



# Caring for Someone with Cancer

A guide for family and friends who provide care and support

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 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 are looking after someone with cancer. You may still be adjusting to the news that someone you know has cancer and that you could become their carer. It's natural to be worried about the demands that come with a caring role, and the impact this might have on your life.

Caring involves managing both your own physical and emotional needs and those of the person you are caring for. This booklet offers practical tips on navigating the experience of cancer while balancing the demands of caring, family, work and your own needs.

You do not need to read this booklet from cover to cover. We have included a chapter on caring for someone when the cancer is advanced (see pages 47–65). This may not be relevant to you, as many cancers are found early and respond well to treatment. If you are caring for someone with advanced cancer, this chapter provides information about managing this complex role.

## How this booklet was developed

This information was developed with help from a range of health professionals who work with carers, and also from people who have cared for someone with 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**

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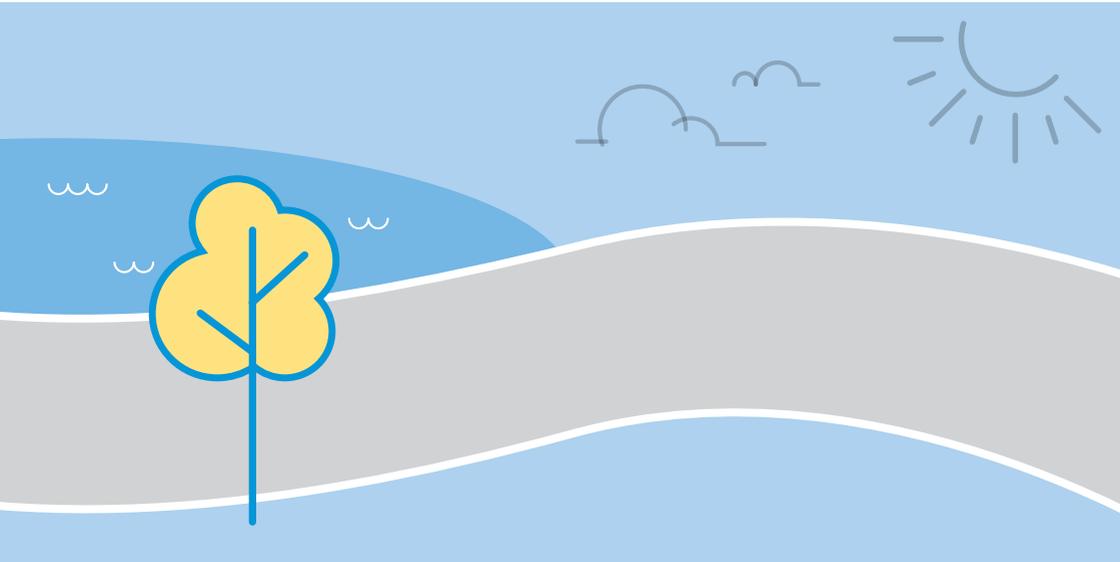
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# Your role as a carer

A carer provides unpaid care and support to a person who needs this assistance because of a disease such as cancer, a disability, mental illness or ageing. Anyone can be a carer, regardless of your age, sex, sexuality, profession or cultural background.

You may be a family member, friend or neighbour. You might not even 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.

## 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 to the role. Some carers are very willing to accept the increased responsibilities; others may be reluctant but feel pressured into accepting the role out of a sense of duty.

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 a week or on a 24-hour basis, and the level of care you provide may change over time. Sometimes a carer lives a long way from the person they are helping and coordinates care by phone, email or the internet.

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 pages 66–70).

## What carers do

The caring role varies depending on the situation and usually changes over time. It often involves a wide range of tasks and sometimes means that you need to learn a new range of skills.

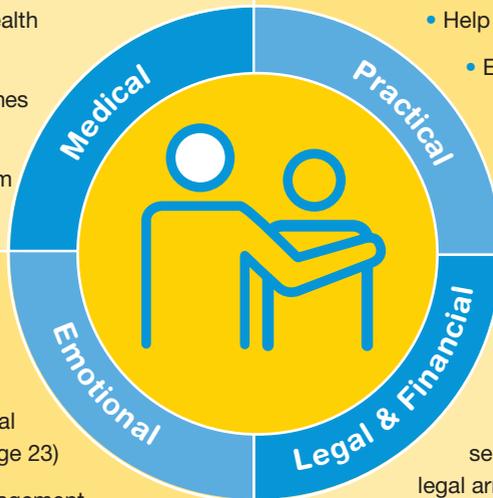
- Advocate for the person with cancer
- Monitor and manage symptoms and treatment side effects
- Keep records of appointments, test results and treatments
- Navigate the health care system
- Manage medicines
- Work with the health care team

- Look after the home, ensuring it is kept clean, safe and well maintained
- Manage family responsibilities, such as care of children or parents
- Provide transport to treatment

- Help with personal care
- Encourage exercise
- Prepare meals
- Do shopping

- Offer companionship
- Be an active non-judgemental listener (see page 23)
- Provide encouragement, comfort and understanding
- Access professional support if needed
- Communicate and negotiate with family and friends

- Talk to the person about planning ahead
- Help the person see a lawyer to make legal arrangements for the future, such as wills and advance care directives (see pages 58–60)
- Arrange for the person to get professional advice to help them manage the financial impact of cancer



## Medical care

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.

Most cancer treatment centres now have multidisciplinary teams (MDTs) made up of specialist doctors, nurses, and allied health professionals such as physiotherapists, dietitians, social workers and psychologists. See pages 8–9 for a description of the various roles.

The MDT will work together closely to manage the care of the person with cancer and recommend the best treatment. They may also refer the person to other specialists for aspects of their care.

## Making the most of a 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. You can call Cancer Council 13 11 20 if you need information or help working out the questions to ask, or see Cancer Council's question checklists.
- Work out your most pressing questions as time may be limited. Ask for a longer appointment if you have a lot of questions.
- Do some research, starting with Cancer Council's information booklets or your local Cancer Council website, so you can ask informed questions. For more information sources, see page 67.
- Make a list of all the medicines being taken, including any vitamin supplements and 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 changes in the person's condition or symptoms so you can tell the doctor about them.

### During the visit

- Take notes or ask the doctor if you can record the discussion (many mobile phones have a recording function).
- Write down any specific instructions.
- Check who to contact if you are worried about any changes and ask for an after-hours number.
- Clarify anything you don't understand.
- Ask the doctor if they can give you printed material or tell you where to find more information, or call Cancer Council 13 11 20.
- Look over the questions you brought along to check that they have all been answered.

### 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.
- Discuss the visit with the person you are caring for.

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.



## Understanding the multidisciplinary team (MDT)

The MDT is there to support the person with cancer and also their carers, but dealing with health professionals can be intimidating, especially if it's something new for you. You may feel overwhelmed by all the new information or working out who to talk to about

### Health professionals you might see

<b>general practitioner (GP)</b>	assists you with treatment decisions and works with specialists to provide ongoing care
<b>surgeon*</b>	treats cancer by operating to remove tumours and performs some biopsies
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
<b>radiation oncologist*</b>	treats cancer by prescribing and coordinating the course of radiotherapy
<b>haematologist*</b>	diagnoses and treats diseases of the bone marrow, blood and lymphatic system
<b>cancer care coordinator</b>	coordinates care, liaises with other members of the MDT, and supports the patient and family
<b>other coordinator</b>	not everyone sees a cancer care coordinator, but a clinical nurse consultant (CNC) or clinical nurse specialist (CNS) may also coordinate care

different issues. Try keeping a notebook to record which members of the MDT are responsible for what area of care. You might need to make the initial contact with them if it doesn't happen automatically. Having a key contact person in the MDT, such as a cancer care coordinator, can help you feel more comfortable.

<b>nurses</b>	administer drugs and provide care, information and support throughout treatment
<b>dietitian</b>	recommends an eating plan to follow during treatment and recovery
<b>physiotherapist</b>	helps with restoring movement and mobility, and preventing further injury
<b>occupational therapist</b>	assesses changes needed to the home and suggests equipment to help with daily activities, improve quality of life and manage fatigue
<b>social worker</b>	links patients and families to support services and helps with emotional or practical issues
<b>counsellor, psychologist</b>	provide emotional support and new strategies to cope with the situation and deal with difficulties
<b>spiritual care practitioner (pastoral carer)</b>	helps people work through spiritual matters

\* Specialist doctor

## Staying organised

Many carers talk about how complicated and time-consuming applications and paperwork can be. The social worker at the treatment centre can offer support with this aspect of your role.

Setting up your own system for paperwork can reduce stress. Use a folder, expanding file or filing cabinet to organise bills, receipts and letters from health professionals. Keep a record of all treatments and test results, and take it with you to appointments.

Paper records can still work well, but if you want to, you can create a My Health Record online at [myhealthrecord.gov.au](http://myhealthrecord.gov.au). This means the person's important health care information is in one place and can be seen by their health professionals with their permission. There are also apps available through the App Store or Google Play that allow you to carry medical records on your smartphone. You can connect some of these apps to your My Health Record.

## Managing medicines

The person with cancer may be taking non-prescription and prescription medicines. 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 medicines?
- Do the drugs interact with other drugs or vitamin supplements or any other over-the-counter medicines?

- Are there any possible side effects? What should I do if the person experiences side effects?
- How long will the medicines be needed?
- What should I do if a dose is missed?
- When is the use-by date, and where can you find it on the medicine packaging?
- How should the drugs be stored?

**Help from the pharmacist** – The pharmacist can provide a written list of all the person’s medicines and when they should be taken, and/or can prepare a blister pack (e.g. Webster-pak) that arranges all the doses that need to be taken throughout the week. The pharmacist can also keep the person’s prescriptions on file to make it easy to get repeats made up.

**The medicines list** – A medicines list can help you keep track of any medicines. It can also help health professionals understand which ones are being used – especially important in an emergency.

You can create your own list on paper or on a computer. You can also download the MedicineWise app from the App Store or Google Play onto your smartphone. This lets you scan the barcode on packaging to add a medicine to the app, record dosages, and set alarms to remind you to give each medicine at the right time.

To find out more about medicines, visit [healthdirect.gov.au/medicines](https://www.healthdirect.gov.au/medicines) or call Medicines Line on **1300 633 424**.



## Carers in Australia

About 12% of Australians are unpaid family carers who provide care to someone with a disability or illness.<sup>1</sup> These carers make a valuable contribution to the community.

The *Carer Recognition Act 2010* (Commonwealth) states that carers should have:

- recognition and respect
- access to appropriate information that makes it easier to get support

- economic security and the opportunity to do paid work
- access to appropriate services
- the skills to do their role and the opportunity to have formal education and training
- improved wellbeing and health, and the capacity to participate in community life.

Each state and territory government has also passed their own Acts and policies.

## Applying for a PBS Safety Net card

Through the Pharmaceutical Benefits Scheme (PBS), the Australian Government subsidises the cost of many medicines. In addition, you can apply for the PBS Safety Net card once you have spent a certain amount on medicines during the calendar year.

You can track what you spend on PBS medicines on a Prescription Record Form (available from pharmacists). If you use the same pharmacist, you can ask them to keep a computer record instead. Once you've spent the threshold amount, your pharmacist can give you a Safety Net card and your PBS medicines will then be cheaper or free for the rest of that year. To find out more, call 132 290 or go to [humanservices.gov.au](http://humanservices.gov.au) and search for "PBS safety net".

## Monitoring symptoms and side effects

Cancer itself can cause a range of symptoms, and cancer treatments often cause side effects. Common symptoms and side effects include:

- pain
- nausea, vomiting and loss of appetite
- breathlessness
- fatigue.

The table on the next two pages offers some tips for helping someone manage these issues. You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about these and other common issues experienced by people with cancer. However, it's always important to let your treatment team know if symptoms and side effects become difficult to manage – they will often be able to offer you medicines and other treatments that can help.

The treatment team will let you know which side effects need to be closely monitored and when you need to contact them. Some issues that require urgent medical attention include:

- a temperature of 38°C or above
- persistent or severe nausea or vomiting
- redness or swelling around the site of an injection
- chills with shaking or shivering
- severe abdominal pain, constipation or diarrhoea
- unusual bleeding (e.g. nose bleeding for over 30 minutes)
- any serious unexpected side effects or sudden deterioration in the person's health.

## Managing common symptoms and side effects

### Pain

- Encourage the person to take medicine as prescribed to keep on top of the pain, and contact your treatment team if the pain is hard to manage. It may take time to find the right pain medicine.
- Use a pain scale to help you understand the intensity of the pain and the need for extra doses of pain medicine.
- Keep a diary of pain levels and symptoms, and let the treatment team know how the medicine is working.
- Try relieving pain and discomfort with hot water bottles or heat packs (but be sure to check the temperature first), ice packs or gentle massage.
- Call Cancer Council **13 11 20** and ask for a free copy of the booklet *Overcoming Cancer Pain*, or download a digital version from your local Cancer Council website (see back cover).

### Nausea and loss of appetite

- Offer the person's favourite or well-tolerated foods often. You usually don't have to follow a strict diet during cancer treatment, though you should follow the advice of your health professionals.
- Provide nutritious snacks throughout the day.
- 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 dietary supplements.
- Encourage the person you are caring for to ask their doctor for different anti-nausea medicines until they find one that works well for them.



## Breathlessness

- Use a fan to direct a cool stream of air across the person's face.
- Set up a pillow on a table so the person can lean forward with an arm crossed over the pillow – this allows their breathing muscles to relax.
- Maintain a calm atmosphere where possible as anxiety can make breathlessness worse.
- Play a relaxation recording to help the person control anxiety that contributes to breathlessness. Your local Cancer Council may have a free relaxation recording on its website or available as a CD.
- Talk to the treatment team about breathing exercises, equipment and treatments to manage breathlessness.

## Fatigue

- Help the person to work out small, manageable goals for the day, and encourage them to rest before they become too tired.
- Encourage the person to say no to things they really don't feel like doing.
- Find ways for the person to do some gentle physical activity every day – research shows that exercise can reduce fatigue. Talk to the treatment team about what sort of exercise would be suitable. Even a walk around the garden can boost energy levels, and the person may feel more motivated if you offer to go with them.
- Establish a regular routine before bed and set up a calm sleeping environment. Ensure the room is dark, quiet and a comfortable temperature. Soothing music helps some people drift off.

## 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 effects of treatment, you may have to make some changes to the home.

### Preparing meals

Treatment can weaken the body's immune system, so it is important to follow good hygiene and food safety practices. Wash your hands before preparing food and take special care when handling raw meat, fish and chicken.

You may notice the person you care for is experiencing changes in appetite or difficulties chewing and swallowing. They may be experiencing nausea (with or without vomiting), or they may have mouth or throat sores that make it painful to eat. Cancer treatment can also affect the sense of taste and smell.

At times, the person may not be able to tolerate even their favourite foods. While you probably want them to eat well to stay strong during treatment, becoming overly stressed about their lack of appetite can increase their anxiety, so gentle encouragement is best. Talk to the treatment team if you're worried about weight loss.



Family and friends often offer to ease your load by preparing meals. Let them know what types of food to prepare, and why hygiene and food safety are especially important at this time.

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 and medicines that can help manage side effects such as nausea or a sore mouth.

For tips and recipes, see Cancer Council's *Nutrition and Cancer* booklet – call 13 11 20 for a free copy or find it on your local Cancer Council website. You can also download two fact sheets: *Understanding Taste and Smell Changes* and *Mouth Health and Cancer Treatment*.

## Managing the home environment

If the person you are caring for becomes unwell or frail during treatment, you may need to make the home safer for them.

Simple measures include rearranging furniture to make access easier, and removing loose rugs and other tripping hazards. Talk to the occupational therapist on the treatment team about other changes you can make – for example, putting handrails on the stairs or in the bathroom, or using a chair in the shower. If you need to lift the person you're caring for, or help them get into or out of bed or a chair, ask a nurse or physiotherapist to show you how to do so safely. They may suggest you hire or buy aids to make lifting easier.

You can ask family and friends for assistance with housework or arrange help through community services. This will free up time for you to spend on caring or other responsibilities. Talk to the nurse or social worker on the treatment team or get in touch with Cancer Council 13 11 20 to find out how to access this support.

## Providing personal care

A person may need help with bathing, toileting and dressing at various times during and after the course of treatment.

Some carers feel uncomfortable doing this care themselves, particularly for their parents or adult children. If this is the case for you, you can arrange visits from care workers who can help with these tasks. Talk to the nurse or social worker on your treatment team or call Cancer Council 13 11 20 to find out how to access this support.

## Finances

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

Speak to a social worker or call Cancer Council 13 11 20 to find out what financial assistance is available to you. Information about financial assistance is also available from your local Carers Association – you can contact them on 1800 242 636.

The Department of Human Services offers a free, confidential Financial Information Service that provides education and information on financial issues. You can call 132 300 to speak to someone about financial issues or to find out about financial information seminars in your area.

For professional advice, you need to speak to a financial adviser (to help you manage your assets, including superannuation) or a financial counsellor (to help you set up a budget and manage debt). Cancer Council may be able to provide some financial assistance and can also refer you for financial advice through our Legal and Financial Referral Service – call 13 11 20 to find out more. You can also request a copy of *Cancer and Your Finances*, or find it on your local Cancer Council website.

## Extra payments

**Centrelink payments** – The Department of Human Services (Centrelink) has various schemes for carers. The Carer Payment is for carers who provide full-time daily care in the home of the sick person. This payment is income- and asset-tested. The Carer Allowance is for carers who provide a significant amount of assistance, either in their own home or in the home of the sick person. The allowance is not means-tested and can be paid even if you are working.

**Travel payments** – If the person travels for cancer

treatment that isn't available in their local area, they may be able to get some of their travel costs back. Eligibility for these patient assistance travel schemes (PATS) varies from state to state. Ask your social worker for more details, or call Cancer Council **13 11 20**.

**Superannuation** – In some cases, you or the person you are caring for may be able to access superannuation early. It is vital to get financial advice as accessing this money may have tax implications and could affect your retirement and insurance policies.

## 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. In some cases, this could help you solve problems or coordinate care more effectively.

- Create a local support network. You could start by reaching out to relatives and friends who can visit the person regularly. You can also talk to the hospital social worker about arranging volunteer and paid care workers, or call Cancer Council **13 11 20** to find out what support is available in the person's area.
- Consider using websites such as **lovlist.org** and **caringbridge.org** to coordinate offers of help.
- 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 to stay in touch. Options include email, blogging, text messaging, Skype, Facebook and video conferencing.
- 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 costs.
- Create an Emergency Care Plan (see opposite) and give copies to the carer and emergency contacts you have nominated.

## Planning ahead

When someone has cancer, it can be difficult to talk about planning for the future, especially if you're feeling optimistic or are uncertain about the possible outcomes. However, it is never too early to think about how you will manage if the situation changes. Knowing plans are in place can actually ease worries and allow you both to focus more fully on the present.

## 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, then give them and your doctors a copy of the plan. Let the person you're caring for know about the alternative arrangements. It is a good idea to carry a Carer Emergency Card in your wallet. This tells people that you are a carer and who to contact in an emergency.

The Department of Health website has a sample Emergency Care Plan on their website at [health.gov.au](http://health.gov.au). You can also get print copies of the plan and card by calling the Commonwealth Respite and Carelink Centre on 1800 052 222.

## Advance care planning

It can be a good idea for a person to plan for their future care and to discuss their wishes with family, friends and the treatment team. This process is called advance care planning and can involve preparing various legal documents. See pages 58–60 to read more about substitute decision-makers, advance care directives and wills.

## Emotional support

An important part of the carer's role can be to provide emotional support to the person with cancer.

You might find it challenging to talk to the person 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, but try to find ways to support each other. You can't change the diagnosis, but listening to each other's concerns can help.

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

While you may be the primary source of emotional support, keep in mind that there may be family members, friends or health professionals who are able to contribute emotional support in different but valuable ways.



### 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 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 other person know that you care about them and want to resolve your differences.
- Try to stay calm and talk through the issues. 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 hard to accept if you feel they are giving up and you want them to try other options.
- Choose your battles – it may help to focus your energy on the issues that really matter.
- If emotions become heated, call time out and arrange to talk later when you are both calmer.
- Consider taking a break and arranging other care for a time.
- Ask your GP or treatment team for a referral to a social worker, counsellor or psychologist who can help you resolve the conflict.

## Communication with the wider circle

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 find it stressful dealing with other people's reactions to the updates. It's also important to ask the person you are caring for how much information they would like you to share.

There are a number of ways to let people know what is happening without having to repeat yourself over and over again:

- Leave a message on your answering machine. You could say something like: "Bill is doing okay with the chemo. He's mainly feeling tired. Thanks for your concern." This will cut down on the time needed to answer or return calls.
- Send out updates via group text messages or emails. You may want to include a statement such as: "We don't have time to reply to everyone individually, but we are reading your messages and appreciate your support."
- Start an online diary, blog, or Facebook or other social media group to share news and coordinate offers of help. You can set up a free, protected website at [caringbridge.org](http://caringbridge.org).
- Ask a family member or friend to update others.

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.

If you need to explain the situation to children, read the *Talking to Kids About Cancer* booklet. Call Cancer Council 13 11 20 for a free copy, or find it on your local Cancer Council website.



## Key points

- Your caring role will depend on the needs of the person you are caring for and also on what you are able to do.
- Carers often need to liaise with health professionals. They may help the person with cancer prepare for medical appointments.
- Your doctor or pharmacist can give you advice about managing medicines, or you can use a paper-based or electronic medicines list.
- Carers often have a key role in monitoring and managing symptoms and side effects. Talk to the treatment team about how you can help ease symptoms and side effects at home, and when you need to contact them.
- Preparing meals can be an important part of someone's care, but it is important to understand that nausea and loss of appetite can last for many months after the end of treatment.
- An occupational therapist can advise you on changes to your home to ensure it's a safe environment.
- Carers often help manage finances. You may be eligible for financial assistance through the Department of Human Services (Centrelink).
- An important part of being a carer can be offering emotional support, but it's also natural to have some disagreements. Good communication can often help resolve conflict.
- 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.



# How will you feel?

It's common for carers to experience a range of feelings about their new role and responsibilities, and many describe it as an emotional roller-coaster. Often these feelings are similar to those experienced by the person with cancer – some studies show that carers can have even higher levels of distress.

Many carers find it reassuring to know that their feelings are a normal reaction to the demands of the role. This chapter describes some of the common emotions experienced by carers. It's important to give yourself permission to take care of your own emotional wellbeing. Start by thinking about how you have coped with difficult times in the past, and see pages 32–33 for some strategies that may help you manage your feelings.

## A sense of satisfaction

While caring can be challenging at times, many carers say that 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.

## Common reactions

Although everyone is different, the following feelings are experienced by most carers at some point.

### Worry

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

- the physical and emotional health of the person you're caring for
- not knowing enough about the treatment and the health professionals involved in their care
- having to wait for test results
- being responsible for giving medicines
- how you will manage other responsibilities, such as work or parenting
- how you will make ends meet if your financial situation is affected
- having so many things out of your control
- not knowing what the future holds
- who to call in an emergency
- the possibility that the person you're caring for will die
- the roles of everyone involved in the care of the person.

Many carers say that learning more about the cancer helps them feel more in control, while others feel overwhelmed by the amount of information available. You need to do what feels comfortable for you. Depending on your situation, it may be helpful to read more about strategies for managing medicines (pages 10–12), managing finances (pages 18–19) and working while caring (page 40).

## Anger and frustration

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

- having to be the carer
- managing the extra responsibilities
- navigating a complex and confusing health care system
- believing that family and friends could do more to help
- having future plans disrupted
- a shift in the nature of your relationship
- having little or no time for activities you used to enjoy
- dealing with the mood changes, anger and frustrations of the person with cancer
- trying to juggle caring with family responsibilities and/or paid work
- feeling the person you're caring for does not seem to really 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. Physical symptoms of stress can include trouble sleeping, headaches, tense muscles, high blood pressure, upset stomach, changes in appetite, and heart palpitations, as well as feeling generally tired and unwell. Emotional symptoms may include feeling overwhelmed or drained, being irritable or moody, feeling agitated, having racing thoughts, and losing confidence in yourself.

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.



## 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.

The support of the hospital social worker was invaluable. She organised domestic assistance and transport to treatment, and reduced many of the day-to-day tasks and

concerns I had. This allowed Louis and me to spend more quality time together.

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.

## Guilt

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

Some carers have said they feel guilty about:

- feeling angry and resentful
- taking a break from caring (or even just wanting to)
- 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.

## Loneliness

It is easy to become isolated or feel lonely as a carer. You may feel too busy or guilty to socialise or maintain contact with 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.

Even if you have many people to support you, you can still feel alone and isolated. You may feel that no-one quite understands what you are going through. This is a common reaction.

## Depression

Research shows that depression is common among carers. 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 and is more than a mood you can snap out of.

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
- feeling tired all the time and/or having trouble concentrating
- having problems sleeping
- feeling restless, agitated, worthless or guilty
- relying on alcohol and sedatives to cope or sleep
- feeling that life isn't worth living.

There are a number of ways to manage depression. Talk to your doctor about your options. Visit [beyondblue.org.au](http://beyondblue.org.au) for more information about depression and anxiety.

## Loss and grief

Many people associate loss and grief with dying. However, feelings of loss and grief can also happen after a diagnosis of cancer. It's natural to miss activities you used to enjoy, such as work, regular exercise or socialising. You may also be dealing with financial changes and/or have lost the future you thought you would have.

As a carer, you may feel that your relationship with the person you are caring for has changed. If the person is your partner and the cancer has affected your sex life, you may miss the physical intimacy. Changes in roles and taking on new responsibilities can cause stress between you and the person you're caring for.

The person may also be experiencing loss and grief, especially if they have lost independence or the ability to do things they used to do. This may cause them to be angry or irritable with you too.

It can take time to adjust to the changes and challenges you are facing. The *How relationships can change* chapter on pages 42–46 outlines some of these changes and how to manage them. For more strategies, read *Emotions and Cancer* – call Cancer Council for a free copy or find it on your local Cancer Council website. It may also help to talk to friends and family about how you are feeling, or you can speak to a health professional by calling Cancer Council 13 11 20.

## Ways to manage your emotions

For many carers, it is hard to find the time or energy to look after their own emotional wellbeing. However, some simple strategies can help you feel more in control.

### Clear your mind

Your local Cancer Council may have relaxation and meditation recordings available online or as CDs – call **13 11 20** to check. You could also try a local yoga or tai chi class.

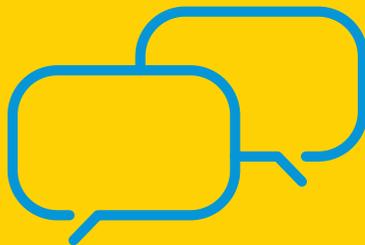


### Get moving

Regular exercise has been shown to help with feelings of anger, stress, anxiety and depression. Remember that some exercise is better than none, and even a brisk walk around the block can help clear your head.

### Take a break

It is important to take time to care for yourself. Do something you find relaxing such as listening to music, reading, taking a bath or having a massage. Respite care is available for short or longer periods (see page 39) and may give you the break you need.



### Talk it over

Share your concerns with the person you care for, or with someone else you trust. Another option is to call Cancer Council **13 11 20** or Carers Australia **1800 242 636** to talk to someone about how you are feeling. They can listen to your concerns without judgement and help you find further support if you need it. You can also call Lifeline **13 11 14** for crisis support at any time of day or night.



### Find out what to expect

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

### Speak to your doctor

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



### Be kind to yourself

No-one is a “perfect” carer. It is often a demanding role and everyone has bad days. Try to avoid using the words “should” or “must”, and accept that you are doing the best you can.



### Join a support group

There are face-to-face, internet and telephone support groups for carers. These groups meet regularly to share their experiences. See page 70 for more information about support groups.



### Connect online

Use technology such as email, Facebook or a blog to stay in touch with family and friends. You can also visit Cancer Council Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC) to connect with others in a similar situation.



### Accept help

If you appear to manage on your own, people may assume you’re okay, but they often do want to help. Reduce your workload by accepting help with practical tasks such as shopping or housework (see page 69).



# Caring for yourself

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

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

It's important to think about yourself for your own sake, but if your natural inclination is to focus completely on the person with cancer, remember that looking after yourself will also help you provide better quality of care 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 can help carers cope with the physical and emotional demands of caring.

## Ways to stay healthy

- Eat healthy meals and snacks. If the person 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. If your sleep is disrupted by your caring responsibilities, try to grab a few minutes' rest throughout the day whenever the opportunity comes up.
- Avoid using alcohol or cigarettes to relax. These may seem to help for a short time, but they contribute to other problems.
- Try to 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 pages 32–33 for ways to look after your emotional health.
- Have regular check-ups with your own doctor and also go to see them if you notice changes in your health such as fatigue, sleep problems, weight changes or depression.

## Asking others for help

Asking for and accepting assistance is sometimes difficult. However, if you seem to be coping, family and friends may not realise you need help. They may be waiting for you to ask because they don't know how to offer or fear they will be intruding or disturbing you. Let them know their support 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 more 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 and then prepare a roster. 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
- staying with the person you care for while you take a break.

## How 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 gaining 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 difficult to wash or provide intimate care to the person you are looking after, investigate alternatives such as regular visits from a care worker.

**Organise your time** – It may not be possible to do everything you want to do, so prioritise your weekly tasks and activities. You can use a diary to keep track of information and appointments. Identifying and dealing with immediate priorities can confirm that you are on track, even when the future is uncertain.

**Keep a journal** – Writing down what has been happening may allow you to release your worries or frustrations. It's also a chance to reflect on how you're coping and identify areas you need assistance with. Reading back through journal entries can provide perspective – you may see 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 not to be perfect. Each new day brings a fresh start and a chance to remind yourself that you're doing your best.

**Take time for yourself** – Try to stay involved in activities you enjoy. It's okay to find pleasure in life, despite the difficulties, and to want to stay connected to and talk about things other than cancer. Even short interludes may give you the chance to do something for yourself (e.g. relaxation/meditation, short walks, reading, music, brief social contact).

**Deal with uncertainty** – When the person you care for is having treatment, life may seem less predictable and it may be hard to plan ahead. Carers often find this uncertainty stressful and feel that their life is in limbo. You may find it easier to cope if you focus on those things you can control right now. Letting go of what you can't control leaves you with more energy and mental capacity.

It may also help to learn more about cancer and possible treatment options (see page 67). Going with the person to doctors' visits can give you a better understanding of the treatment plan.

### **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. It may be that the physical demands are becoming too much, particularly if you are older or have your own health issues. You could also find the role is taking an emotional toll.

Perhaps you know you need support but don't want to disappoint the person you're caring for. Try talking to your GP or the social worker at the

treatment centre, or calling Cancer Council **13 11 20**.

You might also find it helpful to see a counsellor, either in person or via phone, email or Skype. The counsellor may help you see ways to make caring more manageable.

Your GP or Cancer Council can refer you to a counsellor. You can also access the National Carer Counselling Program by calling **1800 242 636**. For 24-hour crisis support, call Lifeline on **13 11 14**.



There are about 275,000 carers under 25 in Australia. The Carers Associations in each state and territory offer information and support tailored for young carers. Visit [youngcarers.net.au](http://youngcarers.net.au) or call **1800 242 636** to find out more.

## Taking a break (respite care)

Respite care allows carers to have a break. It may be provided at home, in a residential care facility (such as an aged care facility) and, in some cases, in a hospital or palliative care unit (hospice). It 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 exists because caring can be difficult and may affect your wellbeing. By taking a break, you will probably find that you can be more effective in your caring role. The person you are caring for can also have a break from you and interact with other people.

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

## 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 a number of factors, including:

- 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. They may be able to support you with flexible working arrangements.

To find out more about working while caring for someone, visit [workingcarers.org.au](http://workingcarers.org.au) or [carersnsw.org.au/advice](http://carersnsw.org.au/advice). You can also contact the Carers Association in your state or territory for support and counselling. Visit [carersaustralia.com.au](http://carersaustralia.com.au) for links to the relevant website or call 1800 242 636. Cancer Council's booklets include *Cancer, Work and You* and *Cancer Care and Your Rights*. Call 13 11 20 for free copies or look for them on your local Cancer Council website.



## 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.
- Try to focus on the value of your caring role, as this may help 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.
- Talk to your employer before deciding to stop work – you may be able to arrange your work in a way that makes it more manageable.



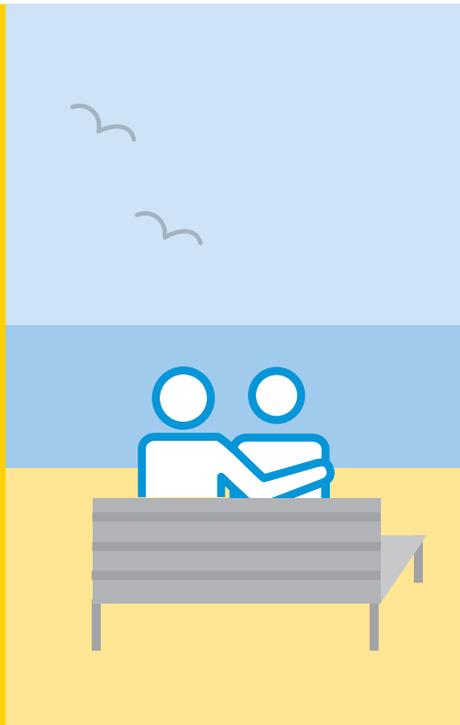
# How relationships can change

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 a relationship varies, 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 looking after.

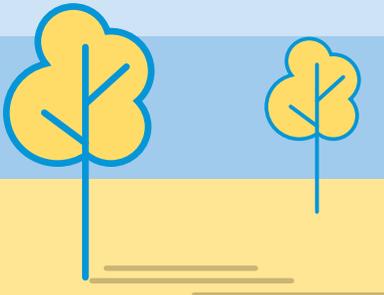
## How will cancer change our relationship?

- I might need to take on new responsibilities that will reverse our roles.
- If I'm doing all the caring, they may feel like they've lost their independence.
- I may feel like it would be selfish to talk about my needs when they are having to go through cancer treatment.
- The intimacy we shared might be replaced by the caring role.
- We might need to re-evaluate our priorities and set new goals.



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. In this case, you may find it best to share the caring role with other people so you are not the full-time carer (see pages 35–36).

It can be helpful to understand the potential changes that cancer can bring. This chapter discusses ways a relationship may change, and how to manage these changes.



### Ways to manage changes in your relationship

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

## Support for LGBTI carers

Lesbian, gay, bisexual, transgender or intersex (LGBTI) people may face specific challenges as carers. They may worry about the family of their partner or friend accepting them, or wonder if support services are LGBTI-friendly. You can ask your local Carers Association (see page 66) what support is available for LGBTI carers in your area. Another option is to visit [qlife.org.au](http://qlife.org.au). QLife is a national counselling and referral service for LGBTI people.

## Changes in sexuality and intimacy

If you are caring for a partner, you may find the cancer and its treatment affects your sexual relationship. This 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.
- Cancer treatments, medicines and pain can also reduce libido and may 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 physical intimacy might be painful.
- You might find it hard to switch from being patient and carer back to being sexual partners.

There are various ways to help manage sexual side effects and maintain intimacy during and after cancer treatment.



## How to manage sexual changes

- Remember that the best sexual tool is communication.
- 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, 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, especially 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 again.
- 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. The occupational therapist on your treatment team can suggest practical strategies for positioning and fatigue management.
- For a free copy of *Sexuality, Intimacy and Cancer*, call Cancer Council **13 11 20** or find it on the website of your local Cancer Council.

## If your caring role ends

Many people find that the most challenging time in their caring role is when treatment finishes. As the person you're caring for starts to get better and tries to resume their usual activities, you could feel a bit lost or not needed anymore. They may even appear to have forgotten how much time and effort you gave. This can be hurtful, but they probably don't realise how you are feeling.

You may be surprised that the person who has had cancer does not seem happy or relieved that they have been given good news. However, this can actually be a difficult time emotionally, and cancer survivors sometimes experience depression as they adjust to the "new normal". It is important to communicate openly about how you are both feeling.

Carers often expect to slip back into day-to-day life as it was before they took on the caring role, but this may not be straightforward. You might feel you are still waiting for the next setback. Your life may also have changed. Going back to work or resuming other responsibilities can be overwhelming. Do things at your own pace and give yourself 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. Studies show that caring often brings positive changes in life philosophy, relationships and personal growth. However, not everyone finds the caring experience to be rewarding and life-changing. You may need time to reflect on the experience and work out what it has meant to you.



## Caring for someone with advanced cancer

**This chapter is about caring for someone who has been told they have advanced cancer. The cancer may have been diagnosed at a late stage or it may have returned after initial treatment. Most cancers are diagnosed at an earlier stage, so this chapter may not be relevant to your situation. However, if you are caring for someone with advanced cancer, we hope that this information helps you navigate the complex challenges of your role.**

## When cancer won't go away

A diagnosis of advanced cancer means the cancer 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.

As well as having to manage your own emotions, you may also have to tell other family members and friends. This can be time-consuming and difficult, and their reactions may add to your distress. If you need support, talk to your GP or the hospital social worker, or call Cancer Council 13 11 20.

Cancer Council has produced several booklets for 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*, or find them on your local Cancer Council website.

Palliative Care Australia also has a range of useful resources on their website at [palliativecare.org.au/resources](http://palliativecare.org.au/resources).

## A changing role

As the disease progresses, the person's needs will change and the demands on you as a carer are likely to increase. Some people live with advanced cancer for many years, so there may not be much difference in your caring role immediately. For others, the disease progresses quickly and your responsibilities may become more complex almost overnight.

The doctors may give a general indication of the person's life expectancy. This is known as the prognosis and it is likely to sound a bit vague, such as months to many months, weeks to months, or days to weeks. The actual time could be shorter or longer, because each individual responds differently to care.

Not everyone wants to know their prognosis. If the person you are caring for prefers not to know, you may still want to get some indication to help you plan ahead. You can do so if the person gives their medical team permission to speak to you alone.

### **Avoiding carer burnout**

Caring for someone with advanced cancer can be physically and emotionally demanding. Carers often put their own needs aside and focus all their energy on supporting the person with cancer. This can be hard to keep up over what may be months or years of caring.

Now more than ever, it is important to look after your own wellbeing (see the tips on pages 34–40). Ask for and accept help and find ways to care for yourself. Even taking

five minutes to do something you enjoy or to still your mind can mean you cope better.

Stress or distress that lasts a long time can lead to carer burnout. This can show in physical and emotional ways. If you are experiencing mood swings, irritability, sleep problems, changes in appetite, overwhelming fatigue or other signs of stress for more than two weeks, or if you are relying on alcohol or other drugs, talk to your GP or the social worker on the palliative care team.

## Palliative care

As a carer, you can be supported in your role by palliative care. This involves a range of services offered by nurses, doctors and allied health professionals, as well as volunteers. It is a team approach that addresses the person's physical, practical, emotional, spiritual and social needs.

Palliative care aims to help people with a life-limiting illness to live as fully and comfortably as possible. It doesn't mean giving up hope – in fact, it can improve quality of life at any stage of advanced cancer and can be given alongside other cancer treatments.

**When to start palliative care** – You can ask your treatment team for a referral to palliative care as soon as advanced cancer is diagnosed. Even if you don't want to access the services right away, it can be reassuring to understand what support is available. Many people say that they wish they had been referred to palliative care earlier.

**How palliative care is provided** – Palliative care may be coordinated by a GP or community nurse or, if the person's needs are complex, by a specialist palliative care team. It can be provided at home supported by a community palliative care service, in hospital, in a palliative care unit (hospice) or at a residential aged care facility (formerly called a nursing home). The palliative care team will help you and the person you're caring for work out the best place for their care. Sometimes people spend a short time in hospital or in a palliative care unit to help get their symptoms under control and then return home again.

**Your role** – Carers are considered part of the palliative care team. If you have been providing most of the person's care, it can be difficult to let other people take over some tasks. However, it is important to realise that the caring demands are likely to keep increasing as the cancer progresses. Accepting help can mean you can spend more quality time with the person you're caring for.

For more information about palliative care, call Cancer Council 13 11 20 and ask for a copy of *Understanding Palliative Care*, or find it on your local Cancer Council website.

## Support for carers

Although carers may have similar responsibilities and need support at any stage of cancer, their workload usually intensifies if the disease progresses. Most people with life-limiting cancer spend almost all their last year at home, and their carers need additional support with many aspects of the role.

The following pages outline common issues you may face as you care for someone with advanced cancer, and lists who can help and where to find more information.

“ I'd tell other carers to get as much information as you can about what your journey will be like, speak to others further down the track, and try to join a support group. Get ready to be out of your comfort zone, but you just have to get on with it. ” Ross

## Sources of support – key to symbols



**Who can help** – Many of the health professionals listed here will be part of the treatment team or palliative care team. You can also ask your GP to refer you to appropriate professionals working in private practice. If you're not sure how to get support or just want to talk through your concerns, call Cancer Council **13 11 20** or your local Carers Association (see page 66).



**Read more** – You can get free copies of the booklets listed by calling Cancer Council **13 11 20**, or you can read them online on your local Cancer Council website.

## Making treatment decisions

It can be confronting and confusing for the person to work out whether to keep pursuing active treatments for the cancer. This decision is theirs alone, but they are likely to discuss it with you. If you are the person's substitute decision-maker (see page 59), you may feel a heavy responsibility in making this decision for them.



Palliative care team, cancer specialists, GP, social worker



*Living with Advanced Cancer, Understanding Palliative Care, Cancer Care and Your Rights*

## Managing symptoms

You may find that symptoms such as pain become more complex to manage, especially because the person is likely to experience a number of symptoms at the same time. However, early medical attention can provide relief and make symptoms easier to manage.



Palliative care specialist, palliative care nurse, pain specialist, cancer specialists, GP, community nurse, physiotherapist



Pages 13–15 of this booklet, *Living with Advanced Cancer, Facing End of Life, Overcoming Cancer Pain*

## Setting up the home

To make it easier and safer to care for the person at home, you may need to modify the environment (e.g. handrails on steps and in the shower) or buy or rent equipment (e.g. shower and toilet chairs, bed pans, walker, harness for helping to lift the person, hospital bed).



Occupational therapist

## Preparing food and drink

It can be challenging to prepare food and drink for a person with advanced cancer, especially if they find it hard to swallow or have lost their appetite. In the very late stages, it is natural to have little appetite so they shouldn't be forced to eat or drink, but this can be distressing for carers.



Dietitian, speech pathologist



*Nutrition and Cancer*

## Providing personal care

If the person becomes weak or unwell, they may need assistance with showering and toileting. If they are unable to get out of bed, they may need sponge baths and help to use a bed pan or urinal bottle. Some carers prefer to provide this support themselves and

just need some guidance from a health professional. Other carers feel uncomfortable doing this personal care and prefer to have it given by someone else.



Community care workers (ask your treatment team or GP for a referral, or contact My Aged Care on 1800 200 422 or at [myagedcare.gov.au](http://myagedcare.gov.au))

## Coping with the increased workload

You may find it difficult to manage all the extra tasks involved in caring for someone with advanced cancer, especially if you have other responsibilities such as paid work or parenting, or if you have your own health issues. There are a range of services available to support you in your caring role.



Social worker, Cancer Council 13 11 20, My Aged Care (1800 200 422), home help provided by local councils or aged care services, Commonwealth Respite and Carelink Centres (see page 39), volunteers, family and friends

## Organising finances

You may need to manage the financial impact of advanced cancer. This can include finding additional financial support and possibly accessing superannuation and insurance. Seek professional advice before changing any financial arrangements.



Social worker, Cancer Council Financial Referral Service on 13 11 20, financial counsellor, financial adviser



Pages 18–19 of this booklet, *Cancer and Your Finances*

## Making legal arrangements

If the person hasn't already done so, it is important to make sure their wishes for the future have been documented. This can include preparing a will, appointing a substitute decision-maker, and preparing an advance care directive.



Social worker, Cancer Council Legal Referral Service on 13 11 20, Advance Care Planning Advisory Service on 1300 208 582



Pages 59–60 of this booklet, *Getting your affairs in order* (online fact sheet on your local Cancer Council website)

## Dealing with the emotional impact

A diagnosis of advanced cancer can be distressing for all who are involved, and it is not unusual to experience grief and symptoms of anxiety and depression. Although strong emotions are natural at this time, seek professional help if they are interfering with the ability to function or enjoy some aspects of life.



GP, social worker, psychologist, counsellor or psychiatrist, support groups (see page 70), Cancer Council 13 11 20, National Carer Counselling Program 1800 242 636, beyondblue 1300 22 4636, Lifeline 13 11 14



Pages 22–23, 26–33 and 62–64 of this booklet, *Emotions and Cancer, Understanding Grief*

## Communicating with family and friends

The carer is often the main point of contact for family and friends. It can be challenging to cope with people's reactions when you are

struggling with your own. Giving constant updates as the disease progresses can also be draining and time-consuming.



Social worker, Cancer Council 13 11 20, particular family members or friends who can relay updates, social media platforms such as Facebook (see page 24)



*Talking to Kids About Cancer*

## Exploring the meaning of the person's life

This may be a time when the person wants to reflect on their life and make sense of their experience. They may appreciate help recording their memories and insights in some way (see page 62). Some people also want to explore spirituality, even if they have never been religious.



Social worker, psychologist or counsellor (ask your treatment team or GP for a referral), spiritual care practitioner (also called a pastoral carer, usually available through your treatment centre), religious leader

## Maintaining hope

The carer can have an important role in helping the person with cancer find reasons to be hopeful. It is possible to be realistic while still maintaining hope. As the disease progresses, the things the person hopes for may change. For example, they may hope to visit special places or spend time with family and friends.



Social worker, psychologist or counsellor, spiritual care practitioner (pastoral carer), family and friends



## Ross's story

My wife Robyn was diagnosed with grade 4 brain cancer soon after turning 50. We were told the average survival rate is 15 months, and Robyn lived for 20 months.

After getting a diagnosis like that, you just go into shock for the first couple of days, then you start thinking about how things will change and what you need to do to help. I kept working for a month or so, but I couldn't be at work with my mind elsewhere, I knew my role was to be beside Robyn.

It's such a different world when you become a carer. You've got no training, I knew no-one else who had been through it. You draw on life skills you've acquired over time, but you can't really appreciate how much responsibility is on your shoulders until you are in it.

I had to look after all Robyn's medications, manage the

appointments, keep track of the symptoms, keep an eye on her as she was moving about in case she needed assistance. It's a bit like being a parent for the first time. Everything is new, but as the weeks roll on, you gradually get things in place and find the strength to manage.

A lot of people give you advice, but it's hard to give it full merit if they haven't been through this kind of experience. So I joined support groups, both a phone group through Cancer Council and a local face-to-face group.

Robyn and I tried to maintain as much of a normal lifestyle as we could. We planned to go out for a walk every morning and then she'd sleep most of the afternoon. Even once Robyn was using a wheelchair, we'd head out to places she liked, the park or the beach. It lifted her spirits for the day, and gave her something to talk about. She tried to enjoy each day she had.

## Different laws

Each state and territory has different laws related to advance care planning. For more information about the legal documents involved, call Cancer Council on **13 11 20** or look for the *Getting your affairs in order* fact sheet on your local Cancer Council website.

If you have questions, you can also call the Advance Care

Planning Advisory Service on **1300 208 582**, or visit [advancecareplanning.org.au](http://advancecareplanning.org.au) or [palliativecare.org.au/advance-care-planning](http://palliativecare.org.au/advance-care-planning).

It is important to seek legal advice. Cancer Council's Legal Referral Service can connect you with a lawyer and arrange free assistance for eligible clients. Call **13 11 20**.

## Advance care planning

The process of advance care planning begins with a discussion about the person's wishes for their future health care. Ideally, this conversation occurs early, when cancer is first diagnosed or even before. It does not mean that the person has given up or will die soon – many people review their wishes from time to time. Palliative Care Australia has developed a resource to help people talk about the issues – visit [dyingtotalk.org.au/discussion-starter](http://dyingtotalk.org.au/discussion-starter).

It is not unusual for a person's wishes to change once they have been told the cancer is advanced. It is important that the person's carer, close family members and health professionals understand how much treatment the person wants for the cancer, and what matters to them most when making treatment decisions. Palliative

care teams are experienced with helping people through these difficult discussions about balancing the quality and length of life.

It can be confronting as a carer if the person you are caring for decides they do not want any more active treatment for the cancer. On the other hand, you may worry about the impact on their quality of life if they decide to keep pursuing active treatment. You may find it helpful to talk to the palliative care team about how you are feeling.

## **Legal arrangements**

If the person hasn't already done so, it is a good idea to make legal arrangements now to ensure their wishes are recorded. This can involve a number of legal documents.

For documents to be legally binding, the person needs to have capacity at the time of signing the document. Capacity includes the ability to understand the choices that are available and the consequences of decisions, as well as the ability to communicate choices. If there could be any doubt about the person's capacity, it's important to talk to both their doctor and their lawyer about this.

**Document appointing a substitute decision-maker** – The person with cancer can appoint someone to make decisions on their behalf if at some point in the future they can't make their own decisions. These can include decisions about finances, property, medical care and lifestyle. This person is called a substitute decision-maker and is often also the primary carer, but that is not always the case. Sometimes the person with cancer will appoint

different substitute decision-makers for financial decisions and medical decisions. Depending on where you live, the documents for appointing substitute decision-makers may be known by different names (e.g. enduring power of attorney, enduring power of guardianship, appointment of enduring guardian) and cover different types of decisions (see the *Different laws* box on page 55 for where to find more information).

**Advance care directive** – Commonly called a “living will”, an advance care directive records a person’s wishes for their future medical care. It provides a record for doctors, family and carers to consider, and may be legally binding in some states and territories. Depending on where you live, the advance care directive may have a different name, such as a health direction, advance personal plan, advance health directive, or refusal of treatment certificate.

**Preparing a will** – This is a legal document that sets out what a person would like to do with their assets (estate) after they die. A will may also record the person’s wishes regarding guardianship of their children. Many people want to make a will or update the one they have as their circumstances change. Some carers choose to make or update their own will at the same time as the person with advanced cancer. This can help to make it feel like a normal, everyday process.

Making a will is not difficult, but it needs to be prepared and written in the right way to be legally valid. It is best to ask a lawyer to help you or contact the Public Trustee in your state or territory (visit [publictrusteesaustralia.com](http://publictrusteesaustralia.com) for links).

## Care at the end of life

It can be confronting to talk about death and dying, but it is important to explore the options for where the person may die and to understand their wishes. Your wishes as the carer also need to be considered. Talking about the options early while the person is still well can help avoid distress and regrets or feelings of guilt later.

Many people say that they would like to die at home. Dying at home usually depends on having at least one carer available at all times. Carers may immediately feel committed to making sure this happens, or they may feel very daunted by the idea. Finding out more about the support available from the palliative care team and other services may help with your decisions and provide reassurance.

Not everyone wants to die at home, and some people change their minds as their situation changes. Depending on the circumstances, a person can be cared for at the end of life by health professionals in a hospital, a palliative care unit (hospice), or a residential aged care facility. Some carers feel guilty about handing over the everyday care to somebody else, but it can allow you to spend more time just being together. If you wish, you can assist the staff with physical duties.

For more information about the options at the end of life, call Cancer Council 13 11 20 and ask for a free copy of *Facing End of Life*, or download a digital version from your local Cancer Council website.

## Ways to say goodbye

A life-limiting illness offers time to say goodbye. You can encourage the person with advanced cancer to share their feelings, and you can share your own in return. It is understandable that you might not know what to say, or worry about saying the wrong thing. Ask the person if they would like to talk about how they are feeling. This can give you an idea of whether they are ready to talk about the situation – they may be avoiding the topic for fear of upsetting you.

Some people who are dying refuse to acknowledge it or may seem to be in denial. This might be because they prefer to focus on the present moment. If you find this upsetting, it may help to talk it over with the social worker on your treatment team or call Cancer Council 13 11 20.

You can ask the person with advanced cancer if they want to visit a special place or contact someone they've lost touch with. They may also appreciate help creating a legacy, such as documenting their life in some way, creating a memory box of keepsakes, or writing letters to family and friends. One option is to create an "emotional will", a document that shares their thoughts with their family and friends. You can download the Groundswell Project's *Emotional Will and Death Checklist* from their website at [thegroundswellproject.com/10-things-workshops](http://thegroundswellproject.com/10-things-workshops).

“ 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. ” Julie

## 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. It is common to have thoughts such as: “How will it be when they are not here? How will I cope on my own?”

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.

Having time to grieve doesn't necessarily make the loss of the person easier to cope with once they have died. Sometimes the experience of anticipating the death and spending a lot of time caring for the person actually makes you become closer to the person, and you feel intense grief when they die.

## When the person you care for dies

There are many services available to help with the practical and legal aspects of the person's death.

You can read more about these services in the *Facing End of Life* booklet – contact Cancer Council 13 11 20 or visit your local Cancer Council website. You can also talk to the social worker on the palliative care team.

After the person dies, you may feel a range of emotions, including:

- numbness and shock, or a sense of disbelief, even if you thought you were prepared
- sadness
- 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 person for dying
- guilt about things you did or didn't do, about not being there at the time of death, or about how you are feeling.

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. Support groups (face-to-face, telephone or online) or counselling can help you get through times when your grief seems overwhelming.

For information about grief after a person has died from cancer, read Cancer Council's free booklet *Understanding Grief*, available by calling 13 11 20 or visiting 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 is a holistic approach that aims to maintain quality of life. It is not just for end of life and can be helpful at any stage of advanced cancer.
- As the demands of the caring role increase, you can draw on support from a range of health professionals and other services.
- 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.
- As part of advance care planning, the person may want to appoint a substitute decision-maker and make other legal arrangements.
- Anticipatory grief is a natural reaction when someone close to you is dying. However, it often doesn't make the loss any easier to cope with.
- 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. If your grief continues to feel overwhelming, carers' and bereavement support groups and counselling may help you. You can also talk to your GP or Cancer Council **13 11 20** about how you are feeling.



# 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

### **Cancer Council NSW**

**13 11 20**

[cancercouncil.com.au/aboriginalcancer](http://cancercouncil.com.au/aboriginalcancer)

Cancer information for Aboriginal and Torres Strait Islander People.

### **Carers NSW**

**1800 242 636**

[carersnsw.org.au/how-we-help/support/aboriginal](http://carersnsw.org.au/how-we-help/support/aboriginal)

Resources include the *Aboriginal Carers Support Guide*, the *Koori Carer Yarning Resource Manual* and the *Looking After Ourselves Carer Support Resource*.

## Carer services

### **Carers Australia**

**1800 242 636**

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

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

### **Carer Gateway**

**1800 422 737**

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

Practical information and resources for carers, and links to support services in your local area.

### **Young Carers**

**1800 242 636**

[youngcarers.net.au](http://youngcarers.net.au)

Supports young people (25 and under) who care for a family member or friend. Run by state and territory Carers Associations, the program offers information, support and opportunities.

## Cancer information

### Cancer Council

**13 11 20**

See back cover for local Cancer Council websites

Cancer Council produces easy-to-read booklets and fact sheets on more than 25 types of cancer, treatment options, and emotional and practical issues. Call 13 11 20 for print copies, or download them from your local Cancer Council website.

### Cancer Australia

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

Information about cancer from Australian Government cancer control agency.

### Hospital or treatment centre

May host workshops or discussions about cancer, treatments and side effects.

### American Cancer Society

[cancer.org](http://cancer.org)

Detailed information about cancer types and topics from the largest voluntary health organisation in the US.

### Macmillan Cancer Support

[macmillan.org.uk](http://macmillan.org.uk)

Information about cancer prevention, diagnosis and treatment from the leading UK cancer charity.

## Counselling

### Cancer Council

**13 11 20**

Referrals to counselling services, as well as peer support programs that you can connect with online, by phone or in person.

### National Carer Counselling Program (NCCP)

**1800 242 636**

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

### Australian Centre for Grief and Bereavement

**1800 642 066**

[www.grief.org.au](http://www.grief.org.au)

Online information for people experiencing grief.

<p><b>Better Access initiative</b> health.gov.au/mentalhealth-betteraccess</p>	<p>Medicare-subsidised referral to psychological counselling through your GP.</p>
<p><b>beyondblue</b> <b>1300 22 4636</b> beyondblue.org.au</p>	<p>Offers a 24-hour telephone counselling service. Online and email counselling are available 7 days a week.</p>
<p><b>GriefLine</b> <b>1300 845 745</b> (landline only) griefline.org.au</p>	<p>Community and family services to support all Australians who have experienced a loss.</p>
<p><b>Kids Helpline</b> <b>1800 55 1800</b> kidshelpline.com.au</p>	<p>A telephone and online counselling service and crisis support for young people aged 5–25.</p>
<p><b>Lifeline</b> <b>13 11 14</b> lifeline.org.au</p>	<p>A 24-hour telephone crisis support and suicide prevention service.</p>
<p><b>Equipment and aids</b></p>	
<p><b>Independent Living Centres Australia</b> <b>1300 885 886</b> 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>
<p><b>Financial assistance</b></p>	
<p><b>Centrelink</b> humanservices.gov.au</p>	<p>Offers financial support for people with a long-term illness and for primary carers.</p>
<p><b>Financial Counselling Australia</b> <b>1800 007 007</b> financialcounsellingaustralia.org.au</p>	<p>Information about financial counselling and help to find a qualified counsellor.</p>

## Home help

**Call your local council, talk to your palliative care team or call Cancer Council 13 11 20**

Some local councils provide a range of community and in-home services, such as Meals on Wheels or respite care. The palliative care team can organise home help for you, or you can contact Cancer Council to find out what services are available in your area.

**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 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

**Legal and Financial Referral Program**  
Cancer Council 13 11 20

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

## Palliative care

**CareSearch**  
caresearch.com.au

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

**Palliative Care Aged Care Evidence**  
palliaged.com.au

Information about palliative care evidence for older Australians, with links to services and resources.

**Palliative Care Australia**  
palliativecare.org.au

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

## Respite care

### Commonwealth Respite and Carelink Centres

**1800 052 222**

during business hours

**1800 059 059**

for emergency respite

Provide information about respite services, which may be available at home, in a respite care centre or, in some cases, in a hospital or palliative care unit (hospice).

## Support groups

### Face-to-face groups

Call Cancer Council

**13 11 20** or 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 or to care for someone with 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. Cancer Council has groups for advanced cancer, for carers, and for those who are bereaved.

### Cancer Council Online Community

[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 of their experiences.

## Reference

1. Australian Bureau of Statistics, *4430.0 Disability, Ageing and Carers, Australia: Summary of Findings, 2015*. Available from: [abs.gov.au/ausstats/abs@.nsf/mf/4430.0](http://abs.gov.au/ausstats/abs@.nsf/mf/4430.0).



# Glossary

## **advance care planning**

When a person thinks about their future health care and discusses their wishes with their family, friends and health care team. The written record of these wishes may be known by different names, such as advance care directive, health direction, or “living will”.

## **carer**

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

## **emergency care plan**

A 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.

## **multidisciplinary care**

A system where health professionals collaborate to address a patient’s physical and emotional needs. The team meets to review cases and decide on 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.

## **palliative care unit**

A place that provides comprehensive care for people with a life-limiting illness. This may include inpatient medical care, respite care and end-of-life care. Also known as a hospice.

## **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 the cost of some prescription medicines.

## **respite care**

Alternative care arrangements that allow the carer and/or 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 appoint this person may be called enduring power of attorney, enduring power of guardianship, or appointment of enduring guardian.



# How you can help

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

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

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

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

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

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

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



# Cancer Council 13 11 20

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

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

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

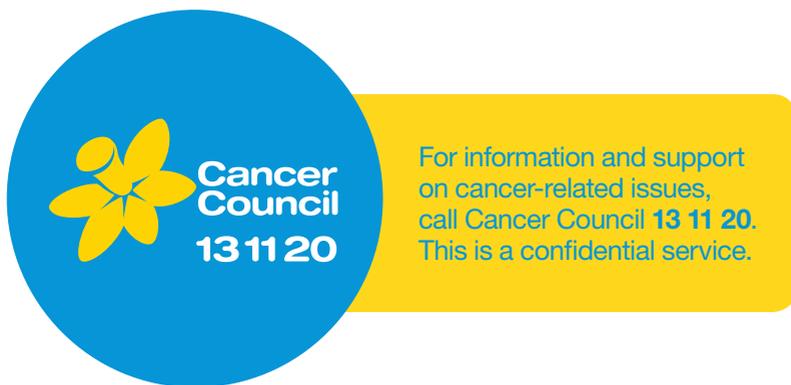
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



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

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



## Visit your local Cancer Council website

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

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

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

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

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

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

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

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

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

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