



# 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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Editor: Jenny Mothoneos. Designer: Julia Gee. Printer: IVE Group.

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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.



### Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

**Telephone** 02 8256 4100 **Email** [info@cancer.org.au](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

ABN 91 130 793 725

# About this booklet

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 47–64). 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 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. You can also visit your local Cancer Council website (see back cover).



**Cancer  
Council**  
**13 11 20**

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# Your role as a carer

You are a carer, or caregiver, if you provide ongoing unpaid care and support to a person who needs this assistance because of a disease such as cancer, a disability, mental illness or ageing. You may be a partner, family member, child, friend or neighbour.

You might not see yourself as a carer, but as someone simply helping out a person in need. You may feel that caring is part of your relationship with the person affected, or you may feel pressured to be a carer out of a sense of duty.

Becoming a carer can be sudden or it may be a gradual process. 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.

## Carers in Australia

About 11% of Australians are unpaid carers who provide care to someone with a disability or illness.<sup>1</sup>

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

- the same rights as other Australians
- recognition and respect
- support to enjoy good health and social wellbeing

- economic security and the opportunity to do paid work and education
- access to appropriate services
- acknowledgement as individuals with their own needs
- recognition as partners with other care providers.

All state and territory governments have also passed their own Act and policies. For more details, visit [carergateway.gov.au](http://carergateway.gov.au).

## What carers do

Every caring situation is different. What you need to do will vary depending on the situation and will usually change over time. It often involves a wide range of tasks and sometimes means that you need to learn a new range of skills.

### Medical care

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

### Practical support

- Look after the home, keeping it safe and comfortable
- Manage family responsibilities, such as caring for children or parents
- Provide transport to treatment
- Help with personal care
- Encourage exercise
- Prepare meals
- Do shopping
- Look after pets

### Financial matters

- Help the person see a lawyer to make legal arrangements for the future, such as a will and advance care directive (see pages 56–58)
- Ensure advance care directives are uploaded to **myhealthrecord.gov.au** and take witnessed copies with you to appointments
- Arrange for the person to get professional advice to help them manage the financial impact of cancer
- Talk about end-of-life plans

### Emotional support

- Offer companionship
- Be an active non-judgemental listener (see page 25)
- Provide encouragement, comfort and understanding
- Arrange professional support if needed
- Keep family and friends up to date
- Negotiate care and responsibilities with others
- Talk about other things aside from cancer

## Medical care

As a carer, you're part of the health care team. Your role is to work with the team to ensure that you understand, and are included in, decisions about the care and treatment of the person you care for. This may sometimes mean speaking on behalf of the person you care for.

Most cancer treatment centres now have multidisciplinary teams (MDTs) made up of specialist doctors, nurse practitioners, nurses, and allied health professionals such as physiotherapists, dietitians, social workers and psychologists. See pages 8–9 for details. The members of the MDT will work together to manage the care of the person with cancer and recommend the best treatment. They may also refer the person to other specialists.

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 medical file, along with copies of any substitute decision-maker or advance care directive documents (see pages 57–58).

## Making the most of a medical appointment

### Before the visit

- Write a list of the questions you both have so you don't forget them during the actual appointment. For suggestions, see the question checklists in Cancer Council's booklets.
- 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 so you can ask informed questions. For reliable information sources, see pages 65–69.

- Keep a record of the medicines the person is taking, including any vitamins and complementary therapies. Note the dose and any side effects.
- Check with the receptionist that the health professional has received results for scans, blood tests and other tests.
- Record any recent changes in the person's condition or symptoms so you can tell the health professional about them.

### During the visit

- Take notes or ask the health professional 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 health professional if they can give you printed material or tell you where to find more information.
- Check what changes in the person's physical condition you should watch out for and what to do about them.
- Look over the list of questions you brought along to check that they have all been answered.

### After the visit

- Review your notes.
- Discuss the visit with the person you are caring for. If you have any questions, call Cancer Council 13 11 20.
- Call the health professional for test results, if appropriate.
- Record the next appointment in a diary or calendar.
- Contact the health professional about changes or side effects.

## Understanding the MDT

The MDT is there to support the person with cancer and their carers. 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 different issues.

### Health professionals you might see

<b>general practitioner (GP)</b>	assists with treatment decisions and works with specialists to provide ongoing care
<b>surgeon*</b>	surgically removes tumours and performs some biopsies; specialist cancer surgeons are called surgical oncologists
<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 overseeing a course of radiation therapy
<b>haematologist*</b>	diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy and other drug therapies
<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>cancer care coordinator</b>	coordinates care, liaises with other members of the MDT, and supports the family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)

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>dietitian</b>	recommends an eating plan to follow during treatment and recovery
<b>social worker</b>	links people with cancer and carers to support services and helps with emotional, practical or financial issues
<b>counsellor, psychologist, psychiatrist*</b>	help people with cancer and their carers and families manage their emotional response during diagnosis and treatment
<b>speech pathologist</b>	helps with communication and swallowing problems
<b>occupational therapist</b>	assists in adapting the living and working environment to help the person with cancer resume their usual activities after treatment
<b>physiotherapist</b>	helps with restoring movement and mobility after treatment and preventing further injury
<b>spiritual care practitioner (pastoral care)</b>	discusses any spiritual matters and search for meaning, if appropriate; may arrange services and other religious rituals

\* *Specialist doctor*

## Organising paperwork

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

The following tips may be helpful:

- Set up a system for organising paperwork to 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.
- Create an online My Health Record for the person with cancer at [myhealthrecord.gov.au](http://myhealthrecord.gov.au). The My Health Record means the person's important health care information is in one place and can be seen by their health professionals with their permission. If the person is not capable of making their own decisions, you can apply to manage their account. You will be known as the authorised representative.
- Download an app from the App Store or Google Play to store medical records on a tablet or smartphone. Some of these apps can be connected to 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 much will the medicines cost?
- How should the drugs be given (e.g. with or without food)?

- 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? Will the dose be reviewed?
- What should I do if a dose is missed?
- When is the use-by date, and where is it on the medicine packaging?
- How should the drugs be stored?

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

**Keep a 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, which is especially important in an emergency. You can create your own list or download the MedicineWise app from the App Store or Google Play onto your tablet or smartphone. You scan the barcode on the packaging to add a medicine to the app, record dosages and set reminders for when to give each medicine at the right time.

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



## Applying for a PBS Safety Net card

The Australian Government subsidises the cost of many prescription medicines through the Pharmaceutical Benefits Scheme (PBS). Once a certain amount has been spent on medicines during the calendar year (the threshold amount), the person can apply for a PBS Safety Net card.

You can track what the person you are caring for spends on PBS medicines on a Prescription Record Form (available from pharmacists). If they use the same pharmacist, you can ask the pharmacist to keep a computer record instead. Once the threshold amount has been reached, the pharmacist can give the person a Safety Net card and the PBS medicines will then be cheaper or free for the rest of that year. To find out more, call 132 290 or visit [servicesaustralia.gov.au](http://servicesaustralia.gov.au) and search for “Pharmaceutical benefits scheme safety net”.

## Monitoring symptoms and side effects

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

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

The table on pages 14–15 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 side effects experienced by people with cancer.

- Listen to *The Thing About Cancer* podcasts for tips on managing pain, nausea and appetite loss, fatigue, sleep, and brain fog.

Some side effects go away quickly; others can take weeks, months or even years to improve. Some side effects may be permanent. A person's body will cope with the treatment and recovery in its own way. It is important not to compare the person to others. It's also important to let the treatment team know of symptoms and side effects – they will often be able to suggest medicines and other treatments that can help.

Some people experience late side effects. These are problems that develop months or years after treatment finishes. They may result from scarring to parts of the body or damage to internal organs. Talk to your doctor about whether the person is at risk of developing late effects from treatment.

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

- a temperature of 38°C or above
- chest pain or shortness of breath
- persistent or severe nausea or vomiting
- redness or swelling around the site of an injection
- confusion
- severe headache with a stiff neck
- chills with shaking or shivering
- severe abdominal pain, constipation or diarrhoea
- unusual bleeding (e.g. nose bleeding for over 30 minutes)
- incontinence or trouble passing urine and/or leg weakness
- 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. Contact their treatment team if the pain is hard to manage. It may take time to find the right pain medicine.
- Always talk to the doctor before stopping or changing the dose.
- Use a pain scale or pain diary to help you understand the intensity of the pain and the need for extra doses.
- Try relieving pain and discomfort with hot water bottles or heat packs (check the temperature first), ice packs or gentle massage.
- Understand the different roles of long-acting and short-acting pain medicines and support the person with cancer to use them appropriately.
- See our *Overcoming Cancer Pain* booklet and listen to our “Managing Cancer Pain” podcast episode.

### Nausea and loss of appetite

- 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.
- Offer the person their favourite or well-tolerated foods often. Most people don't need a strict diet during cancer treatment, though you should follow the advice of the health professionals.
- Provide nutritious snacks and drinks throughout the day.
- Focus on creating a pleasant atmosphere for meals and sitting together and talking.
- Celebrate the small amounts the person eats rather than how much is not finished.
- Offer small, simple meals.
- If the person you care for is losing weight or feels too nauseous to eat, talk to their doctor to identify the cause. The person may need medicine changes or a review by a dietitian or pharmacist to arrange dietary supplements.
- Find an accredited practicing dietitian at [dietitiansaustralia.org.au/find-an-apd](http://dietitiansaustralia.org.au/find-an-apd).



## Breathlessness

- Use a handheld fan to direct a cool stream of air across the person's face.
- Place 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. You can also ask a doctor or GP about seeing a psychologist to help manage anxiety.
- Talk to the treatment team about breathing exercises, equipment and treatments to manage breathlessness.
- Set up a recliner chair to help the person sleep in a more upright position.

## Fatigue

- Help the person to set small, manageable goals for the day, and suggest they take regular breaks before they become too tired.
- Encourage the person to say no to activities 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. This may include walking or strength-training exercises. See an exercise physiologist or physiotherapist for other suggestions.
- Establish a regular bedtime routine 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 preparing meals, doing household chores and providing transport. If the person you care for has difficulty moving around because of the cancer or treatment side effects, 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 with soap and water 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 feel nauseated (with or without vomiting), or they may have mouth or throat sores that make it painful to eat. Cancer treatment can also change the taste and smell of food.

At times, the person may not be able to eat even their favourite foods. While you may want them to eat well during treatment, focusing on their 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 help by preparing meals. Let them know what types of food to prepare, and why hygiene and food safety are especially important at this time. Use online tools such as [mealtrain.com](https://mealtrain.com) and [candoapp.com.au](https://candoapp.com.au) to help coordinate meal giving.

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 sores in the mouth.

- See our *Nutrition and Cancer* booklet, and *Understanding Taste and Smell Changes* and *Mouth Health and Cancer Treatment* fact sheets.

## Managing the home environment

If the person you are caring for becomes unwell or frail during treatment, you may need to make some changes to their home to make it safer for them to do everyday activities such as self care and to prevent falls. This may include small adjustments such as moving furniture to make access easier, removing loose rugs and other tripping hazards, putting handrails on the stairs or in the bathroom, or putting a chair in the shower.

Talk to the occupational therapist or physiotherapist on the treatment team about aids or equipment you can buy or rent. For example:

- bed or chairs
- commodes, bedpans and urinals
- bathing equipment
- mobility equipment such as four-wheeled walkers, pick-up frames or walking sticks
- cart with wheels to carry things.

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 physiotherapist to show you how to do so safely. They can suggest equipment you can use to make lifting easier.

You can ask family and friends for help 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 social worker on the treatment team or get in touch with Cancer Council 13 11 20 to find out how to access this support.

Social work services are also available through Services Australia – visit [servicesaustralia.gov.au](http://servicesaustralia.gov.au). If the person you are caring for is 65 or over, contact My Aged Care for an assessment. Call 1800 200 422 or visit [myagedcare.gov.au](http://myagedcare.gov.au).

## Providing personal care

A person may need help with bathing, toileting and dressing at various times during and after the course of treatment. There are aids or equipment available (see previous page) to make bathing and going to the toilet easier.

If treatment means the person has trouble with incontinence (accidental loss of urine or faeces), talk to a continence nurse or physiotherapist for exercises to strengthen pelvic floor muscles or about protective bed covers and pads. You can also call the National Continence Helpline on 1800 33 00 66 or visit [health.gov.au/health-topics/bladder-and-bowel](http://health.gov.au/health-topics/bladder-and-bowel).

Some carers feel uncomfortable providing personal care themselves, particularly for their parents or adult children. Or the person with cancer may prefer that a professional assists with daily personal tasks. To find out how to arrange visits from care workers to help with these tasks, talk to the social worker on your treatment team or call Cancer Council 13 11 20.

## Long-distance caring

Some people live away from the person with cancer. You may feel guilty for not being closer, and you may feel you are the last one to know about treatment and care.

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. If you want to stay involved, there are many things you can do.

- If someone else is the primary carer, ask what you can do to support them.
- Create a local support network. You could start by connecting with 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 local area.
- Consider using websites such as **[gathermycrew.org.au](http://gathermycrew.org.au)** to coordinate offers of help.
- Keep an up-to-date contact list of the health care team members who are looking after the person with cancer.
- Use technology to stay in touch. Options to consider include email, blogging, text messaging, Skype, Facebook and video conferencing apps such as Zoom.
- Ask the person if their health professional will allow them to record consultations so you can hear what was discussed, or join the consult by telephone.
- Research telephone (landline and mobile) and internet plans with different providers to reduce costs.
- Set aside money so you are prepared if you have to travel suddenly.
- Create an emergency care plan (see page 22) and give copies to the carer and emergency contacts you have nominated.

## Financial matters

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 and tests. Treatment may mean you need to buy or rent equipment and aids.

You may be able to get government benefits and payments and other financial support to help with these costs. For more information, read the box opposite, speak to a social worker or visit [carergateway.gov.au/financial-help](http://carergateway.gov.au/financial-help).

The government agency Services Australia offers a free, confidential Financial Information Service that provides education and information on financial matters. Call 132 300 to find out more.

Getting advice from a professional can help. Options include:

- **Financial planner** – help people manage their assets, including superannuation. To find a planner, visit [fpa.com.au/find-a-planner](http://fpa.com.au/find-a-planner).
- **Financial counsellor** – can help set up a budget and manage debt. The National Debt Helpline can help you find a financial counsellor. Call 1800 007 007 or visit [ndh.org.au](http://ndh.org.au).

Cancer Council may be able to provide some financial assistance and you may be eligible for financial advice through our Legal and Financial Referral Service – call 13 11 20 to find out more.

➤ See our *Cancer and Your Finances* booklet.

## Finding financial support for carers

**Centrelink benefits** – Services Australia offers various payments 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 extra daily care. There is an income test but no asset test. Visit [servicesaustralia.gov.au](http://servicesaustralia.gov.au).

**Travel payments** – Every state and territory has a government scheme that provides financial help to people who need to travel long distances to access specialist medical treatment that is not available in their local area. Many of these schemes include accommodation. In some cases, financial assistance may also be available if a carer needs to travel with the patient to treatment. 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** – You or the person you are caring for may be able to access superannuation

early. Keep in mind that accessing this money may have tax implications and could affect your retirement income and insurance policies.

**NDIS** – The National Disability Insurance Scheme (NDIS) provides Australians aged under 65 who have a permanent and significant disability with funding for support and services. Call **1800 800 110** or visit [ndis.gov.au](http://ndis.gov.au).

**GP management plan** – People diagnosed with cancer may be eligible to claim through Medicare for up to five allied health service appointments a year, including with a psychologist, physiotherapist, occupational therapist or dietitian. Ask the GP for more information.

**Hardship programs** – Most electricity, gas, water or phone providers offer flexible payment options to customers who are having trouble paying their bills. Check whether the person's providers have hardship programs.

## Planning for the future

A cancer diagnosis can make it difficult to talk about the future, especially if you're feeling optimistic or are uncertain about the possible outcomes of treatment. It is never too early to think about how you will manage if the situation changes. Knowing plans are in place can help ease worries, give you a sense of control 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.

To download a sample emergency care plan and carer emergency card, visit [carergateway.gov.au](http://carergateway.gov.au). To get a printed copy of the plan and card, call 1800 422 737.

### Advance care planning

It can be a good idea for a person to plan for their future medical treatment and care, and to discuss their preferences and values with family, friends and the health care team. This process is called advance care planning and can involve preparing various legal documents. See pages 56–58 to read more about substitute decision-makers, advance care directives and wills.

## Communicating with others

As the main carer, you'll usually be the person family and friends contact for information. You may find keeping others up to date on the condition of the person with cancer time-consuming and tiring. Some carers find it stressful dealing with other people's reactions to the latest news. It's also important to ask the person you are caring for how much information they would like you to share.

Ways to keep family and friends up to date include:

- 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.
- Use technology such as text messages or emails to send group messages. You may want to include a statement such as: "We are not able to reply to everyone individually, but we are reading your messages and appreciate your support."
- Start an online diary, blog, or Facebook group or other social media group to share news and coordinate offers of help. You can set up a protected online community at [gathermycrew.org.au](http://gathermycrew.org.au).
- Let family and friends know how you'll keep them up to date. You may want to ask a family member or friend to update others.
- If you need to explain the situation to children, see our *Talking to Kids About Cancer* booklet.

## Emotional support

An important part of the carer's role can be to provide emotional support to the person with cancer. You might want to talk to them about their cancer diagnosis and treatment, but not know how. 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 become emotional.

It's likely the person you're caring for will experience a range of strong emotions. It can help to ask if they would like to talk. Sometimes they might talk openly about how they're feeling. Or they may prefer not to share their thoughts, and it's important to respect this. They may also try to hide their feelings because they don't want to upset you.

It's natural to have disagreements from time to time, especially when you're both under stress. Try to understand how a cancer diagnosis can affect how a person feels and behaves. Although dealing with conflict can be hard, it can also bring you closer together and help you understand each other's point of view.

While you may be the main source of emotional support, you can encourage the person you're caring for to speak to family members, friends or health professionals who can provide emotional support in different but valuable ways.

- Listen to our “Cancer affects the carer too” podcast episode.



## Ways to communicate

### Be a good listener

- Sit somewhere private where you will not be interrupted.
- Make it clear 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.
- Acknowledge that this is a difficult time. Ask open questions to help you understand how the other person is 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.
- Use humour to relieve tension.

### Resolve conflict

- Let the other person know that you care about them and want to resolve your differences.
- Try to talk through the issues calmly. Hear each other out and work towards a solution, rather than seeing the other person as the problem.
- 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 a discussion becomes heated, take a break and talk later when you are both calmer.
- Arrange for others to take on the caring role for a short time.
- Ask your GP or treatment team for a referral to a social worker, counsellor or psychologist who can help you manage the conflict.



## Key points about being a carer

Your caring role will depend on the needs of the person you are caring for and also on what you are able to do.

### Medical care

- Carers often liaise with health professionals, and 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 can help monitor and manage symptoms and side effects. Talk to the treatment team about how you can ease symptoms and side effects at home.

### Practical support

- 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 or physiotherapist can suggest changes to the home to ensure it's a safe environment.

### Financial matters

- Carers may be eligible for financial assistance through Services Australia (Centrelink).

### Emotional support

- Carers often provide 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. If you have a history of anxiety or depression, this could make you more vulnerable now. It's important to manage emotional distress – 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 a sense of satisfaction when you're caring for someone on a day-to-day basis. But some people find that when their caring role ends, they are able to reflect on the positive and rewarding parts of their caring experience.

## Common reactions

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

### Fear and anxiety

Cancer treatments and outcomes have dramatically improved in recent years, but caring for someone with cancer can still be frightening and overwhelming. It's natural to worry about the treatment, side effects, test results and the long-term outcome, as well as the impact that the diagnosis will have on your family, work and other responsibilities.

Many carers say that learning more about the diagnosis and treatment options 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.

### Stress

Looking after someone with cancer can be 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.

## 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
- not sleeping well
- 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 other family responsibilities 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.

## 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 enough or feeling they aren't doing a perfect job as a carer.



## 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.

## 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. Joining a support group may help you connect with others in a similar situation.

## Depression

Feeling down or sad after a cancer diagnosis is common. It's a natural response to loss and disappointment, and usually lasts a short time without severely affecting your life.

If you have continued feelings of sadness for several weeks, have trouble getting up in the morning, and have lost interest and pleasure in activities you used to enjoy, you may be experiencing depression. Research shows that depression is common among carers.

There are a number of ways to manage depression. Talk to your health care team 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. But feelings of loss and grief can also happen when you are caring for someone diagnosed with cancer. It's natural to miss activities you used to enjoy, such as work, regular exercise, socialising or volunteering. It is normal to feel both grief for the “normal” you have lost and grief at the need to adjust to a “new normal”.

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 *How relationships can change* chapter on pages 43–46 discusses ways to manage changes.

➤ See our *Emotions and Cancer* booklet.

## Ways to manage your emotions

It may feel hard to find the time or energy to look after your own emotional wellbeing. These simple strategies may help you cope and feel more in control.

### Try complementary therapies

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.



### Take time for yourself

Make time each day to do something you find relaxing. Respite care is available for short or longer periods (see page 39) and may give you the break you need.



### Be active

Research shows that regular exercise can help with feelings of anger, stress, anxiety and depression. It can also improve fatigue and sleep. Even a brisk walk around the block offers benefits.



### Talk about how you're feeling

If at any stage you feel overwhelmed, speak to your health care team, as counselling or medicine – even for a short time – may help. You may be referred to a psychologist (see page 66). The organisation Beyond Blue has information about coping with depression and anxiety at [beyondblue.org.au](http://beyondblue.org.au). You can also call Lifeline **13 11 14** for crisis support at any time of day or night.



### Speak to your GP

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



### 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.



### 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 69 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. To connect with others in a similar situation, visit Cancer Council Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).





## Caring for yourself

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

The responsibility of looking after someone with cancer may mean that you ignore your own needs. You may feel as though your career, interests and health are no longer important or have to take second priority for a period of time.

It's important to look after yourself as this will help you provide better quality of care over a longer period of time.

### Keeping healthy

While you are busy looking after someone, you may find it difficult to look after your own health and wellbeing.

You may downplay your own health needs. It's okay to 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.

“ I had to reassess how I was looking after myself. I ended up being really overdue for a Pap smear because I just hadn't had the opportunity or even the headspace really to think about myself very much. ” Susan

## Ways to stay healthy

**Eat healthy meals and snacks** – If the person has long treatment sessions or appointments, or is in hospital, you may need to bring healthy foods and drinks from home. Avoid snacks that are high in added fats, sugars and salt, such as chips, biscuits and chocolate.

**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. If you smoke, call the Quitline on 13 7848 to talk to an adviser and request a free Quit Pack.

**Be active for 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. A stationary exercise bike, a yoga/meditation mat or an online program can allow you to exercise at home. Doing any physical activity is better than none.

**Have regular check-ups** – It's important to maintain regular visits to your GP, dentist, optometrist and other health professionals. See your GP if you notice changes in your sleep patterns, weight or mood.

**Stay in touch with friends and family** – Maintaining relationships can help you feel connected to others, reduce stress and provide an opportunity to talk about topics aside from your role as a carer.

## Finding ways to cope

Caring for someone with cancer is not always easy or satisfying. Many carers say they feel overburdened and resentful. The following strategies may help you cope. See also pages 32–33.

**Focus on the value of caring** – Acknowledging the benefits of caring may help you feel better. These may include learning new skills, strengthening your relationship as you demonstrate your love, 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, consider organising regular visits from a care worker. You are allowed to say no.

**Organise your time** – Use your phone or a diary to keep track of information and appointments, and to help you prioritise your weekly tasks and activities.

**Draw on spirituality** – Some people find meaning and comfort in their religion, faith and spiritual beliefs. Others may experience spirituality more generally. A cancer diagnosis can challenge the beliefs of some people. It may help to talk about your feelings with a spiritual care practitioner, religious leader or counsellor.

**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 cannot control leaves you with more energy and mental capacity.

**Keep a journal** – Writing down what has been happening may allow you to release your worries or frustrations. Reading back through journal entries can provide perspective – you may see that some days are better than others. It also lets you reflect on how you're coping and identify areas you need assistance with.

**Look for reliable information** – It may help to learn more about cancer and possible treatment options – see page 66 for some reliable sources. Going with the person to medical appointments can give you a better understanding of the treatment plan.

### **If caring becomes too much**

You might find providing care difficult. It may be that the physical demands are becoming too much, especially if you are older or have your own health issues. Perhaps you know you need support but don't want to disappoint the person you're caring for. See pages 38–39 for ways to get practical help.

You could also find that caring is emotionally exhausting. You

may find it helpful to see a counsellor. They may help you see ways to make caring more manageable. Your GP or local Cancer Council can refer you to a counsellor. You can also access the Carer Gateway Counselling Service by calling **1800 422 737**. For 24-hour crisis support, call Lifeline on **13 11 14**.

For more ways to find support, see the next two pages.

## Asking others for help

It can be difficult to ask for and accept assistance, but if you seem to be coping, others may not realise you need help. Family and friends 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 they're not interfering.

Asking for help is not a sign of failure; it may allow you to spend more time with the person you're caring for or to take a break.

You may want to hold a family meeting to work out how everyone can help and then prepare a roster. This lets family and friends know exactly what help you need and when you would like it. It means others don't have to guess what they can do to help. Tasks that can be done by or shared with others include:

- household chores such as cooking, cleaning, laundry, ironing, shopping, gardening or looking after pets
- 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.

“ 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



There are about 235,000 carers under the age of 25 in Australia. The Carers Associations in each state and territory offer information and support tailored for young carers. Visit [youngcarersnetwork.com.au](http://youngcarersnetwork.com.au) 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:

- taking time out to access health care for yourself
- visiting friends or other family members
- catching up on some sleep at home
- running errands, such as grocery shopping
- attending 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. 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. It also gives the person you are caring for an opportunity to interact with other people.

Availability of respite care can vary depending on where you live. For more information, visit [carergateway.gov.au](http://carergateway.gov.au). If you need emergency respite, call 1800 422 737.

## 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 their job. You may also be caring for your own family.

Your decision to continue working will probably depend on several factors, including:

- how unwell the person with cancer is
- what your caring and work duties involve
- your family situation
- the amount of help or respite care available
- your finances and whether you need to earn an income
- whether the situation is likely to be temporary or long term
- what will give you peace of mind.

Caring can impact on your job in various ways. It may affect your work hours, what you can achieve at work, how much time off you need, your concentration, and your emotional and physical wellbeing.

Before making decisions about work, talk to your employer about your caring responsibilities. They may be able to support you with flexible working arrangements.

To find out more about working while caring for someone, visit [carergateway.gov.au/help-advice/working-while-caring](http://carergateway.gov.au/help-advice/working-while-caring).

- See our *Cancer, Work & You* and *Cancer Care and Your Rights* booklets.

## When your caring role ends

Many people find that the most challenging time in their caring role is when the need for care finishes. You could feel a bit lost or not needed anymore. If the person has recovered, they may 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. The end of treatment 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.

You may expect that you'll slip back into day-to-day life as it was before you 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 changes in life philosophy and relationships, and personal growth. Many people find these changes are rewarding and life-changing, but it's not a positive experience for everyone. You may need time to reflect on what has happened and what it has meant to you.



## Key points about caring for yourself

Being a carer can be rewarding but it can also be physically and emotionally demanding.

### Ways to cope

- 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 break.
- Carers often forget to look after their own health. Try to eat well, get some exercise, rest and keep up with regular 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.
- Plan your day 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 cancer may help you feel more in control.

### Respite care

- Organise respite care so you can have a break from your caring duties.

### Work

- 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. This can be challenging and hard to adjust to.

The impact of cancer on a relationship often depends on what your relationship was like before the cancer diagnosis. You may find caring for someone strengthens your relationship with them.

For others, particularly those who had a strained relationship before the diagnosis, the pressure of a cancer diagnosis and treatment, financial worries 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 page 38).

It can be helpful to understand the potential changes that cancer can bring. Being open and honest can help you and the person you are caring for through the anxieties, sadness and uncertainty. This chapter discusses ways a relationship may change, and how to manage these changes.

“ I think sometimes trying to be his carer, his partner, his lover, his companion – just swapping between roles can sometimes be a bit tricky. It can be a bit tiring but I’m happy to do it. It’s more an issue of making sure I don’t lose myself and my own life in all of this. ” Susan

## Impact of caring on relationships

Examples of changes	Ways to manage changes
<ul style="list-style-type: none"><li>• I might need to take on new responsibilities that will reverse our roles.</li><li>• If I'm doing all the caring, they may feel like they've lost their independence.</li><li>• My concern might come across as being overprotective or controlling.</li><li>• I may feel like it would be selfish to talk about my needs when they are having to go through cancer treatment.</li><li>• I may avoid sharing how I'm feeling because I'm scared of overwhelming the other person when they have enough to worry about.</li><li>• The intimacy we shared might be replaced by the caring role.</li><li>• We might need to re-evaluate our priorities and set new goals or put them on hold.</li></ul>	<ul style="list-style-type: none"><li>• Talk about the changes to avoid misunderstandings. Discuss ways to meet each other's needs.</li><li>• Allow time to get used to the changes, particularly if roles have reversed.</li><li>• Set boundaries to maintain independence and allow both of you to feel in control.</li><li>• Arrange home help if you or the person you are caring for feel uncomfortable doing the bathing and dressing.</li><li>• Give the person you're caring for the chance to do things for themselves.</li><li>• Use touch to show you care.</li><li>• If you and the person you're caring for find it difficult to discuss your different needs without both becoming defensive, consider seeing a counsellor or psychologist. They can suggest ways to approach such conversations.</li></ul>

## Support for LGBTQI carers

Lesbian, gay, bisexual, transgender, queer or questioning, and intersex (LGBTQI) people may face specific challenges as carers. They may worry about health professionals or the person's family or friends accepting them, or wonder if support services are LGBTQI-friendly. Visit [carergateway.gov.au/tips/tips-lgbti-carers](http://carergateway.gov.au/tips/tips-lgbti-carers) for more information. You can also contact the national counselling and referral service for LGBTQI people at [qlife.org.au](http://qlife.org.au), or the National LGBTI Health Alliance at [lgbtihealth.org.au](http://lgbtihealth.org.au).

## 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 during and 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 carer and patient back to being sexual partners.
- You might feel guilty if your partner is unable or unwilling to be sexually active and you still want a sexual relationship.



## How to manage sexual changes

- Talk about how you're feeling – communication is an important sexual tool.
- Spend time together to maintain intimacy in your relationship. 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 chat 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 changes from their illness or treatment.
- Have your partner show you any body changes before sexual activity. This may allow both of you to get used to how the differences make you feel.
- Discuss any concerns you have about being intimate with your partner. If you keep quiet and withdraw, your partner may misinterpret your actions and think they're no longer desirable. Being open with your partner about your sexual needs can help you identify ways to manage them.
- 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.
- See our *Sexuality, Intimacy and Cancer* booklet and listen to our "Sex and Cancer" podcast episode.



## 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. We hope that this information helps you provide comfort and support to the person you're caring for.

## When cancer won't go away

Some people's cancer may be advanced when they are first diagnosed. For others, the cancer may have spread or come back (recurred) after treatment. Advanced cancer means the cancer is unlikely to be cured, but it can often be managed.

Some people live with advanced cancer as a chronic illness for many years, so there may not be much difference in your caring role immediately. For others, your responsibilities as a carer are likely to increase and may become more complex almost overnight. This may give you little time to adjust to the new situation.

Caring for someone with advanced cancer can feel overwhelming. You may be trying to support the person, while coming to terms with the diagnosis yourself. You may be experiencing a range of strong emotions such as denial, fear, anger, sadness and grief. A diagnosis of advanced cancer also means living with uncertainty about what lies ahead, and this can be challenging.

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. Use text messages, email, blogs or social networking sites, or write one letter and send copies to people. If you need support, talk to your GP or the hospital social worker, or call Cancer Council 13 11 20.

- ▶ See our *Living with Advanced Cancer*, *Understanding Palliative Care* and *Facing End of Life* booklets, and listen to *The Thing About Advanced Cancer* podcast. Palliative Care Australia also has a range of useful resources – visit [palliativecare.org.au/resources](http://palliativecare.org.au/resources).

## Discussing prognosis

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

If the person you are caring for prefers not to know, you may still want some idea of their prognosis to help you plan ahead. You can ask the person if they can give their treatment team permission to speak to you alone.

The health professionals may give you a general idea 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 treatment.

### Avoiding carer burnout

Caring for a person with advanced cancer can be physically and emotionally demanding.

Now more than ever, it is important to look after your own wellbeing (see the tips in the *Caring for yourself* chapter, on pages 34–42).

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

You can also be supported in your caring role by palliative care. This is person-centred care that helps people with a progressive, life-limiting illness to live as fully and comfortably as possible. It's also called supportive care. The main aim is to maintain quality of life by dealing with the person's physical, emotional, cultural, social and spiritual needs.

Palliative care doesn't mean giving up hope. It is not just for end-of-life care – it may be beneficial for people at any stage of advanced cancer. Palliative care involves a range of services that will be tailored to the person with cancer's individual needs.

Services may include:

- relief of pain, breathlessness, nausea and other symptoms
- help organising equipment for home (e.g. wheelchairs, special beds)
- assistance for families and carers to talk about sensitive issues
- links to other services such as home help and financial support
- support for people to meet cultural obligations
- counselling, grief and bereavement support
- support for emotional, social and spiritual concerns
- referrals to respite care services.

“ I only found out about palliative care a few years ago. For me, this made such a positive difference – I now have equipment such as a walking frame, wheelchair, shower seat and toilet seat. My palliative care nurses visit me at home twice a week. ” Agnes

## How palliative care works

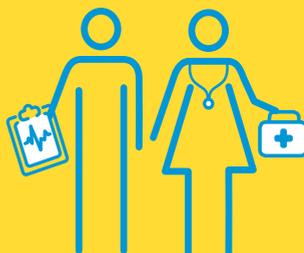


### When to start

Palliative care is useful at all stages of advanced cancer and can be provided alongside active treatment for cancer. Starting palliative treatment from the time of diagnosis can help improve quality of life.

### Who provides care

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.



### Where care is provided

Options include 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). 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.

### How you can help

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. But because 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.



## Support for carers

Although carers may need support at any stage of cancer, their responsibilities usually increase if the disease progresses. Following are common issues you may face as you care for someone with advanced cancer, people who can help and where to find more information.

What support is needed	Who can help
<p><b>Making treatment decisions</b></p> <p>It can be confronting and confusing for the person to work out whether to keep having active treatment 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 pages 57–58), you may feel a heavy responsibility when making this decision for them.</p> <p>▶ See our <i>Living with Advanced Cancer</i>, <i>Understanding Palliative Care</i>, <i>Cancer Care and Your Rights</i> and <i>Facing End of Life</i> booklets, and listen to our “Making Treatment Decisions” podcast episode.</p>	<ul style="list-style-type: none"><li>• palliative care team</li><li>• cancer specialists</li><li>• GP</li><li>• social worker</li></ul>
<p><b>Managing symptoms</b></p> <p>You may find that symptoms such as pain become more complex to manage, especially as the person is likely to experience a number of symptoms at the same time. Early medical attention can provide relief and make symptoms easier to manage.</p> <p>▶ See pages 12–15 of this booklet, our <i>Living with Advanced Cancer</i>, <i>Facing End of Life</i> and <i>Overcoming Cancer Pain</i> booklets, and listen to <i>The Thing About Cancer</i> podcast.</p>	<ul style="list-style-type: none"><li>• palliative care specialist</li><li>• palliative care nurse practitioner</li><li>• pain specialist</li><li>• cancer specialists</li><li>• GP</li><li>• community nurse</li><li>• physiotherapist</li><li>• exercise physiologist</li></ul>

What support is needed	Who can help
<p><b>Setting up the home</b></p> <p>To make it easier and safer to care for someone at home, you may need to make some changes (e.g. handrails on steps and in the shower) or buy or rent equipment (e.g. shower and toilet chairs, bedpans, walker, harness for helping to lift the person, hospital bed).</p>	<ul style="list-style-type: none"> <li>• occupational therapist</li> <li>• physiotherapist</li> </ul>
<p><b>Preparing food and drink</b></p> <p>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.</p> <p>➤ See our <i>Nutrition and Cancer</i> booklet.</p>	<ul style="list-style-type: none"> <li>• dietitian</li> <li>• speech pathologist</li> </ul>
<p><b>Providing personal care</b></p> <p>If the person becomes weak or unwell, they may need help with showering and toileting. If they are unable to get out of bed, they may need sponge baths and assistance to use a bedpan or urinal bottle.</p>	<ul style="list-style-type: none"> <li>• community care workers</li> <li>• My Aged Care <b>1800 200 422</b></li> </ul>
<p><b>Coping with the extra workload</b></p> <p>You may find it difficult to manage the extra tasks, especially if you have other responsibilities such as a job or looking after children, or if you have your own health issues.</p>	<ul style="list-style-type: none"> <li>• My Aged Care <b>1800 200 422</b></li> <li>• home help provided by local councils</li> <li>• Carer Gateway (see page 65)</li> <li>• family and friends</li> </ul>

What support is needed	Who can help
<p><b>Organising finances</b></p> <p>You may need to find additional financial support and possibly access superannuation and insurance. Seek professional advice before changing any financial arrangements.</p> <p>➤ See pages 20–21 of this booklet, and our <i>Cancer and Your Finances</i> booklet.</p>	<ul style="list-style-type: none"> <li>• social worker</li> <li>• Cancer Council Financial Referral Service <b>13 11 20</b></li> <li>• financial counsellor, financial adviser</li> </ul>
<p><b>Making legal arrangements</b></p> <p>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.</p> <p>➤ See pages 56–58 of this booklet, and the <i>Getting your affairs in order</i> fact sheet on your local Cancer Council website.</p>	<ul style="list-style-type: none"> <li>• social worker</li> <li>• Cancer Council Legal Referral Service <b>13 11 20</b></li> <li>• Advance Care Planning Australia <b>1300 208 582</b></li> </ul>
<p><b>Dealing with emotions</b></p> <p>A diagnosis of advanced cancer can be distressing for all involved, and it is common to experience grief, anxiety and depression. Seek professional help if these emotions are making it hard to function or enjoy some aspects of life.</p> <p>➤ See pages 24–25, 27–33 and 61–62 of this booklet, and our <i>Emotions and Cancer</i> and <i>Understanding Grief</i> booklets.</p>	<ul style="list-style-type: none"> <li>• GP</li> <li>• social worker</li> <li>• psychologist, counsellor or psychiatrist</li> <li>• support groups (page 69)</li> <li>• Cancer Council <b>13 11 20</b></li> <li>• Carer Gateway Counselling Service <b>1800 422 737</b></li> <li>• Beyond Blue <b>1300 22 4636</b></li> <li>• Lifeline <b>13 11 14</b></li> </ul>

What support is needed	Who can help
<p><b>Communicating with family and friends</b></p> <p>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.</p> <p>➤ See our <i>Talking to Kids About Cancer</i> booklet.</p>	<ul style="list-style-type: none"> <li>• social worker</li> <li>• Cancer Council <b>13 11 20</b></li> <li>• particular family members or friends who can relay updates</li> <li>• social networking websites to connect with family and friends online (see page 23)</li> </ul>
<p><b>Exploring the meaning of the person's life</b></p> <p>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 61). Some people also want to explore spirituality, even if they have never been religious.</p> <p>➤ Listen to Cancer Council's podcasts.</p>	<ul style="list-style-type: none"> <li>• social worker</li> <li>• psychologist or counsellor (ask your treatment team or GP for a referral)</li> <li>• spiritual care practitioner (also called a pastoral carer, usually available through your treatment centre)</li> <li>• religious leader</li> </ul>
<p><b>Maintaining hope</b></p> <p>The carer can have an important role in helping the person with cancer maintain 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.</p>	<ul style="list-style-type: none"> <li>• social worker</li> <li>• psychologist or counsellor</li> <li>• spiritual care practitioner (pastoral carer)</li> <li>• family and friends</li> </ul>

## Advance care planning

Planning for a person's future medical care and discussing their treatment preferences and values with family, friends and the health care team is known as advance care planning. 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-starters](http://dyingtotalk.org.au/discussion-starters). Many people think of this process as part of “hoping for the best and preparing for the worst”.

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. It is ideal if the advance care plan can be as detailed as possible so that their preferences are clear. Studies show that families of people who have done advance care planning feel less anxiety and stress when asked to make important health decisions for others.

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 even if it may not be beneficial for them. You may find it helpful to talk to the palliative care team about how you are feeling. Palliative care teams are experienced at helping people through these difficult discussions about balancing the quality and length of life.

## Different laws

Each state and territory has different laws related to advance care planning.

To find out more about what legal documents are needed where you live, call Cancer Council **13 11 20** or see the *Getting your affairs in order* fact sheet on your local Cancer Council website.

If you have questions, you can also call Advance Care Planning Australia on **1300 208 582**.

When preparing legal documents, 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**.

## Legal arrangements

If the person hasn't already done so, now is a good time to appoint a substitute decision-maker, make an advance care directive and prepare a will. These legal documents ensure that their wishes are recorded.

For any of these documents to be legally binding, the person needs to have capacity at the time of signing the document. Having capacity means the person has the ability to understand the choices that are available and the consequences of decisions, as well as the ability to communicate choices. For more information, talk to your lawyer and doctor, or visit [end-of-life.qut.edu.au/capacity](http://end-of-life.qut.edu.au/capacity).

**Document appointing a substitute decision-maker** – The person with cancer can appoint someone to make medical decisions on their behalf if at some point in the future they lose capacity to make their

own decisions. These can include decisions about medical care and treatment. This person is called a substitute decision-maker. The substitute decision-maker may be the primary carer or someone else the person trusts. Depending on where you live, the documents for appointing a substitute decision-maker may be known as enduring power of attorney, enduring power of guardianship, or appointment of a medical treatment decision maker. See the *Different laws* box on the previous page for where to find more information.

**Making an advance care directive** – This directive records a person's wishes for their future medical care. Doctors, family members and carers can consider this directive if the person is unable to communicate or make decisions, and may be legally binding in some states and territories. Depending on where you live, the advance care directive may also be known as an advance health directive or advance personal plan. Download forms from [advancecareplanning.org.au](http://advancecareplanning.org.au).

**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 can also record the person's wishes regarding who will look after any children under the age of 18 (guardianship). Many people want to make a will or update the one they have as their situation changes. 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.

## Voluntary assisted dying

Voluntary assisted dying is when a person with an incurable condition or illness chooses to end their life and uses medicines specially prescribed by a health practitioner.

At the time of publication (2022), voluntary assisted dying is illegal in most Australian states and territories. In Victoria and Western Australia, voluntary assisted dying is legal only for people who meet all the strict

conditions and follow certain steps. Visit [health.vic.gov.au](http://health.vic.gov.au) or [health.wa.gov.au](http://health.wa.gov.au) and search for “voluntary assisted dying”.

Voluntary assisted dying laws have been passed in Tasmania, South Australia and Queensland, and voluntary assisted dying will start between late 2022 and early 2023. The laws in other states and territories are under review.

Visit [end-of-life.qut.edu.au](http://end-of-life.qut.edu.au) for updates.

## Caring at the end of life

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

Many people say that they would like to die at home. Carers may want to respect the person's wishes, but may feel worried because they don't know what to expect. Dying at home is possible with

planning and support. Finding out more about the support available from the palliative care team and other services may help you feel more comfortable.

Not everyone wants to die at home, and some people change their minds as their illness progresses. Other options for end-of-life care include 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 others, but it can allow you to spend more time just being together. If you wish, you can assist the staff with physical duties.

➤ See our *Facing End of Life* booklet.

## How to support someone in distress

If an illness is ongoing or causing uncomfortable symptoms, some people may become distressed. This may be because they feel particularly ill, or scared or guilty about the strain they are putting on others. Some people become distressed because pain or symptoms such as depression are not well controlled. If the person you are caring for is becoming distressed, encourage them to discuss how they're feeling with a doctor or counsellor.

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

If you urgently need somebody to talk to because the person you are caring for is in distress, call Lifeline on 13 11 14 at any time.

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

## 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).

## 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?” This doesn’t mean you are a bad or uncaring person.

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.

You may also feel anticipatory grief if the person you are caring for undergoes a change such as long periods of confusion or reduced consciousness. Although they are still physically present, you may feel as though you have somehow already lost the person that you love. This form of grief is a natural reaction to a very difficult situation.

There is also the grief for a life not led, and the loss of the future you may have imagined or hoped for with that person, and that things have not worked out as you had planned.

Even when a death is expected, it may still feel like a great shock and it 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 strengthens your relationship to the person, which can increase your grief.

## Life after caring

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
- shock 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 who died
- questioning whether there were things that you or the treatment team could have done differently to prolong life or make things better for the person
- guilt about things you did or didn't do, about not being there at the time of death, or about how you are feeling
- anxiety about the future – what will you do or how will you manage financially.

All these reactions are common. These emotions may come and go and change over time. Support groups (face-to-face, telephone or online) or counselling can help you get through times when your grief seems overwhelming. You do not need to rush to make decisions about your life.

There are many services available to help with the practical and legal aspects of the person's death. Services Australia has a useful checklist of who may need to be notified. Visit [servicesaustralia.gov.au](http://servicesaustralia.gov.au) and search for "What to do when someone dies".

➤ See our *Facing End of Life* and *Understanding Grief* booklets.



## Key points about caring and advanced cancer

Caring for a person with advanced cancer can feel overwhelming. As a person's illness progresses, their needs may change and a different level of care may be needed.

- Palliative care**
- Palliative care 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.

- Legal arrangements**
- 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.

- Grief**
- Anticipatory grief is a natural reaction when someone close to you is dying, but 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 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 in your area.

## Aboriginal resources

**Carers Australia**  
[carersaustralia.com.au/  
about-carers/aboriginal  
and-torres-strait-islander  
carers](http://carersaustralia.com.au/about-carers/aboriginal-and-torres-strait-islander-carers)

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

## Carer services

**Carer Gateway**  
**1800 422 737**  
[carergateway.gov.au](http://carergateway.gov.au)

Practical information, resources and support for carers.

**Carer Help**  
[carerhelp.com.au](http://carerhelp.com.au)

Includes resources and information on five pathways that may be experienced when caring for someone approaching end of life.

**Carers Australia**  
[carersaustralia.com.au](http://carersaustralia.com.au)

National body representing carers to the Australian Government. Provides information and advocacy.

**Young Carers Network**  
[youngcarersnetwork.  
com.au](http://youngcarersnetwork.com.au)

Support and information for young people aged under 25 who are caring for someone who is ill. Run by state and territory Carers Associations.

## 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.

**Cancer Council**  
**podcasts**  
**cancercouncil.com.au/**  
**podcasts**

Information and insights for anyone affected by cancer. Includes a separate series about advanced cancer.

**American Cancer**  
**Society**  
**cancer.org**

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

**Cancer Australia**  
**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.

**Macmillan Cancer**  
**Support**  
**macmillan.org.uk**

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

## Counselling

**Cancer Council**  
**13 11 20**

Referrals to counselling services, as well as peer support programs. Can connect online, by phone or in person.

**Australian**  
**Psychological**  
**Society**  
**psychology.org.au**

Use the “Find a Psychologist” search to look for a practitioner in your area.

<p><b>Better Access initiative</b>  <a href="http://health.gov.au/mentalhealth-betteraccess">health.gov.au/mentalhealth-betteraccess</a></p>	<p>Information about Medicare rebates for mental health services.</p>
<p><b>Beyond Blue</b>  1300 22 4636  <a href="http://beyondblue.org.au">beyondblue.org.au</a></p>	<p>24-hour telephone counselling service; online and email counselling also available.</p>
<p><b>Carer Gateway Counselling Service</b>  1800 422 737  <a href="http://counselling.carergateway.gov.au">counselling.carergateway.gov.au</a></p>	<p>Free counselling service for carers; available each day 8am–6pm.</p>
<p><b>GriefLine</b>  1300 845 745  <a href="http://griefline.org.au">griefline.org.au</a></p>	<p>Counselling and support services to support all Australians who have experienced a loss.</p>
<p><b>Kids Helpline</b>  1800 55 1800  <a href="http://kidshelpline.com.au">kidshelpline.com.au</a></p>	<p>Telephone and online counselling service and crisis support for young people aged 5–25.</p>
<p><b>Lifeline</b>  13 11 14  <a href="http://lifeline.org.au">lifeline.org.au</a></p>	<p>24-hour telephone crisis support and suicide prevention service; online chat service in the evening.</p>
<p><b>Suicide Call Back Service</b>  1300 659 467  <a href="http://suicidecallbackservice.org.au">suicidecallbackservice.org.au</a></p>	<p>24-hour telephone and online crisis support for anyone affected by suicide.</p>
<p><b>Equipment and aids</b></p>	
<p><b>Independent Living Centres Australia</b>  1300 885 886  <a href="http://ilaustralia.org.au">ilaustralia.org.au</a></p>	<p>Offer advice on a range of products and services to help with aspects of day-to-day living, including mobility, sleeping, eating and transport.</p>

## Financial assistance

**Centrelink**  
**servicesaustralia.gov.au**

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

## 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, or contact Cancer Council to find services in your local area.

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

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

## Home nursing

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

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

## Legal and financial advice and information

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

Referral service for people affected by cancer who need professional advice about legal or financial issues. Free for eligible clients.

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

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

## Palliative care

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

Evidence-based website that provides palliative care information and links to services for people affected by cancer, as well as resources for health professionals.

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

Information and resources; includes links to local palliative care organisations.

## Respite care

**Carer Gateway**  
**1800 422 737**  
[carergateway.gov.au](http://carergateway.gov.au)

Provides information about respite services, including emergency respite care.

## Support groups

**Cancer Council Online Community**  
[cancercouncil.com.au/OC](http://cancercouncil.com.au/OC)

An online discussion forum where people can connect with each other at any time, ask or answer questions, or write a blog of their experiences.

**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 care for someone with cancer. Many people find that they benefit from the close bonds with others.

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

Includes groups for people with advanced cancer, for carers and for the bereaved.



# Glossary

## **advance care directive**

A written document intended to apply to a point in the future when a person doesn't have the capacity to make medical treatment decisions. It provides a legal means for a competent adult to appoint a substitute decision-maker or record their preferences for future medical and personal care. May also be called a health direction, an advance health directive or an advance personal plan.

## **advance care planning**

When a person thinks about their future health care and discusses their values, beliefs and preferences with their family, friends and health care team.

## **advanced cancer**

Cancer that is unlikely to be cured. The cancer may have spread to other parts of the body (secondary or metastatic cancer). Treatment can often control advanced cancer and manage symptoms.

## **allied health professional**

A tertiary-trained professional who works to support a person's medical care. Examples include a psychologist, social worker, occupational therapist, physiotherapist and dietitian.

## **anticipatory grief**

Grief that occurs before an impending loss, usually of a close friend or family member.

## **carer**

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

## **depression**

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

## **emergency care plan**

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

## **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 (MDT).

## **hospice**

See palliative care unit.

## **life-limiting distress**

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

## **metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary or advanced cancer.

## **multidisciplinary care**

A system where health professionals collaborate to deal with 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 maintain quality of life by dealing with physical, emotional, cultural, spiritual and social needs. Also known as supportive care.

### **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. It may also offer day care facilities and home visiting teams. Also known as a hospice.

### **PBS Safety Net**

Reduces the cost of prescription medicines for individuals and families once the PBS Safety Net threshold has been reached.

### **Pharmaceutical Benefits Scheme (PBS)**

A government-funded scheme that subsidises the cost of some prescription medicines.

### **quality of life**

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

### **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 for appointing this person may be called enduring power of attorney, enduring power of guardianship, or appointment of medical treatment decision maker.

### **supportive care**

See palliative care.

### **voluntary assisted dying**

When a person with an incurable condition or illness chooses to end their life and uses medicines specially prescribed by a health practitioner. It is legal in Victoria and Western Australia for people who meet all the strict conditions. The law has recently changed in Tasmania, South Australia and Queensland, but voluntary assisted dying is illegal until the laws begin. It is illegal in all other states and territories.

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

*For more cancer-related words, visit:*

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

## **Reference**

1. Australian Bureau of Statistics, *4430.0 Disability, Ageing and Carers, Australia: Summary of Findings, 2018*, viewed 2 July 2020, available from: [abs.gov.au/ausstats/abs@.nsf/mf/4430.0](http://abs.gov.au/ausstats/abs@.nsf/mf/4430.0).



## 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).



Interpreter

**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. [communications.gov.au/accesshub/nrs](http://communications.gov.au/accesshub/nrs)**



## 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**  
[cancer.org.au/nt](http://cancer.org.au/nt)

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

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

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

**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.*