person better, even though this is unrealistic
- saying or doing the wrong thing at the wrong time
- having to care for someone they do not really like
- not doing a perfect job as a carer.

Loss and grief

Many people associate loss and grief with dying. However, feelings of loss and grief can also happen when someone receives a diagnosis of cancer.

As a carer, you may feel that your relationship with the person you are caring for has changed. You may also miss activities you used to enjoy, such as work, regular exercise or socialising. Changes in roles and taking on new responsibilities can cause stress between you and the person you're caring for. You may have lost the future you thought you would have and/or be dealing with financial changes.

It can take time to adjust to the changes and challenges you are facing. The *How relationships change* chapter on page 40 outlines some of these changes and how to manage them. It may also help to talk to friends and family about your feelings, or you can contact Cancer Council 13 11 20.

Ways to cope with how you're feeling – You can use these suggestions to

Anger

- Notice the warning signs – tensing jaw, pounding heart, gritting teeth, shaking – and use strategies to calm yourself down.
- Take some deep breaths, and think about what has triggered your anger.
- Let the anger out – for example, go for a brisk walk or talk about your frustrations with a friend, relative or another carer.
- Recognise the situations that make you angry and learn to respond differently. It may help to acknowledge that under the circumstances these feelings are normal.
- Use your anger to motivate you to change what you can about the situation or to find out more about cancer and its treatment.
- Try relaxation or meditation. Call Cancer Council **13 11 20** for copies of CDs with guided exercises.
- Take a break – have a massage or do something you enjoy.
- Talk to your GP or a counsellor about your feelings. They may be able to offer both emotional and practical ways to help you manage.

Stress

- Look out for signs of stress, and find ways to deal with how you are feeling.
- Learn to meditate or practise breathing or stretching exercises such as yoga or tai chi.
- Do something you find relaxing such as listening to music, reading, or taking a bath.
- Talk to someone about how you're feeling.
- Accept offers of help from others or suggest tasks others can do. This will help reduce your workload. If you appear to manage on your own, people may assume you're okay.
- Try to rest and get enough sleep. You need energy to look after someone.
- Eat nourishing food to give you energy and keep you well. Ask your doctor if any vitamin or mineral supplements would be beneficial for you.
- Take time to care for yourself. Respite care may give you the break you need.

manage a variety of emotions.

Loneliness	Depression	Guilt
<ul style="list-style-type: none">● Use technology, i.e. email, Facebook or a blog, to stay in touch with family and friends.● Try to make contact with someone – either in person or by phone – on a daily basis, or ask a friend to ring you every few days.● Arrange for people to visit you at home. Reassure them it's natural to feel uncomfortable or upset by illness, and it's okay if they don't know what to say.● Join a local carers or cancer support group (see page 55). Sharing your feelings with someone in a similar situation may help you feel less isolated.	<ul style="list-style-type: none">● Plan time to do something you enjoy every day.● Get up as soon as you wake up rather than lying in bed.● Catch up with friends – either in person or on the phone.● Try to do some exercise; even a daily 30-minute walk may be beneficial.● Make an appointment with your GP to talk about what you are experiencing. Your doctor might refer you to a counsellor or talk about other options, such as medication.● Visit beyondblue.org.au for more information about depression and anxiety.	<ul style="list-style-type: none">● Talk about how you feel with the person you care for, a friend or family member. Keeping your feelings to yourself could add to the guilt you are already experiencing.● Consider talking to a counsellor. This may help you to communicate your feelings and change the way you are thinking.● Avoid using the words 'should' or 'must' – they can make you feel more guilty.



What carers do

Every caring situation is different. What you are required to do will depend on the needs of the person you are caring for and what you are able to do. The level of care you provide may change over time. This chapter discusses a range of tasks that may or may not be part of your role as a carer.

Caring can be more than a one-person job. Family and friends are often willing to help, but don't know how – consider telling them what you need help with. You can also access a range of support services (see page 52–55).

Recognising carers

The Australian Government has developed the National Carer Recognition Framework to acknowledge the valuable contribution of carers to the Australian community.

The framework is made up of the *Carer Recognition Act 2010* (Commonwealth) and the *National Carer Strategy 2011* (Commonwealth), and outlines six priorities to ensure that carers have rights and choices. Each state and territory government has also passed their own Acts and policies.

Carers should have:

- recognition and respect
- access to appropriate information that makes it easier to get support
- economic security and the opportunity to participate in paid work
- access to appropriate services
- the skills to do their role and the opportunity to participate in formal education and training
- improved wellbeing and health and the capacity to participate in community life.

Coordinate medical care

Working with the health care team

Most cancer treatment centres now have multidisciplinary teams (MDTs) made up of specialist doctors, nurses and allied health professionals including physiotherapists and dietitians. MDTs work together closely to manage the care of patients.

The team will discuss the needs of the person with cancer and recommend the best treatment. They may also refer the person to other specialists to ensure all aspects of their care are covered.

As a carer, you're part of the health care team. You can work with the team to ensure you understand, and are included in, decisions about the care and treatment of the person you care for.

Dealing with health professionals can be intimidating, especially if it's something new for you. You may feel overwhelmed with all the new and complex information or finding your way around a new clinic or treatment centre. Having one contact person in the multidisciplinary team, such as a cancer care coordinator, can help you feel more comfortable.



tip

The person you are caring for needs to give written consent for the treatment team to talk with you about their care. This consent and your contact details should be formally recorded in their case file.

Preparing for the doctor's appointment

Before the visit

- Write a list of all the questions you both have so you don't forget them during the actual appointment. Call Cancer Council 13 11 20 if you need information or help working out the questions to ask.
- Do some research at the library or on the internet so you can ask informed questions. For suggestions, see *Learn more about cancer* on page 56 and *Useful websites* on page 57.
- Make a list of all the medications being taken, including complementary therapies. Note the dose and any side effects.
- Check with the doctor's receptionist about what you need to bring, e.g. test results, scans, blood tests.
- Record any recent change in the person's condition or symptoms.
- Ask for a longer appointment if you have a lot of questions.

During the visit

- Take notes or record the discussion with the doctor.
- Write down any specific instructions.
- Clarify anything you don't understand.
- Ask the doctor if they can give you printed material or tell you where to find further information.

After the visit

- Review your notes.
- Record the next appointment in a diary or calendar.
- Call the doctor for test results, if appropriate.
- Contact the doctor about changes in the condition or symptoms.

What do we need to bring?

What do we need to ask about?

What changes can we expect?

Is there any information we can read?

Do we need to write a list of medications?

What side effects have we noticed?

Do we need to ask for a longer appointment?

What to think about before visiting the doctor

A cancer diagnosis and treatment often means many medical appointments. Before visiting the doctor, take some time to prepare for the appointment.

Health professionals you might see and their roles

general practitioner (GP)	responsible for general health and coordinates specialist treatment
surgeon	operates to remove tumours
medical oncologist	prescribes and coordinates the course of chemotherapy
radiation oncologist	prescribes and coordinates the course of radiotherapy
haematologist	diagnoses and treats diseases of the bone marrow, blood and lymphatic system
nurses	provide support and help during all stages of treatment and administer chemotherapy
nurse care coordinator	provides care, information and support throughout treatment

palliative care specialist and nurse consultant	responsible for control of symptoms such as pain, nausea, depression and anxiety
pharmacist	responsible for dispensing medication
dietitian	supports and educates patients about nutrition and diet during treatment and recovery
physiotherapist	helps with restoring movement and mobility, and preventing further injury
occupational therapist	assesses changes needed to your home and recommends equipment
pastoral care worker	helps provide emotional and spiritual support
counsellor, psychologist, social worker	provide emotional support and new ways to think about your situation and deal with difficulties

Managing medications

The person with cancer may be taking non-prescription and prescription medications. Knowing the answers to the following questions can help save time and confusion.

- What are the names of the drugs and what are they for?
- How much should be given and when?
- How should the drugs be given (with or without food, etc.)?
- Is there anything, such as alcohol or driving, that should be avoided while taking the medications?
- Do the drugs interact with other drugs or vitamin supplements?
- Are there any possible side effects? What should I do if the person experiences side effects?
- How long will the medications be needed?
- What should I do if a dose is missed?
- When is the use-by date?
- How should the drugs be stored?

Keeping track of medications

The National Prescribing Service (known as NPS MedicineWise) can help you record information about medications in several ways. See [nps.org.au](https://www.nps.org.au).

Medicines list (paper) – Download from website or order a copy online.

Medicines eList – Create a list online and save as a PDF.

MedicineList+ smartphone app – Scan the barcode on the medicine packaging to add the medicines to the app, and set up personalised dosages and reminders.

Applying for a PBS Safety Net card

Many medicines cost a lot more than the price they're sold for. The Australian Government helps reduce the cost through the Pharmaceutical Benefits Scheme (PBS) and Safety Net card.

To apply for a PBS Safety Net card, you need to keep a record of what is spent on PBS medicines on a Prescription Record Form (available from pharmacists). If you always use the same pharmacist, you can ask them to keep a computer record instead. Once the threshold is reached, your pharmacist can give you a Safety Net card so your PBS medicines are less expensive or free for the rest of that calendar year. To find out more, call 1800 020 613 or go to pbs.gov.au.

Managing pain

The following strategies can help you work with the person you're caring for to control their cancer pain:

- Use a pain scale to help you understand the intensity of the pain, and the need for extra doses of pain medication.
- Keep a diary of pain levels and symptoms. Let the health care team know how the medication is working and of any changes.
- Try relieving pain and discomfort with hot water bottles, ice packs or gentle massage. For more information about massage you can do at home, see Cancer Council's booklet *Massage and Cancer*.

To learn more about managing pain, call Cancer Council 13 11 20 and ask for a copy of *Overcoming Cancer Pain*, or download it from your local Cancer Council website.

Provide practical support

Carers often provide practical care. This can include doing household chores, preparing meals and providing transport.

If the person you care for has difficulty moving around because of the cancer or its treatment, you may have to make some changes to their home environment.

Preparing food and drinks

You may notice the person you care for has appetite changes or difficulties chewing and swallowing. At times, they may not even be able to tolerate their favourite foods.

Treatments such as chemotherapy and radiotherapy can damage and kill cancer cells but also affect healthy cells. This may cause side effects such as:

- loss of appetite
- nausea
- fatigue and tiredness
- mouth or throat sores
- taste changes
- constipation or diarrhoea.

Nausea and poor appetite can last for several months after treatment ends. A dietitian, doctor or nurse can provide advice on a suitable eating plan. The tips on the opposite page will also help. For more practical suggestions on eating well during and after cancer treatment, call Cancer Council 13 11 20 and ask for a copy of the *Nutrition and Cancer* booklet.

Helping with food

- Offer the person's favourite or well-tolerated foods often. You don't have to follow a strict diet.
- Try not to worry too much if the person you're caring for refuses food you have prepared. While you may want them to eat well to stay strong during treatment, the side effects may have changed their taste and appetite.
- Make meals a time when you can sit together and talk.
- If the person you care for is losing weight or feels too nauseous to eat, talk to your doctor, dietitian or pharmacist about digestive aids or dietary supplements.
- Follow good hygiene and food safety practices because treatment can weaken the body's immune system. Wash your hands before preparing food and take special care when handling raw meat, fish and chicken.
- Encourage the person you are caring for to ask their doctor for different nausea medications until they find one that works well.
- Ask others to prepare meals.

Making the home safer

- Rearrange furniture to make access easier, and remove loose rugs and other tripping hazards.
- Talk to an occupational therapist about changes you can make or equipment you can hire or buy – for example, putting handrails on the stairs or in the bathroom, or using a chair in the shower.
- Look after your back if you need to lift the person you're caring for. Ask a nurse or physiotherapist to show you how to lift safely and about aids you can hire or buy.
- Use a folder, expanding file or filing cabinet to organise bills, receipts and letters from health professionals. Although it might take a bit of time to set up, carers who have a system for paperwork say it reduces stress.
- Get help with bathing, toileting and dressing. Some carers feel uncomfortable doing this care themselves, particularly for parents or adult children.
- Organise help with housework through community services or ask family and friends for assistance.

Manage finances

Caring for someone with cancer can cause financial problems. There may be a drop in your household income if you or the person you are caring for need to reduce work hours or stop working. There may also be new expenses such as transport, medications, scans, tests and equipment.

Financial payments

The Department of Human Services (Centrelink) supports carers financially through various schemes:

Carer Payment (adult and child) – for carers who provide full-time daily care in the home of the ill adult or child. This payment is income- and asset-tested.

Carer Allowance (adult and child) – for carers who provide a significant amount of assistance, either in their own home or in the home of the sick adult or child under 16. The allowance is not means-tested and can be paid even if you are working. A carer who receives the Carer Payment for a child, generally receives Carer Allowance automatically.

Carer Adjustment Payment – a one-off payment to help a family care for a child under 7 years of age who has had a sudden and severe illness. Must also receive Carer Allowance for the child.

Carer Supplement – an annual lump sum payment made to people receiving the Carer Allowance. An additional payment is made to those who qualify for a carer payment.

Financial services

The Department of Human Services also offers a free, confidential Financial Information Service that provides education and information on financial issues. You can book a seminar on 136 357 or email fis.seminar.bookings@humanservices.gov.au.

Travel payments

If the person with cancer travels for treatment that isn't available in their local area, they may be entitled to partial reimbursement of travel costs from their state or territory government. Eligibility for these patient travel assistance schemes varies from state to state. Talk to your social worker or community health centre for more details, or call Cancer Council 13 11 20.

tips

- Speak to a social worker to find out what you can apply for and how.
- Visit humanservices.gov.au to check if you're eligible for the carer payment or allowance.
- Contact your local Carers Association on **1800 242 636** for help and information on financial assistance.
- Cancer Council may also be able to provide some financial assistance. Call **13 11 20** for more details, and to request a copy of *When cancer changes your financial plans*.
- Seek professional help, e.g. financial counsellor, to set up budgets and manage debt.
- Find out if you or the person you are caring for are eligible to access superannuation early. Get financial advice as accessing this money may affect your retirement.

Long-distance caring

Living away from the person with cancer can be difficult. You may feel guilty for not being closer, and you may feel you are the last one to know about treatment and care. This can be frustrating when you want to stay involved.

However, there are many things you can do. Living away from the everyday care may give you a different perspective on the situation. This may help you solve problems or coordinate care more effectively.

- Create a support network of volunteer and paid care workers, service providers, relatives and friends to visit the person regularly. These people should be reliable in case of an accident or emergency.
- Write a contact list of the health professionals who are looking after the person with cancer, and keep this list handy in case you need to contact them.
- Use technology (such as email, blogging, text messaging, Skype, Facebook and video conferencing) to stay in touch.
- Ask the person if their doctor will allow them to record consultations, so you can hear what was discussed.
- Look for the best possible telephone (landline and/or mobile) plan to reduce your costs.
- Create an Emergency Care Plan (see page 28) and give copies to the nominated carer and emergency contacts.

Make legal arrangements

There are several legal steps a person with cancer can take to ensure their wishes and future care plans are known and acted upon. These steps will help ease worry and stress if medical needs change. As a carer, you will need to be aware of these plans as you might be a part of them.

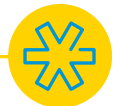
Appoint a substitute decision-maker – If the person with cancer becomes unable to make their own decisions, the substitute decision-maker will manage their financial and legal affairs while they are alive, and make decisions relating to their health and lifestyle.

Make an advance care directive (living will) – This document outlines the plan for future medical care of the person with cancer, taking into consideration their values and beliefs.

Prepare a will – This is a legal document that sets out who will receive the assets of the person with cancer after their death.

Contact Cancer Council's pro bono service on 13 11 20 for assistance with preparing these documents.

Depending on which state or territory you live in, the document used to appoint a substitute decision-maker may have a different name, such as enduring power of attorney, enduring power of guardianship or appointment of enduring guardian.



Emergency Care Plan

An Emergency Care Plan is a document that provides direction and instructions to allow others to provide the care that you would usually provide.

Think about the best people to fulfil your carer's role. Discuss the duties with them and ask for their commitment. Let the person you're caring for know about the alternative arrangements.

The Department of Health website has a sample Emergency Care Plan. Download a copy from health.gov.au or contact the Commonwealth Respite and Carelink Centre on 1800 052 222.

Offer emotional support

Carers often provide emotional support to the person with cancer. However, some carers find it can be challenging to talk to someone about their cancer diagnosis and treatment. This may be because you:

- fear saying the wrong thing
- don't know what to say or how to respond
- feel you shouldn't talk about the cancer
- don't want to say something upsetting
- feel you have to be supportive and strong for the person with cancer, and worry you could break down.

Not everyone finds talking about what is happening helpful, and it's important to respect this. If you are caring for your partner, try to find ways to support each other. You can't change the diagnosis, but listening to each other's concerns can help.

Ways to be a good listener

- Sit somewhere private where you will not be interrupted.
- Signal that you are there for as long as needed, e.g. switch off your mobile phone.
- Maintain eye contact.
- Listen carefully to what may be behind the words. Try not to think about something else or plan what you will say next.
- Ask open questions to help you understand how they are feeling.
- Avoid interrupting or changing the subject.
- Allow the person to be sad, upset or cry. You don't have to keep them happy and in good spirits all the time.
- Check your understanding of what they've said by repeating information or paraphrasing.
- Wait to be asked before giving advice.
- Respond to humour.
- Avoid filling the gaps in conversation. Silence can allow you both some time to gather your thoughts.

Ways to resolve conflict

- Let the person you are caring for know that you care about them and want to resolve your differences.
- Try to stay calm and talk through the issues involved. Hear each other out and work towards making a decision together. Sometimes people disagree because there has been a misunderstanding.
- Compare your expectations. For example, some people with advanced cancer choose to stop having treatment. You may find this difficult to accept if you feel they are giving up and you want them to keep trying different options.
- Choose your battles – it may help to focus your energy on the issues that really matter.
- Consider taking a break and organising another arrangement for care.
- Ask your GP or medical team for a referral to a social worker, counsellor or psychologist who can help you resolve the conflict.

Conflict and disagreements

During your role as a carer, there may be occasions when you don't agree with the person you are caring for. It's natural to have disagreements from time to time. Although dealing with conflict can be challenging, it can also bring you closer together and help you understand each other's point of view.

Communicating with family and friends

Many carers say they find it time-consuming and tiring to keep family and friends up to date on the condition of the person with cancer. Some carers also find it stressful dealing with other people's reactions to the updates.

tips

- Explain to family and friends how you'll keep them up to date. It's okay to let them know that it is stressful and time-consuming responding to a range of inquiries.
- Use technology such as group text messages or emails to keep others up to date. You may want to start an online diary, Facebook page or blog to coordinate offers of help.
- Ask a family member or friend to keep others up to date.
- Leave a message on your answering machine to cut down on the time needed to answer or return calls. You could say something like: "Bill is doing okay with the chemo. He's mainly feeling tired. Thanks for your concern."
- Read the *Talking to Kids About Cancer* booklet, if children are involved. Call Cancer Council **13 11 20** and ask for a copy, or download it from your local Cancer Council website.



Key points

- Your caring role will depend on the needs of the person you are caring for and what you can do.
- Carers often liaise with various health professionals. Some carers help the person with cancer prepare for medical appointments.
- You might need to give medications to the person with cancer. Your doctor or pharmacist can give you advice about managing medications, or you can use a paper-based or electronic medicines list.
- Preparing food and drinks can be an important part of someone's care. To find out more call **13 11 20** for a copy of *Nutrition and Cancer*.
- You may need to make changes to your home to ensure it's a safe environment.
- Create a system to keep track of paperwork such as bills, receipts, test results, reports and letters.
- You may be eligible for financial assistance through the Department of Human Services (Centrelink).
- Carers often help manage finances. If you have an enduring power of attorney, you can act on the person's behalf on all financial matters.
- Consider using technology, such as blogging or social media, to update friends and family about the condition of the person with cancer. A friend or family member can also help with this.
- It can be challenging if you don't live close to the person with cancer, but there are ways that you can provide support from a distance.



Caring for yourself

Many carers say that providing care can affect their relationships, career, finances and health and wellbeing. Caring can be rewarding, but many carers also find it difficult at times, both physically and emotionally.

Looking after yourself

The responsibility of attending to the needs of the person you're caring for may mean that you neglect your own needs. Some carers have said they felt like they lost their identity when caring. It may feel as though your career, interests and health are no longer important or have to take second priority.

Looking after yourself will help you provide better quality of care to the person you care for over a longer period of time.

Keeping healthy

As carers are busy looking after someone else, they can find it difficult to find time to look after their own health and wellbeing.

When they do notice that they're not feeling well, they might downplay their own health needs. You can acknowledge that you are not feeling well without comparing it to how the person with cancer is feeling.

Maintaining fitness and eating well will help carers more easily cope with the physical demands of caring. Getting enough sleep will also give you more energy.

Ways to look after yourself

- Make time for a break every day, even if it's just 10 minutes.
- Plan breaks or respite care in advance, so you can arrange some time for yourself.
- Stay involved in activities you enjoy. It's a good stress relief, and will give you something else to think and talk about aside from caring.
- Let friends or family know that you want to chat about things other than caring.
- Ask family and friends to help you so you can have regular breaks. See page 34.
- Try not to hold in how you feel about caring, particularly if you are angry or frustrated. You may want to share how you're feeling with friends or family members.
- Be kind to yourself and ensure your expectations are reasonable.

Ways to stay healthy

- Eat healthy meals and snacks. If the person you care for has long appointments or is in hospital, you may need to bring healthy food from home.
- Try to get enough sleep and rest. Tiredness and exhaustion often make everything seem harder. Have regular check-ups with your own doctor.
- Avoid using alcohol or cigarettes to relax. These may make you feel better for a short time, but they contribute to other problems.
- Exercise for 15–30 minutes each day. This can increase your energy levels, help you sleep better and improve your mood. If you can leave the house, a walk, run or swim may help. An exercise bike or a yoga/meditation mat can allow you to exercise at home.
- See a doctor if you notice changes in your health such as fatigue, sleep problems, weight changes and depression.

Asking others for help

Asking for and accepting assistance is sometimes difficult. You may find it hard to let others know what help you need, but if you seem to be coping, family and friends may not realise you need help. They may be waiting for you to ask for help because they don't know how to offer or fear they will be intruding or disturbing you. Let them know their help is appreciated and that it's not an interference. Asking for help is not a sign of failure, and it may relieve some pressure and allow you to spend time with the person you're caring for.

“ 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. ” *Gavin*

You may want to hold a family meeting to discuss how everyone can help. Tasks that can be done by or shared with others include:

- doing household chores such as cooking, cleaning, laundry, ironing, shopping or gardening
- driving the person with cancer to appointments and/or attending appointments with them
- picking up children from school or other activities
- looking up information
- keeping others updated
- sitting and talking with the person you care for while you take a break.

Ways to cope

Caring for someone with cancer is not always easy or satisfying. Many carers say they feel overburdened and resentful. The following strategies may help you cope:

Focus on the value of caring – Acknowledging the rewards of caring may help you feel better. These include learning new skills, strengthening your relationship as you demonstrate your love and commitment, and satisfaction from providing care to someone in need.

Set boundaries and limits – Outline what you are comfortable helping with, the level of workload you can manage, and what your own needs are. For example, if you find it uncomfortable or are physically unable to wash or provide intimate care to the person you care for, look at alternatives such as regular visits from a community nurse.

Organise your time – It may not be possible to do everything you want to do. You will need to prioritise your weekly tasks and activities. You may want to use a diary to keep track of information and appointments.

Keep a journal – Writing down what has been happening allows some carers to release their worries or frustrations. It's also an opportunity to reflect on how they're coping and identify areas they need assistance with. Reading back through journal entries can give carers some perspective – you may notice that some days are better than others.

Don't expect to be perfect – Sometimes you may feel like you could have done something differently or handled a situation better. Allow yourself to not be perfect. Each new day brings a fresh start and a chance to remind yourself that you are doing your best.

Deal with uncertainty – When the person you care for is having treatment, life may seem less predictable. You may have to put some plans on hold because you are not sure what is ahead. Carers often find this uncertainty stressful. You may find it easier to cope if you focus on things you can control.

You may be able to schedule doctors' visits so you can accompany the person you're caring for. It may also help to learn more about cancer and possible treatment options so you feel like you have a better understanding of what is happening.

If caring becomes too much

You might find providing care too difficult, particularly if the person you're caring for insists you do all the caring rather than involving others.

Perhaps you know you need support but don't want to disappoint them. Consider seeing a professional

counsellor, either alone or with the person you are caring for. The counsellor may be able to discuss options to make caring more manageable.

Ask your GP or call Cancer Council **13 11 20** for information on how to get a referral to a counsellor.

Taking a break (respite care)

Respite care allows carers to have a break from their caring role. Respite can be given at home, in a respite care centre or, in some cases, a hospital or hospice.

Respite care can be for a couple of hours, overnight or a few days.

You can access respite care for any reason, including to:

- take time out to access health care for yourself
- visit friends or other family members
- catch up on some sleep at home
- run errands, such as grocery shopping
- attend events, such as a school assembly or a wedding.

Some carers don't access respite care because they feel guilty or anxious about leaving the person they are caring for. However, the service is there because caring can be a difficult role and can affect your wellbeing. By taking a break, you will probably find that you can continue your caring role more effectively.

Commonwealth Respite and Carelink Centres, located across Australia, provide free and confidential information on local carer support services and respite options. Call 1800 052 222 during business hours. Call 1800 059 059 for emergency respite support outside standard business hours.

“ I cannot speak highly enough of the Commonwealth emergency respite services for carers. They played a very important role in my case. ” Geoff



Key points

- Caring can be physically and emotionally demanding.
- Looking after your own wellbeing can relieve stress and tiredness, and reduce feelings of frustration and isolation.
- You may feel that your health and interests are second priority to the person with cancer. Try to take time for yourself every day, even if it's only a short amount of time.
- Carers often forget to look after their own health. Try to eat well, get some exercise, rest and keep up your regular medical check-ups.
- Talk to your doctor about any health concerns, especially if you are feeling depressed.
- Focusing on the value of your caring role can make you feel more satisfied.
- Organise your time wisely and try to concentrate on one task at a time. Using a diary and getting help from others can relieve some of the pressure.
- Life can be unpredictable and uncertain at times. Learning more about the condition of the person you are caring for may help you feel more in control.
- Organise respite care so you can have a break from your caring duties.



Working while caring

Many people who care for someone with cancer are also employed. They may work full-time, part-time, casually or have their own business. Working carers often have to balance the needs of the person they are caring for with the demands of the workplace. If the person with cancer does not work and is dependent on you, there may be financial pressure on you to continue earning an income.

Your decision to continue working will probably depend on:

- how unwell the person with cancer is
- what your caring and work duties involve
- the amount of help or respite care available
- your finances
- what will give you peace of mind.

Before making changes to your working arrangements, talk over your thoughts with your employer, family and friends. You can also contact the Carers Association in your state or territory for support and counselling. Visit carersaustralia.com.au or call 1800 242 636.

To find out more about working while caring for someone, see workingcarers.org.au or contact your local Carers Association. Call Cancer Council 13 11 20 and ask for free copies of *Cancer, Work and You* and *Cancer Care and Your Rights*.



How relationships change

Taking on a caring role often changes relationships. For many carers, a cancer diagnosis affects the established roles they have with their partner, parent, friend, dependent or adult child or sibling, and this can be a challenging adjustment.

The effect of cancer on your relationship will vary, and the impact often depends on what your relationship was like before the cancer diagnosis. Some carers find the opportunity to care for someone strengthens the relationship with the person they are

How will cancer change our relationship?

- If I'm doing all the caring they may feel like they've lost their independence.
- I might need to take on new responsibilities that will reverse our roles.
- The intimacy we shared might be replaced by the caring role.
- We might need to re-evaluate our priorities and set new goals.

looking after. For others, particularly those who had a strained relationship before the diagnosis, the pressure of a cancer diagnosis and treatment and the demands of caring add further tension. You may find it best to share the caring role with other people so you are not the full-time carer (see page 34).

Understanding potential changes can help. See the illustration below for ways a relationship may change, and how to manage these changes.



Ways to manage changes in your relationship

- ✓ Arrange home help if you feel uncomfortable doing the bathing and dressing.
- ✓ Set boundaries to maintain independence and allow both of you to feel in control.
- ✓ Talk about the changes to avoid misunderstandings.
- ✓ Listen to each other's needs and find ways to meet them.
- ✓ Allow time for both of you to get used to the change in roles, particularly if your roles have reversed.
- ✓ Give the person you're caring for the chance to do things for themselves so they feel useful.
- ✓ Use touch to show you care.

Support for LGBTI carers

Lesbian, gay, bisexual, transgender or intersex (LGBTI) people may face specific challenges when caring for their partner. They may worry about the family of their partner accepting them, or wonder if support services are LGBTI-friendly. Ask the Carers Association in your state or territory what support is available for LGBTI carers in your local area.

Changes in sexuality and intimacy

If you are caring for a partner, you may find the cancer and its treatment affects your sexual relationship. The effects on your sexuality and intimacy will depend on the type of cancer, the treatment and its side effects.

- Tiredness can make people lose interest in sex during and after treatment. This is called a lowered libido.
- Pain, medications and treatment can also reduce your libido and can affect someone's physical ability to have sex.
- A person's body image may change after treatment, making them feel self-conscious and embarrassed.
- The emotional strain of cancer or caring may preoccupy you and cause you to lose interest in sex.
- Many people worry that touching their partner intimately will cause pain.

There are ways you may be able to manage sexual side effects and maintain intimacy with your partner who has cancer.

- Restore the intimacy in your relationship by spending time together. If your partner is well enough, you may be able to go to the cinema or out to dinner. Otherwise, watch a movie at home together, give each other massages, do a crossword together, look through old photo albums, or talk about how you first met.
- Tell your partner you care. Your partner may need reassurance that you love them and find them attractive despite the physical changes from their illness or treatment.
- Discuss any concerns you have about being intimate with your partner. If you keep quiet and withdraw, your partner may misinterpret your distance and think they're no longer desirable. Being open with your partner about your sexual needs can help you identify changes to make.
- Keep an open mind about ways to give and receive sexual pleasure. You may need to try different things if your usual ways of lovemaking are now uncomfortable or not possible. Some people find lubricants or sexual aids help. For a while, you may need to focus on kissing and cuddling.
- Take things slowly and spend time getting used to being naked together.
- Be patient. You may find that any awkwardness will improve with time and practice.
- Talk to a counsellor who specialises in helping couples with intimacy and sexual issues.
- For more information, call Cancer Council **13 11 20** and ask for a free copy of *Sexuality, Intimacy and Cancer*.

If your caring role ends

There may come a time when your assistance is not needed as much. It may be because the person you are caring for is getting better and trying to resume their usual activities. This may make you feel a bit lost or not needed any more.

The person you are caring for may gain a new independence and appear to have forgotten how much time and effort you gave. This can be hurtful, but the person is probably not aware of how you are feeling.

You may expect to slip back into your day-to-day life as it was before you took on the caring role, but this can be challenging. You might feel you are still on call for the next setback. Your life may also have changed. Going back to work or resuming other responsibilities you had put on hold can be overwhelming. Do things at your own pace and give yourself some time to adjust. You might be able to return to work part-time or take on fewer responsibilities.

Talking about your feelings with someone you trust can help you to process the changes and think about what is next.



Key points

- Caring for someone with cancer may put your relationship under greater stress. However, some people say that facing a cancer diagnosis together strengthens their relationship.
- If you have a difficult relationship with the person you care for, the demands of caring may add further tension.
- If you or your partner are gay, lesbian, bisexual, transgender or intersex and your relationship is not recognised, you may face extra challenges caring for your partner.
- Cancer may affect your sexual relationship. For example, some treatments leave people with little or no interest in sex, or you may feel too tired to have sex. You can maintain intimacy by spending quality time together, exploring other ways to be intimate, discussing your feelings, and taking things slowly.
- The person with cancer may not want your help with some tasks, such as toileting or showering. You may also be uncomfortable with these tasks or you may find it hard to step back and respect their privacy. Seek in-home help if needed.
- At some point, your assistance may not be needed as much or at all. This may make you feel redundant or hurt. It might be difficult to resume your life as it was before. Give yourself time to adjust to the situation and to find other activities that give you pleasure and a sense of worth.
- Professional counselling can help you cope with these relationship changes.



Caring for someone with advanced cancer

The person you are caring for may have been told that they have advanced cancer. This means the cancer won't go away and is unlikely to be cured. Caring for someone with advanced cancer can feel overwhelming at first. You may both be trying to come to terms with the diagnosis and experiencing a range of strong emotions such as fear, sadness and grief.

Some people can live with advanced cancer for many years, and their needs will change as the disease progresses.

The demands on you as a carer might increase. You may have to reassess the type of care you can offer and think about who else can help. The person with advanced cancer may need to be admitted to hospital or another type of care facility. Some carers feel guilty when this happens, but handing over the everyday care to somebody else will allow you to spend more time just being together. If you wish, you can assist the staff with physical duties.

Palliative care

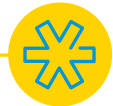
The aim of palliative care is to enhance quality of life and help people with cancer maintain their independence for as long as possible. It also supports carers in their role.

Palliative care is tailored to each person's circumstances and involves the coordination of services to meet their medical, emotional, spiritual and social needs. A GP or community health nurse can coordinate palliative care at home, but if the person's needs change, they may be referred to a specialist palliative care team.

Discussing the person's wishes

A person with advanced cancer may wish to discuss their thoughts about dying. This is more likely if you are their partner or close family member. Although discussing death and dying can be difficult, they are important issues. Getting advice from a counsellor, social worker or pastoral care worker may help you prepare for these discussions.

Where a person dies can be important. Some people prefer to be in a hospital or hospice. Others wish to die at home in familiar surroundings and in the company of their family. Talking about these options early while the person is still well can help avoid distress and regrets or feelings of guilt later.



Cancer Council has produced several booklets to help you cope when cancer has advanced. Call **13 11 20** and ask for free copies of *Living with Advanced Cancer*, *Understanding Palliative Care* and *Facing End of Life*.

Anticipatory grief

Some carers experience anticipatory grief. This is the grief you feel when you are expecting the death of someone close to you.

You may feel sad, down and depressed or become anxious and concerned for your family member or friend. Or you may find yourself preparing for the death and beginning to think about what life might be like once they are gone.

A long illness can give family and friends time to slowly get used to the person dying, to say what they want to say or to share memories. One idea is to write about what the person has meant to you and then read it aloud to them.

Having time to grieve doesn't necessarily make the loss of the person easier to cope with once they have died.

“ I would find myself rehearsing the eulogy in the shower, and then feel guilty. Talking to others at my support group helped me to realise my thinking was normal. ” *Carer*

When the person you care for dies

There is no right way to cope with the loss of the person with cancer. You need to grieve in a way that feels natural to you, particularly if you have religious or cultural customs that influence how you grieve.

You may feel a range of emotions, including:

- sadness
- numbness and shock, even if you thought you were prepared
- relief that the person is no longer in pain
- shocked that you feel relieved to be free of the burden of caring and can now make plans for your future
- anger towards the doctors or the hospital, your god or the deceased person for dying
- guilt that you are thinking of yourself at this time.

All these reactions are common. Feeling relief or guilt is not a sign that you didn't care. These emotions may come and go and change in intensity over time.

There are many services available to help with the practical and legal aspects of the death. For more information, contact Cancer Council 13 11 20.

What is grief like?

Grief is different for everyone. Reactions vary, but may include:

- physical symptoms such as difficulty breathing, a physical ache in the chest, nausea, loss of appetite, crying and sleep problems
- forgetfulness, difficulty concentrating or making decisions
- a sense of disbelief.

There is no right or wrong way to cope with a loss. You may have religious or cultural customs that influence how you grieve.

Some people are critical of themselves for not coping as well as they think they should or for not reacting in the way others may expect them to grieve. Coping with grief is an ongoing process and your response may not be what you expected. The feelings of loss don't go away, but the intensity generally eases with time.

Most people will continue to grieve in subtle ways for the rest of their lives. You may find that little incidents, memories or anniversaries (like birthdays or the day the person died) bring back an intense sense of loss. It may help to arrange to be with

family or friends at these difficult times. Support groups or counselling can also help you get through times when your grief seems overwhelming.

Everyone grieves differently and takes different amounts of time to learn to live with the loss of a loved one. However, if your sadness is ongoing and affects your ability to function day to day, talk to your GP about your feelings.

For more information, see the Cancer Council's booklet *Understanding Grief*, available free by calling 13 11 20, or download a copy from your local Cancer Council website.

“ I feel I am now coping well with the loss of my husband. It is coming up to four years and I will always miss him; however, my life now has to be lived without him. I keep myself busy and I am doing okay. ” Fiona



Key points

- Caring for a person with advanced cancer can be daunting and upsetting.
- As a person's illness progresses, their needs may change and a different level of care may be needed.
- Palliative care aims to manage symptoms and pain or discomfort to maintain quality of life.
- Discuss the person's wishes about end-of-life care and where they would like to die as early as possible so you can prepare.
- Anticipatory grief is a natural reaction when someone close to you is dying.
- When the person you care for dies, you may feel a range of emotions, from sadness and numbness to anger and despair. Even if you were expecting the person to die, the loss can still be shocking and painful.
- Everyone grieves in a different way. You may feel a range of physical and emotional changes.
- Coping with grief is an ongoing process and, at times, can feel overwhelmingly difficult. Some days are better than others. Memories and anniversaries can stir up strong feelings.
- Carers' and bereavement support groups and counselling may help you. Seek professional help if you are not coping or think you might be depressed.



Support and information

Help and support can help make the life of a carer easier.

The availability of services may vary depending on where you live. Some services are free, but others may have a cost. Talk to the social worker at the treatment centre or call Cancer Council 13 11 20 to find out what services are available.

Aboriginal resources

Looking After Ourselves:

Carers NSW

1800 242 636

carernsw.org.au

This kit includes a DVD that covers how Aboriginal carers can take breaks and look after their own wellbeing.

Aboriginal Cancer Journeys:

Cancer Council NSW

cancercouncil.com.au

Stories from Aboriginal people and carers about living with a cancer diagnosis.

Carer services

Carers Australia

1800 242 636

carersaustralia.com.au

National body represents Australia's carers and can help with referrals, counselling and support. Carers Associations are available in each state and territory.

National Carer Counselling Program (NCCP)

1800 242 636

Offers short-term counselling for carers. The program is delivered by qualified, professional counsellors either in person, by telephone, one-on-one or in a group. The NCCP service is run by your local Carers Association.

<p>Young Carers 1800 242 636 youngcarers.net.au</p>	<p>Supports young people caring for a parent who is physically or mentally ill. Run by Carers Australia, the program offers support and information.</p>
<p>Counselling</p>	
<p>Better Access initiative health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat</p>	<p>Medicare-subsidised referral to psychological counselling through your GP.</p>
<p>Beyondblue 1300 22 4636 beyondblue.org.au</p>	<p>Offers a 24-hour telephone counselling service. Online and email counselling are available 7 days a week.</p>
<p>Kids Helpline 1800 55 1800 kidshelp.com.au</p>	<p>A telephone and online counselling service and crisis support for young people aged 5–25.</p>
<p>Lifeline 13 11 14 lifeline.org.au</p>	<p>A 24-hour telephone crisis support and suicide prevention service.</p>
<p>Cancer Council's peer support programs 13 11 20</p>	<p>Communities of people affected by cancer that you can connect with online, by phone or in person.</p>
<p>Equipment and aids</p>	
<p>Independent Living Centres Australia 1300 885 886</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

humanservices.gov.au

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

Financial Counselling

Australia

1800 007 007

financialcounsellingaustralia.org.au

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

Home help

Call your local council

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

Home nursing

Talk to your palliative care team and/or your private health fund

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

Legal and financial advice and information

Cancer Council Pro Bono Program

13 11 20

Supports people affected by cancer who need legal or financial advice.

Respite care

Commonwealth Respite and Carelink Centres

1800 052 222 during business hours

1800 059 059 for emergency respite

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

Support groups

Face-to-face groups

Cancer Council **13 11 20**

Contact your hospital social worker to see if they run any support groups.

It can help to meet with others who understand what it is like to have cancer. You may be reluctant to share your story or listen to other people's, but many people find that they benefit from the close bonds with others.

Telephone support groups

Cancer Council **13 11 20**

Provide a chance to connect with others over the phone. There are groups for advanced cancer and for carers.

Online discussion groups

cancerconnections.com.au

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

Learn more about cancer

You may find it helpful to learn more about cancer. Having a better understanding of treatments and services may give you more confidence when speaking to health care professionals.

You can call Cancer Council 13 11 20 for information and support, or visit your local Cancer Council website. The hospital, treatment centre or Cancer Council may also run workshops or discussions about cancer, treatments and side effects.

Related publications

Cancer Council has a range of free publications:

- *Emotions and Cancer*
- *Nutrition and Cancer*
- *Massage and Cancer*
- *Exercise for People Living with Cancer*
- *Understanding Complementary Therapies*
- *Cancer, Work and You*
- *Cancer Care and Your Rights*
- *When Cancer Changes Your Financial Plans*
- *Overcoming Cancer Pain*
- *Sexuality, Intimacy and Cancer*
- *Living with Advanced Cancer*
- *Understanding Palliative Care*
- *Facing End of Life*
- *Understanding Grief*

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



Useful websites

The internet can be a useful source of information, although not all websites are reliable. The websites listed below are good sources of reliable information.

Australian

Cancer Council Australia.....	cancer.org.au
Cancer Australia.....	canceraustralia.gov.au
Cancer Institute NSW.....	cancerinstitute.org.au
Carers Australia.....	carersaustralia.com.au
Carer Life Course.....	carerlifecourse.com.au
Young Carers.....	youngcarers.net.au
Department of Health.....	health.gov.au
Department of Human Services.....	humanservices.gov.au
Commonwealth Respite and Carelink Centres.....	commcarelink.health.gov.au
healthdirect Australia.....	healthdirect.gov.au
beyondblue.....	beyondblue.org.au
Palliative Care Australia.....	palliativecare.org.au
Australian Centre for Grief and Bereavement.....	grief.org.au
Pharmaceutical Benefits Scheme.....	pbs.gov.au
ReachOut.com.....	au.reachout.com

International

American Cancer Society.....	cancer.org
American Society of Clinical Oncology.....	cancer.net
Macmillan Cancer Support.....	macmillan.org.uk
US National Cancer Institute.....	cancer.gov



Glossary

advance care directive

A written document intended to apply to a point in the future when you don't have the capacity to make decisions. It provides a legal means for a competent adult to appoint a substitute decision-maker and/or record their choices for future health and personal care. Also called a living will.

carer

A person who supports someone with a disability or disease such as cancer.

emergency care plan

Document that provides direction and instructions to allow someone else to provide the care that you would usually provide.

empathise

To understand the feelings of someone else.

enduring power of attorney/

enduring power of guardianship

See substitute decision-maker.

health care team

A group of health professionals who are responsible for treating the person you care for. This may also be called the multidisciplinary team.

hospice

A place that provides comprehensive care for people with a life-limiting illness. This may include inpatient medical care, respite care and end-of-life care for people who are unable to die at home.

multidisciplinary care

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

palliative care

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

PBS Safety Net

This government scheme reduces the cost of prescription medicines for individuals and families once the Safety Net threshold has been reached.

Pharmaceutical Benefits Scheme (PBS)

A government-funded scheme that subsidises some prescription medicines.

respite care

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

substitute decision-maker

A person who makes decisions on your behalf if you become incapable of making them yourself. Documents used to make a substitute decision-maker may be called enduring

power of attorney, enduring power of guardianship or appointment of enduring guardian.

¹ Australian Bureau of Statistics, 4430.0 – Survey of Disability, Ageing and Caring, Commonwealth of Australia, 2012.

² Edwards B, Higgins DJ, Gray M, Zmijewski N and Kingston M. The nature and impact of caring for family members with a disability in Australia. Research Report No. 16, 2008.

Can't find what you're looking for?

*For more cancer-related words, visit
www.cancercouncil.com.au/words or
www.cancervic.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.

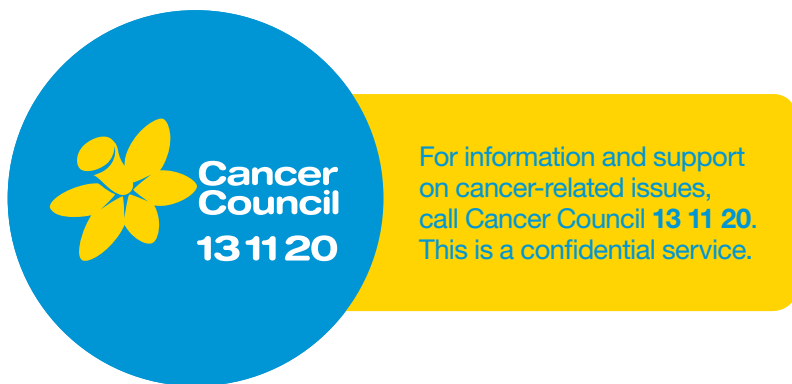
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



Interpreter

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

If you are deaf or have a hearing or speech impairment, the National Relay Service is available.
relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

*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.*