Cancer Council

COPING WITH CANCER

Caring for Someone with Cancer

A guide for family and friends who provide care and support

For information & support
call **Cancer Connect 13 11 20**

Caring for Someone with Cancer
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Note to reader
Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this booklet 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 8 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 change the future of cancer, visit cancerconnect.org.au or call 13 11 20.

Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past and present.

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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 how taking on a caring role might impact your life.

The experience of being a carer is different for everyone – it can bring a sense of satisfaction, but it can also be challenging and stressful. This booklet offers practical tips on balancing the demands of caring, family, work and your own needs, and suggests where to find support.

This booklet does not need to be read from cover to cover – just read what is useful and relevant to you. You may also like to pass this booklet to family and friends for their information.

We have included a chapter on caring for someone when the cancer is advanced (see pages 46–65). This may not be relevant to you, as many cancers are found early and respond well to treatment. If you are caring for someone with advanced cancer, this chapter provides information about managing this complex role.

How this booklet was developed – This information was developed with help from a range of health professionals who work with carers, and people who have cared for someone with cancer.



If you or your family have any questions or concerns, call **Cancer Connect on 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit the Cancer Connect website at cancerconnect.org.au.

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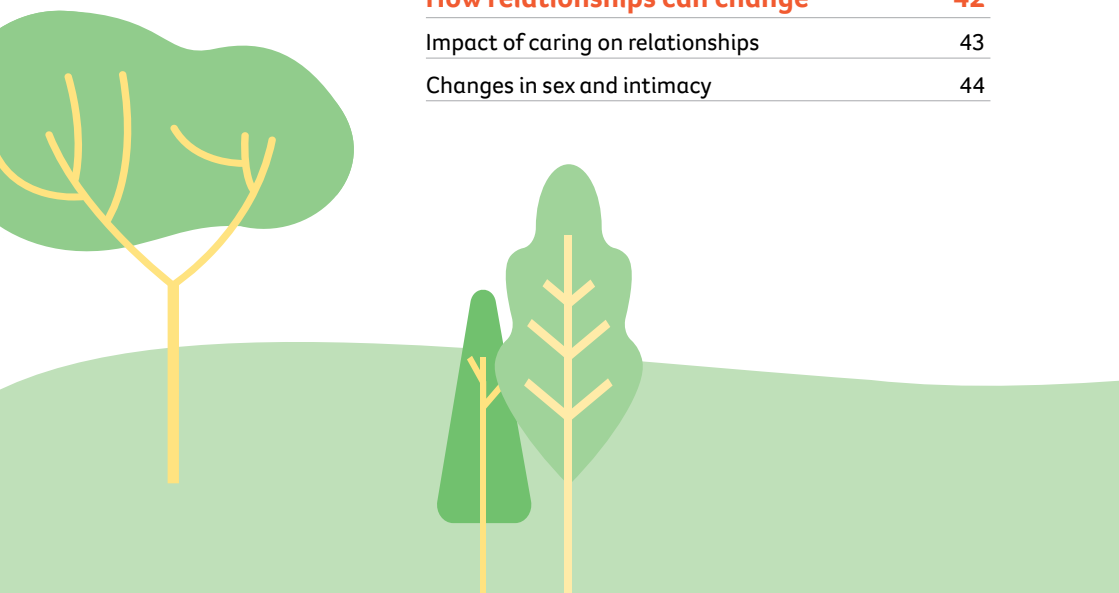
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Key to icons

Icons are used throughout this booklet to indicate:

- More information
- Alert
- Personal story
- Tips

Is this Cancer Council booklet helpful?
Please follow this QR code for a quick 3-minute survey, or call 13 11 20 to provide your feedback.

SCAN ME



Your role as a carer

You are a carer if you provide ongoing unpaid care and support to a person who needs help because of an illness, disability or ageing. Becoming a carer can happen without warning or develop over time.

There are many different types of caring situations:

- 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
- care may be needed for a few hours a week or on a 24-hour basis, and this may change over time
- you may provide care for a short time (days to weeks) or long term (months to years).

Carers in Australia

About 12% of Australians provide care to someone with a long-term illness, disability or ageing.[1] This does not include people who are employed to look after someone.

Under Commonwealth legislation[2] 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 seek an 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 Acts and policies to recognise carers.

What carers do

Although every caring situation is different, the range of tasks involved can be grouped into 4 general areas. There may be other tasks involved depending on what the person you are caring for wants help with. Remember: not every carer will take on all of these responsibilities. Support can be shared with family, friends, and healthcare or community services.



Medical care (see pages 6–16)

attend medical appointments and treatment; speak up for the person with cancer; help the person deal with symptoms and medicines; look after paperwork



Practical support (see pages 16–19)

provide transport to medical appointments; prepare meals; do shopping; look after the home; care for children, parents and pets; help with personal care (showering, dressing and toileting); arrange for aids and mobility equipment



Emotional support (see pages 21–23)

offer companionship, encouragement and comfort; arrange professional support if needed; talk about things other than cancer; talk with family and friends



Legal and financial matters (see pages 24–26)

pay bills; investigate sources of financial support; arrange professional legal and financial advice; help the person plan for the future; help organise legal documents; talk about end-of-life plans and wishes

- For information about your rights as a carer, see our *Cancer Care and Your Rights* fact sheet and our *Cancer, Work and You* booklet.

Providing medical care

Carers often help with medical care. Medical care should be based around the needs, preferences and values of the person with cancer, as well as your needs as the carer.

Talking to the healthcare team

As a carer, you are part of the healthcare team. One of your key roles is to help the person you care for communicate with their healthcare team and make decisions about their care. At times, you may also need to speak on behalf of the patient, if that is what the person you care for would like. The person you are caring for must give written consent before the healthcare team can talk with you about their care when they are not present. This consent should be included in their medical record. See also pages 57–58 for information about what happens if the person you care for is unable to make decisions.

Most cancer centres now have multidisciplinary teams (MDTs) made up of specialist doctors, nurses and other health professionals (see pages 8–9). The MDT is there to support the person with cancer and their carers.

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 to answer your questions, such as a cancer care coordinator, can help you feel more comfortable.

Dealing with health professionals can be intimidating, especially if this is new for you. You may feel overwhelmed by all the new information or working out who to talk to about different issues. Having a regular general practitioner (GP) can help you and the person you are caring for find a way through the healthcare system and be a source of support.

Making the most of a medical appointment

Before the visit

- Ask the person if they want you to go to the appointment with them.
- Talk with the person with cancer about how you should be involved in the appointment. Ask if there's a topic they want you to mention or avoid.
- Write a list of questions so you don't both forget them during the appointment. For suggestions, see the question checklists in Cancer Council's booklets or call Cancer Connect on 13 11 20.
- Keep a record (see page 15) of all medicines the person is taking, including any vitamins, over-the-counter medicines and complementary therapies. Take it with you to the appointment to discuss with the health professional.
- Check with the receptionist that the health professional has received any test results. Ask for copies so you can take them to other appointments.
- Write down any recent changes in the person's condition or symptoms so you can discuss these with the health professional.

During the visit

- Take notes or ask if you can record the discussion on your phone.
- Check anything you don't understand. Write down any specific instructions.
- Check what changes you should watch out for and what to do if they happen.
- Ask who to contact about any changes or treatment side effects, including an after-hours contact number.
- Ask the health professional if they can give you printed material or tell you where to find more information.
- Look over your list of questions to check that they have all been answered.
- Ask about follow-up plans, test results, appointments and referrals.

After the visit

- Review your notes and discuss the visit with the person you are caring for. If you have any questions, call Cancer Connect on 13 11 20.
- Follow up about test results as agreed at the appointment.
- Record the next appointment in your phone or a diary.

Health professionals you may see

GP	assists with referrals and treatment decisions, and works in partnership with specialists to provide ongoing care
surgeon	surgically removes tumours and performs some biopsies; specialist cancer surgeons may be called surgical oncologists
medical oncologist	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
radiation oncologist	treats cancer by prescribing and overseeing a course of radiation therapy
haematologist	diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy and other drug therapies
nurse or nurse practitioner	administers drugs and provides care, information and support throughout treatment; a nurse practitioner works in an advanced nursing role and may prescribe some medicines and tests
cancer care coordinator	coordinates care, liaises with other members of the MDT, and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
community nurse	visits you at home to supervise medical treatment, assesses your needs for supportive care, and liaises with your GP and MDT as required

dietitian	helps with nutrition concerns and recommends changes to diet during treatment and recovery
social worker	links people to support services and helps people with cancer, and their carers and families, with emotional, practical and financial issues
counsellor, psychologist, psychiatrist	help people with cancer, and their carers and families, manage their emotional response to diagnosis and treatment
speech pathologist	evaluates and treats communication, voice and swallowing difficulties during and after treatment
physiotherapist, exercise physiologist	help with restoring movement and mobility during and after treatment, returning to daily activities, and improving fitness and wellbeing
occupational therapist	helps people with cancer, their carers and families, manage everyday activities during and after treatment by suggesting ways to adapt the living and working environment with aids, equipment or strategies
spiritual care practitioner (pastoral carer)	discusses spiritual matters and search for meaning, if appropriate; may arrange prayer services and other religious rituals
palliative care team	specialist doctors and nurses who work closely with the GP and cancer team to help control symptoms and maintain quality of life

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; fatigue; breathlessness; nausea and loss of appetite.

Carers often help the person they are caring for manage these issues (see pages 12–13 for some suggestions). You can also call Cancer Connect on 13 11 20 or visit cancerconnect.org.au to find out more about these and other common side effects experienced by people with cancer.

How long side effects last – 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 you are caring for to others. It's also important to let the treatment team know about any symptoms or side effects – they will often be able to suggest medicines and other treatments that may help.

Late side effects – These are problems that develop months or years after treatment finishes. Talk to the person's doctor about whether they are at risk of developing late side effects from treatment and the symptoms to watch out for. Ask the treatment team for a survivorship care plan to help guide you both through follow-up care.

▸ See our *Living Well After Cancer* booklet.



Some cancer treatments increase the risk of getting an infection. If the person you are caring for has low immunity, you may need to ask family and friends with a cold, COVID-19, the flu or other contagious infections not to visit while they have symptoms.

When to see a doctor – The treatment team will let you know of any side effects that need to be closely monitored and when to contact them. Issues that require urgent medical attention include:

- a temperature of 38°C or above
- chest pain or breathlessness
- severe nausea or vomiting that lasts more than a few hours
- redness or swelling around the site of an injection or wound
- confusion
- severe headache with a stiff neck
- chills with shaking or shivering
- severe abdominal (belly) pain, constipation or diarrhoea
- unusual bleeding or bruising, such as heavy nosebleeds, blood in the urine (wee) or black faeces (poo)
- not being able to control the bladder (incontinence) or having trouble passing urine and/or leg weakness
- burning or stinging feeling when urinating (weeing)
- rash or skin lesions
- any serious unexpected side effects or if the person suddenly gets a lot sicker.

Cancer Council videos and podcasts for carers

Video series

Watch *Australian Carers Talk* at cancer.org.au/caring-for-someone-with-cancer to see carers and health professionals share experiences and provide practical tips.

Podcast series

Listen with a podcast app or at cancercouncil.com.au/podcasts:

- *The Thing About Cancer* – for tips on managing treatment side effects and insights on being a carer
- *The Thing About Advanced Cancer* – for information about caring for someone in their last months of life
- *Finding Calm During Cancer* – for a series of meditation and relaxation exercises.

Managing common symptoms and side effects

Pain



- Support the person with cancer to use pain medicines appropriately. Immediate release medicines work quickly but for a few hours. Slow release medicines provide pain control for a longer period of time, often 12–24 hours.
- If the pain is hard to manage, when you give pain medicine keep a record of the dose and time so you can discuss this with the treatment team. 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 and the person you are caring for understand how strong the pain is and the need for extra doses of pain medicine.
- Try hot water bottles or heat packs (check the temperature first), ice packs or gentle massage to relieve pain and discomfort.
- Complementary therapies such as massage or meditation may help.

▸ See our *Understanding Cancer Pain* booklet and listen to our "Managing Cancer Pain" podcast episode.

Fatigue



- Help the person to set small, manageable goals for the day. Suggest they take regular breaks before they become too tired.
- Encourage the person to prioritise activities that they enjoy.
- 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 a physiotherapist for other suggestions.
- Help them set up a calm sleeping environment. Ensure the room is dark, quiet and a comfortable temperature. Soothing music or relaxation tracks help some people sleep.
- Investigate services that can help with household chores, cooking or gardening (see page 17).

▸ See our *Understanding Fatigue and Cancer* fact sheet.

Breathlessness



- Use a handheld fan to direct a 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.
- Set up a recliner chair to help the person sleep in a more upright position.
- Offer regular drinks throughout the day. Dehydration can contribute to breathlessness.
- Talk to the treatment team about breathing exercises, equipment and ways to manage breathlessness.
- Maintain a calm atmosphere, when possible, as anxiety can make breathlessness worse.
- Ask a doctor or GP about seeing a psychologist to help manage anxiety.
- Encourage the person to try relaxation and meditation techniques to help reduce anxiety.

▸ Listen to our *Finding Calm During Cancer* podcast.

Nausea and loss of appetite



- Focus on creating a pleasant atmosphere for meals, sitting together and talking.
- Celebrate how much the person eats rather than comment on how much is not finished.
- 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 meal 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.
- Offer small meals or snacks every 2–3 hours during the day.
- Provide regular drinks to help the person avoid becoming dehydrated.
- If the person you care for is losing weight or feels too nauseated to eat, talk to their doctor. The person may need medicine changes or a review by a dietitian or pharmacist to arrange dietary supplements.

▸ See our *Nutrition for People Living with Cancer* booklet and listen to our "Appetite Loss and Nausea" podcast episode.

Managing medicines safely

The person with cancer may be taking several different medicines throughout the day. These may be non-prescription and/or prescription medicines. It is common for carers to provide help with medicines.

It is important to use medicines safely. Knowing the answers to the following questions can help save time and confusion. Ask the doctor or pharmacist:

- What is the name of each medicine and what is it for?
- How much should be given (the dose) and when?
- How should each medicine be given (e.g. with or without food)?
- Is there anything, such as alcohol or driving, that should be avoided while taking the medicine?
- Does the medicine interact with other prescription or over-the-counter medicines, vitamin supplements or complementary therapies?
- Are there any possible side effects?
- What should I do if the person has side effects?
- How long will the medicine 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 medicine be stored?
- What should I do with any unused medicine?

Let the person's healthcare team know about any side effects. They may be able to adjust the dose or change the medicine.

"I was actively involved with helping Mum use the oxygen machine, administering the liquid morphine for her when she was in pain, and making sure that she took the anti-anxiety medication." LIBBY

Ways to manage medicines

It can be hard to remember what medicines you need to give to the person you are caring for. There are different ways to help ensure you give the correct dose at the right time.

Keep a medicines list – A medicines list can help you keep track of the person's medicines, what each one is for and when it should be given. It can also help health professionals understand which ones are being used, which is important in an emergency. You can:

- create your own list on paper or online
- ask the person's doctor or pharmacist for a list
- download an app or add electronic diary reminders on your tablet or smartphone to create a medicines list and set medicine reminders.

Get help from the pharmacist – The pharmacist can prepare a blister pack (e.g. Webster-pak), which arranges all the doses that need to be taken throughout the week. They may also sell containers you can use to organise pills by the day and time they should be taken. The pharmacist can keep prescriptions on file to make it easy to get repeats made up. As well as paper prescriptions, doctors can provide electronic prescriptions. If the person has a lot of electronic prescriptions, talk to the pharmacist about registering for an Active Script List – visit digitalhealth.gov.au to learn more.

Track prescriptions – When you fill the last repeat of a prescription, make a note to see the person's doctor for another prescription. This helps ensure you don't run out of medicines, particularly after-hours.



Visit healthdirect.gov.au/medicines to find out more information about specific medicines that are approved for use in Australia.

Organising paperwork

Many carers talk about how complicated and time-consuming paperwork can be. A social worker at the treatment centre can offer support with this part of your role. The following tips may also help:

- 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.
- Consider helping the person with cancer set up an online My Health Record. This stores their important healthcare information in one place and they can give permission for their health professionals to see it. If the person is not capable of making their own decisions, you may be able to apply to manage their account as the authorised representative. Visit digitalhealth.gov.au for more information.
- Consider using an app to store medical records on a smartphone or tablet. The Australian Government's 1800MEDICARE app (formerly my health) can be connected to My Health Record.

Providing practical support

Carers often provide practical care. This can include cooking, doing household chores, driving the person to medical appointments, making the house safe, and helping with personal care.

But remember you don't have to do it all – there are many support services that can help. The availability and wait times for services may vary depending on where you live, and some will be free but others might have a cost. Talk to the treatment team about what support services are available or see the information on the opposite page. You can also talk to family and friends about ways they can help (see page 35).

Finding services that can help

- Carer Gateway provides information on local support services for carers and other support that may suit your needs – call 1800 422 737 or visit carergateway.gov.au.
- Your local council or social worker can put you in touch with services for help at home (such as house cleaning, meals or shopping).
- Get in touch with Cancer Connect on 13 11 20 or talk to the treatment team to find out how to get support.
- Social work services are also available through Services Australia – visit servicesaustralia.gov.au.
- If the person you are caring for is 65 or over (50 and over for Aboriginal and Torres Strait Islander peoples), contact My Aged Care for an assessment – call 1800 200 422 or visit myagedcare.gov.au.
- See pages 66–69 for other sources of support.

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. If you are feeling unwell, ask a family member or friend to prepare meals instead.

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, focusing on their appetite can increase their anxiety, so gentle encouragement is best (see also page 13).



Family and friends may offer to prepare meals. Let them know what types of food to prepare, and why food safety is especially important now. Use online tools such as mealtrain.com and gathermycrew.org.au to help coordinate meal giving.

Nausea and poor appetite can last for several months after treatment ends. Talk to the treatment team if you're worried about weight loss. 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 for People Living with Cancer* booklet, and our *Understanding Taste and Smell Changes* and *Understanding Mouth Health and Cancer Treatment* fact sheets.

Managing the home environment

If the person you are caring for becomes unwell or frail, you may need to help them make changes to their home to make it safer for them to do everyday activities, care for themselves and prevent falls. This may include 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 may need and options to buy or rent. Examples include:

- hospital beds, pressure mattresses or lift chairs
- commodes, over toilet frames, bedpans and urine bottles
- bathing equipment, such as shower chairs or bath boards
- mobility equipment, such as 4-wheeled walkers, pick-up frames or walking sticks
- carts with wheels to carry things.

If the person you're caring for needs help to get into or out of bed or a chair, ask a physiotherapist to show you how to do so safely. They can suggest equipment or techniques to help the person move.

You may also have to take on other family responsibilities, or arrange for someone else to take them on. These may include caring for children and parents, housework, gardening, shopping or looking after pets.

Providing personal care

A person may need help with bathing, toileting and dressing while you are caring for them. 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 about exercises the person can use 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 continence.org.au.

Some carers feel uncomfortable providing personal care, particularly for their parents or adult children. The person with cancer may also prefer that a professional helps with these tasks. To find out how to arrange visits from a professional, talk to a social worker on the treatment team or call Cancer Connect on 13 11 20. You can also review the person's insurance policies to see if they provide any benefits that may help with home care services.

"Often it was the little practical suggestions that were the most helpful – such as getting a foam wedge to help my husband sleep." ANNA

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 a social worker on the treatment team about arranging volunteer and paid care workers. Call Cancer Connect on 13 11 20 to find out what support is available in the person's local area.
- Consider using websites such as gathermycrew.org.au to coordinate offers of help.
- Keep an up-to-date contact list of the health professionals who are looking after the person with cancer.
- Use technology to stay in touch. Options include email, blogs, text messages, video calls and social media apps.
- Ask the person if their health professional will allow them to record consultations so you can hear what was discussed, or see if you can join the consult by phone.
- Set some money aside so you are prepared if you have to travel suddenly.
- Create an emergency care plan (see page 26) and give copies to the carer and emergency contacts you have nominated.



Providing emotional support

An important part of the carer's role can be to provide emotional support to the person with cancer. Your presence can help them feel less isolated and lets them know you care.

Sharing how you both feel

You might want to talk to the person about their cancer diagnosis and treatment, but not know how. This may be because you:

- fear saying the wrong thing or don't want to say something upsetting
- feel you shouldn't talk about the cancer
- don't know what to say or how to respond
- 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. Other times 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.

Try not to change the subject if a conversation gets uncomfortable. Instead share how you feel and respect each other's feelings. It's natural to have disagreements from time to time, especially when you're both under stress. Although dealing with conflict can be hard, it can also bring you closer together and help you understand each other's point of view. See the next page for tips on resolving conflict.

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.

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 dealing with cancer is difficult. 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 any advice.
- Try to not make comparisons with other people's situations.
- Use humour to relieve tension, if appropriate.

Resolve conflict

- Let the other person know that you care about them and want to resolve your differences.
- Be honest about what you're thinking and feeling.
- 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.
- Talk about 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.
- Discuss the situation with your GP or ask for a referral to a social worker, counsellor or psychologist who can help you manage the conflict.

Communicating with others

As the main carer, you'll usually be the person family and friends contact for information. You may find it time-consuming and tiring keeping others up to date on the condition of the person with cancer. 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

- Leave a message on your voicemail giving a quick update. You could say something like: "Bill is doing okay with the chemo. He's mainly feeling tired. Thanks for your concern." This will cut down on the time needed to answer or return calls.
- Send text messages or emails to groups of people. 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, private Facebook or other social media group to share news and coordinate offers of help. You can set up a protected online group at 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 take responsibility for keeping others up to date and acting as the main point of contact. If not, let people know the best times and days to contact you.
- If you need to explain the situation to children, see our *Talking to Kids About Cancer* booklet.

"A lot of the difficulties of communicating with family and friends come about because of uncertainty and feeling uncomfortable." ROB

Helping with legal and financial matters

Legal and financial challenges can add to the stress of being a carer. Getting professional help can take a great weight off your mind.

Financial concerns

Caring for someone with cancer can cause money worries. 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 medicines, tests, 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 opposite page, speak to a social worker on the treatment team or call Cancer Connect on 13 11 20. The person you are caring for may also be eligible for financial support.

▸ See our *Cancer and Your Finances* booklet.

Getting help with finances

Services Australia – This government agency offers a free, confidential Financial Information Service that provides information on financial matters. Call 132 300 or visit servicesaustralia.gov.au to find out more.

Qualified professionals – Consider getting professional advice:

- Financial counsellors help people manage their personal budget and finances, including debt. To talk to a financial counsellor, call the National Debt Helpline on 1800 007 007 or visit ndh.org.au. This is a free and confidential service.
- Financial advisers (also called financial planners) help people manage their assets and financial affairs, including superannuation. To find a financial adviser, visit moneysmart.gov.au and search for "financial advisers register". Financial advisers usually charge fees.

Finding financial support for carers

Centrelink benefits – Services Australia offers various payments. The Carer Payment is for carers who provide full-time daily care in the home of the sick person. The Carer Allowance is for carers who provide extra daily care. Centrelink benefits may be income and asset tested or have other eligibility requirements. For more information, contact Services Australia (phone 132 717 or visit servicesaustralia.gov.au) or ask a hospital social worker.

Hardship programs – Most utility providers offer payment options to customers who are having trouble paying bills. Credit providers also offer hardship variations to people having difficulty repaying loans and credit cards. For more information, talk to a hospital social worker or speak to a financial counsellor.

Travel payments – Every state and territory has a government scheme that provides financial help to people who need to travel long distances for specialist medical treatment that is not available in their local area. Many schemes also assist with the cost of accommodation. In some cases, financial assistance may also be available if a carer needs to travel with the patient to treatment. The eligibility rules are different for each state and territory. Ask a hospital social worker for more details or call Cancer Connect on 13 11 20.

Taxi subsidy scheme – Your state or territory may have a scheme that subsidises taxi travel for people with disabilities and their carers. For more information, visit carergateway.gov.au and search for "taxi subsidy scheme".

Superannuation – In very limited circumstances, you may be able to access your superannuation early, such as to pay for a dependant's medical treatment or due to severe financial hardship. Keep in mind that accessing this money may have tax implications and could affect your retirement income and insurance policies. To find out more, visit ato.gov.au, contact your super fund and seek professional advice.

Cancer Council – Depending on where you live and if you meet the eligibility criteria, Cancer Council may be able to provide some financial support or refer you to a professional for free assistance – call Cancer Connect on 13 11 20 to check.

Planning for the future

A cancer diagnosis can make it difficult to talk about the future. It is never too early to think about how you and the person you are caring for 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 gathers information about the care you provide in one place, so that someone can take over from you if you are unable to provide care for any reason. It records the care routine, medicines taken and details of services that come to the house to help with care.

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 the person's 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. To get a printed copy of the plan and card, call 1800 422 737.

Advance care planning – It is important for the person with cancer to plan for their future medical treatment and care, and to discuss their preferences and values with family, friends and the healthcare team. This process is called advance care planning and it can involve preparing various legal documents. See pages 57–59 to read more about substitute decision-makers, advance care directives and wills.

Key points about being a carer

Your caring role will depend on the needs of the person you are caring for, what they would like help with, and what you are able to do.

Medical care	• A key role is to help the person communicate with their healthcare team. • You may help the person with cancer prepare for medical appointments and go with them to the visit. • You 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. • Your doctor or pharmacist can give you advice about managing medicines, or you can use a paper-based or electronic medicines list.
Practical support	• Preparing meals can be an important part of caring. If the person has difficulty eating, a dietitian can recommend suitable foods. • You may need to make changes to the home to ensure it's a safe environment. An occupational therapist or physiotherapist can help with this. • They can also suggest aids and equipment to make bathing and going to the toilet easier.
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 to update friends and family about the condition of the person with cancer.
Legal and financial matters	• Talk to a financial counsellor if you are finding it difficult to manage your finances. • Carers may be eligible for financial assistance through Services Australia (Centrelink). • It's a good idea to prepare an emergency care plan.

How you might feel

It's common for carers to experience a range of feelings about their new role, 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.

It can take time to adjust to the changes that becoming a carer brings. It's important to give yourself permission to take care of your own emotional wellbeing. If you have a history of anxiety or depression, this could make you more vulnerable now.

You may find it helpful to think about how you have coped with difficult times in the past – see pages 32–33 for some strategies that may help.

- See our *Emotions and Cancer* booklet and listen to our "Cancer Affects the Carer Too" podcast episode.

A sense of satisfaction

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

This section describes some of the emotions commonly experienced by carers. There is no right or wrong way to feel. Although everyone is different, many carers find it reassuring to know that their feelings are a normal reaction to the demands of the role.

Fear and anxiety

Cancer treatments and outcomes have greatly 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.

Stress

Looking after someone with cancer can be stressful. It's common for carers to say they feel out of control or under extreme pressure. If stress is ongoing, it can affect the way you react to people around you, and could lead to exhaustion and burnout. Symptoms of stress include:

Physical – 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 – feeling overwhelmed or drained, being irritable or moody, feeling agitated, having racing thoughts and losing confidence in yourself.

"You don't know if you're making the right decisions at the time, but down the track, you can look back and know that you did what you could." ROSS

Anger and frustration

Feeling angry or frustrated can happen for many reasons, including:

- having to be the carer and take on extra responsibilities
- navigating a complex and confusing healthcare system
- believing that family and friends could do more to help
- having short-term and long-term 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 emotions of the person with cancer
- trying to juggle caring with other family responsibilities or paid work
- feeling that the person you're caring for does not seem to really appreciate the hard work and 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.

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. Or they may not be able to visit because they have a contagious illness. Some people are uncomfortable

being around someone who is ill. Maybe you did a lot of activities with the person who has cancer and you miss that. 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 (see next page).

Depression

Feeling down or sad after someone you love is diagnosed with cancer 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 healthcare team about your options and visit beyondblue.org.au for more information.

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 stop enjoying your regular activities or miss activities you can no longer do, such as work, exercise, socialising or volunteering. It is normal to feel grief both for the "normal" you have lost and 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. 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 42–45 discusses ways to manage changes to emotional and physical intimacy.

Finding ways to cope

Caring for someone with cancer is not always easy or satisfying. It may feel hard to find the time or energy to look after your own wellbeing.

Clear your mind



Relaxation and meditation techniques can help carers maintain their energy levels and improve their quality of life. Listen to our relaxation and meditation podcast *Finding Calm During Cancer*. You could also try a local yoga or tai chi class.

- See our *Understanding Complementary Therapies* booklet.

Connect with others



You can share your thoughts and experiences with other carers through support groups. This can be by phone, in person or online. See page 69 for more information.

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. Acknowledging the benefits you get from caring may help you feel better.

Seek support



If at any stage you feel overwhelmed, speak to your GP, as counselling or medicine – even for a short time – may help. You may be referred to a psychologist. Beyond Blue has information about coping with depression and anxiety at beyondblue.org.au. You can also call Lifeline on 13 11 14 for crisis support at any time of the day or night. Some people find online programs or smartphone apps helpful in managing depression and anxiety.

The simple strategies described below may help you cope and feel more in control. See also pages 38–39 for some ways to keep healthy.

Draw on spirituality



Some people find meaning and comfort in spiritual practices, such as prayer, meditation or quiet contemplation. It can be challenging when someone you care for is diagnosed with cancer, and it may help to talk about your feelings with a spiritual care practitioner, religious leader or counsellor.

Learn to live 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.

Find out what to expect



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

Get creative



If you are having trouble expressing how you are feeling, you could try writing a journal or you may prefer to keep an art journal of sketches and notes. Looking back through journal entries can give some perspective – you may see that some days are better than others.

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.

It's important to look after yourself. While you are busy looking after someone, you may downplay 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 okay to acknowledge that you are not feeling well, without comparing it to how the person with cancer is feeling. Think about what you are comfortable helping with, the level of workload you can manage, and what your own needs are. You are allowed to say no.

If caring becomes too much

You might find providing care challenging. It may be that the physical demands are becoming too much, especially if you are older, have your own health issues, or are caring for other people.

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 Cancer Connect can refer you to a counsellor. You can also try the Carer Gateway Counselling Service by calling 1800 422 737. For 24-hour crisis support, call Lifeline on 13 11 14.

Perhaps you know you need support but don't want to disappoint the person you're caring for. See pages 66–69 for ways to get practical help and support.

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 help or fear they will be intruding or disturbing you. Let them know their support is appreciated and that they're not interfering.

Sharing the caring role – 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. Many carers say they feel overburdened and resentful. Sharing the caring role with other people can ensure that the person with cancer gets the necessary support they need without overloading you.

How to share tasks – You may want to hold a meeting to work out how everyone can help and then prepare a roster. Or you could share a list of tasks through a website such as gathermycrew.org.au. 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, mowing the lawn 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
- keeping others updated
- staying with the person you care for while you take a break.

"I decided I had to swim daily. I had a roster of friends who looked after my wife for an hour every morning." ROB

Taking a break (respite care)

Respite care lets carers have a break. You may feel you need respite care for a couple of hours, overnight or for several days. You can use respite care for any reason, such as visiting friends or family members, catching up on sleep, or attending an event such as a wedding.

Why – Some carers don't arrange respite care because they feel guilty or concerned about leaving the person they are caring for. But by taking a break, you will probably find that you can continue your caring role with more energy and enthusiasm. It also gives the person you are caring for an opportunity to interact with other people.

Where – Respite care can sometimes be given at home, or the person you are caring for may be admitted to a respite care centre, residential aged care facility or, in some cases, a hospital or palliative care unit (hospice).

How – It's a good idea to start looking into respite care before you need it. Talk to your doctor or social worker about what services are available where you live and how you can access them. Carer Gateway provides information on respite options, including emergency respite. For more information, call 1800 422 737 or visit carergateway.gov.au.

Cost – You may have to pay part or all of the cost of respite care. Fees will depend on the care provider, whether the care is subsidised by the government, how long the care is for, and the type of care required.

"The social worker helped my husband and me talk about difficult and confronting issues. The respite care was also a welcome relief and helped me remain strong." JANINE

Working while caring

Many carers also work. Your caring duties and your job may both be important and necessary parts of your life. But it may be difficult to balance the demands of caring, family and work.

Caring can impact 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. Your decision to continue working will probably depend on several things, including:

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

Before changing your working arrangements, talk with your employer, an Employee Assistance Program (EAP) counsellor, family or friends. You may be able to rearrange your working hours, take carer's leave or make other flexible working arrangements. You can ask the healthcare team for a letter of support for your workplace. To find out more about working while caring, visit carergateway.gov.au/working-while-caring.

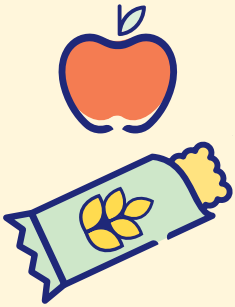
Depending on where you live, Cancer Council may be able to connect you with a human resources (HR) professional or employment lawyer to provide information about how to manage your work and caring responsibilities. Call Cancer Connect on 13 11 20 to find out more.

▸ See our *Cancer, Work and You* booklet and *Cancer Care and Your Rights* fact sheet for information about your rights at work.

Keeping healthy

Looking after your health can help you cope with the demands of caring, and provide better care for longer. People with cancer often need support for a long

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.

Be active for 30 minutes each day



Research shows that regular physical activity can help with feelings of anger, stress, anxiety and depression. It can also help boost your energy levels and improve sleep. 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. Even a brisk walk around the block offers benefits.

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.

Organise your time



Use your phone or a diary to help you keep track of appointments, and prioritise your tasks and activities.

time, so it's important to find ways to support your wellbeing. See also pages 32–33 for some ways to manage your emotions.

Get enough sleep and rest



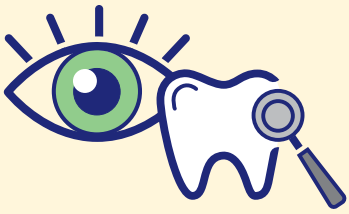
Tiredness and exhaustion often make everything seem harder. If your sleep is disrupted by your caring responsibilities, try to grab a few minutes' rest throughout the day whenever the opportunity comes up.

Take time for yourself



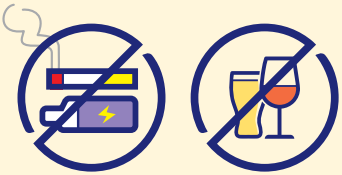
Make time each day to do a hobby or activity that you find enjoyable and relaxing. Respite care is available for short or longer periods (see page 36) and may give you the break you need. Don't underestimate the emotional impact of supporting someone through cancer – you need to look look after your own health if you're going to give support.

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. Take part in any cancer screening programs you're eligible for.

Avoid using alcohol, cigarettes or vapes to relax



These may seem to help for a short time, but they contribute to other problems. If you smoke or vape, call the Quitline on 13 7848 for advice and support tailored to your situation. Talk to your GP if you need support managing your anxiety.

When your caring role ends

Many people find it challenging when the need for care finishes. You could feel a bit lost or no longer needed. If the person has recovered, they may appear to have forgotten how much you did. This can be hurtful, but they probably don't realise how you're feeling.

How the person may feel – You may be surprised that the person who had cancer does not seem happy or relieved that they have been given good news. The end of treatment can 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.

Take the time you need – 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.

Share your feelings – 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 rewarding, but it's not always positive. You may need time to reflect on what has happened and what it has meant to you.



If the person you are caring for has been diagnosed with advanced cancer, the caring role may be different. See the *Caring for someone with advanced cancer* chapter on pages 46–65 for some information about what to expect.

Key points about caring for yourself

Being a carer can be rewarding but it can also be demanding.

How you might feel

- Common reactions include fear and anxiety; stress, anger and frustration; guilt; loneliness; depression; and loss and grief.
- Looking after your own wellbeing can relieve stress and tiredness, and reduce feelings of frustration and isolation.

Ways to cope

- You may feel that your interests take second place to the person with cancer. Try to take time for yourself every day, even if it's only a short break.
- Try to focus on the value of your caring role, as this may help you feel more satisfied.
- Talk to your doctor about any health concerns, especially if you are feeling depressed.
- Life can be unpredictable and uncertain at times. Learning more about cancer may help you feel more in control.
- Remember you don't have to do it all yourself, you can ask family and friends for help.
- Consider organising respite care for the person with cancer so you can have a break from your caring duties.
- You may find it helpful to get support from your GP or talk to a counsellor or psychologist.
- Carers often forget to look after their own health. Try to eat well, get some exercise, rest and keep up with regular check-ups.

Working while caring

Talk to your employer before deciding to quit or take a break from 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, dependant 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 35).

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



There are many carers under the age of 25 in Australia. When young adults take on a caring role for their parents, the role reversals can be difficult for both sides. Young carers may also be trying to keep up with their studies and social life with friends. The Carers Associations in each state and territory offer information and support tailored for young carers. Visit youngcarersnetwork.com.au to find out more.

Impact of caring on relationships

Caring for someone with cancer can affect relationships in many ways.

- You might have to take on new responsibilities that mean you reverse your usual roles.
- The person you are caring for may feel like they have lost their independence or that you are being overprotective.
- You might be worried about talking about your needs when the other person is going through cancer treatment.
- You may avoid sharing your feelings because you don't want to overwhelm the other person when they have enough to worry about.
- You might need to re-evaluate your priorities and set new goals.
- You might feel lonely if friends and family aren't as supportive as you would like.
- You may feel too tired to socialise or enjoy your usual activities.



Ways to manage changes

- Talk about the changes to avoid misunderstandings. Discuss ways to meet each other's needs.
- Allow time to get used to the changes, particularly if roles have reversed.
- Set boundaries to maintain independence and allow both of you to feel in control.
- Give the person you're caring for the chance to do things for themselves.
- If you and the person you're caring for find it difficult to discuss your different needs without becoming defensive, consider seeing a social worker, counsellor or psychologist. They can suggest ways to approach these conversations.
- Contact a local community group or carers' support group, visit our Online Community at cancercouncil.com.au/OC, listen to our "Family Dynamics and Cancer" podcast episode or call Cancer Connect on 13 11 20.

Changes in sex and intimacy

If you are caring for a partner, you may find your sexual relationship is affected. The changes will differ depending on the type of cancer, the treatment and its side effects.

Having cancer can affect physical intimacy in different ways:

- Tiredness can make people lose interest in sexual activities 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 person with cancer may be feeling sensitive and sore, and may not want to be touched.
- 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 between the roles of carer and lover.
- If your partner is unable or unwilling to be sexually active and you still want a sexual relationship, you might feel guilty about this.

LGBTIQA+ carers

Although all carers have the same rights, regardless of sexuality or gender, LGBTIQA+ carers may face specific challenges. They may worry about health professionals or the person's family or friends accepting them, or wonder if support services are LGBTIQA+ friendly.

Talk to your GP about local services that can help. You can also contact QLife, a national counselling and referral service for LGBTIQ+ people. Call 1800 184 527 or visit qlife.org.au.

▸ See our *LGBTIQA+ People and Cancer* booklet for ways to deal with the challenges you may face.



How to manage sexual changes

- Talk openly with your partner about how you're feeling – communication is an important sexual tool. Sharing your concerns will help you explore new ways to be intimate.
- Being open about your sexual needs can help you find ways to manage them. If you keep quiet and withdraw, your partner may misinterpret your actions and think they're no longer desirable.
- Try other forms of intimacy such as touching, holding, hugging and massaging. Physical contact that doesn't lead to sexual activity can still be comforting.
- Spend time together doing other things you both enjoy. This way sex isn't the only way that you show your affection and intimacy.
- Tell your partner you care. Your partner may need reassurance that you love them and find them attractive despite the changes from their illness.
- Have your partner show you any body changes before sexual activity. Looking at and touching these areas may help both of you get more comfortable with the changes.
- Keep an open mind about ways to give and receive sexual pleasure, especially if your usual sexual activities are now uncomfortable or not possible. Try different lubricants or sexual aids.
- 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. An occupational therapist on the treatment team can suggest practical strategies for positioning and fatigue management.

▸ See our *Sex, 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. 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 at a late stage 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 controlled for months or, sometimes, years.

Changes to the caring role

Some people live with advanced cancer as a chronic illness for a long time, so there may not be much difference in your caring role immediately. Other people may feel very unwell, so 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.

How you might feel – 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.

Family and friends – 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 media, or write one letter and send copies to people. If you need support, talk to your GP or a hospital social worker, or call Cancer Connect on 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/im-a-carer.

Ross's story

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

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

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

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

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

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

"Get ready to be out of your comfort zone, but you just have to get on with it."

Discussing prognosis

After a diagnosis of advanced cancer, some people want to know how long they have left to live. 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 what to expect. This can help you understand what is happening and prepare for the changes. You can ask the person if they will 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.

They will probably talk about the time in terms of days, days to weeks, weeks to months, or months to years. The actual time could be shorter or longer, because each individual responds differently to treatment.

Avoiding burnout

Being a carer for someone 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 34–41).

Stress or distress that lasts a long time can lead to burnout. This can affect your mind and body. See page 29 for a list of symptoms.

If you are experiencing mood swings, irritability, sleep problems, changes in appetite, overwhelming fatigue or other signs of stress for more than 2 weeks, or if you are relying on alcohol or other drugs, talk to your GP or a social worker on the palliative care team.

Palliative care

What palliative care is – Palliative care is person-centred care that helps people with a progressive, life-limiting illness to live as comfortably as possible. The goal of palliative care is to improve quality of life for both the person with cancer, and their family and carers.

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 services – The palliative care team will help identify services that can offer emotional and practical support to you in your caring role. These may include:

- relief of the person's symptoms (e.g. pain, breathlessness, nausea)
- help organising equipment for home (e.g. mobility aids, special beds)
- help with discussions about sensitive issues and suitable care options
- 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.

If the person chooses not to have active treatment for the cancer, palliative care can help ensure any symptoms are well controlled and the person is comfortable. The palliative care team can help you understand what is happening and what happens next.

"Our cancer care team talked about how palliative care could make my husband's life easier and more meaningful. I found it so useful to know that help was available when I needed it." ANNA

How palliative care works



When to start

Palliative care is useful at all stages of advanced cancer and can be given alongside active treatment for cancer. Connecting with the palliative care team early on can help improve quality of life.



Who provides care

Palliative care may be led by a GP, nurse practitioner or community nurse or, if the person's needs are complex, by a specialist palliative care team.



Where care is provided

The palliative care team will work with you and the person you are caring for to plan the best place for care. This may be at home supported by community palliative care services, in hospital, at a residential aged care facility or in a palliative care unit (hospice).



Your role

Carers are considered part of the palliative care team. With the agreement of the person being cared for, the palliative care team will include you in decisions about their care and treatment.



Accepting help

If you have been providing most of the person's care, it can be difficult to let other people take over some tasks. As 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 common issues carers face

Although carers may need support at any stage of cancer, their responsibilities usually increase if the disease progresses. This table lists some common issues you may face as you care for someone with advanced cancer, the people who can help and where you can find more information. Your hospital or treatment centre may also host workshops or discussions about cancer, treatments and side effects.

Support with medical care	Who can help
Making treatment decisions It can be confronting for the person to work out whether to keep having 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. ▸ See our *Living with Advanced Cancer, Understanding Palliative Care* and *Facing End of Life* booklets, our *Advance Care Planning* fact sheet and listen to our "Making Treatment Decisions" podcast episode.	• palliative care team • cancer specialists • GP • social worker
Managing symptoms You may find that symptoms such as pain become more complex to manage, especially as the person is likely to experience several symptoms at the same time. Early medical attention can provide relief and make symptoms easier to manage. ▸ See pages 10–13 of this booklet, our *Living with Advanced Cancer, Facing End of Life* and *Understanding Cancer Pain* booklets, and listen to *The Thing About Advanced Cancer* podcast.	• palliative care team • pain specialist • cancer specialists • GP • community nurse • physiotherapist • occupational therapist • exercise physiologist • after hours GP

Practical support	Who can help
Setting up the home 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 chair, bedpans, walker, hoists to help lift the person, hospital bed). Talk to your healthcare team to see if there is any financial support you may be able to get for home modifications.	• occupational therapist • physiotherapist • Home Modification Information Clearinghouse (homemods.info)
Preparing food and drink It can be challenging to prepare food and drink for a person with advanced cancer, especially if they find it hard to swallow or have lost their appetite. Try not to force them to eat or drink. In the late stages, it is natural to have little appetite, but this can be distressing for carers. ▸ See our *Nutrition for People Living with Cancer* booklet.	• dietitian • speech pathologist
Providing personal care You may have to: help the person get in and out of bed, shower or wash their hair; give them a sponge bath; help them on and off the toilet or commode; help them use a urine bottle or bedpan; and help them to wipe themselves. Ask an occupational therapist or physiotherapist about suitable equipment and how to support the person's movement safely and correctly. You may need someone else to help you.	• occupational therapist • physiotherapist • palliative care team • community care workers • Carer Gateway 1800 422 737 • My Aged Care 1800 200 422
Coping with the extra workload You may find it difficult to manage extra tasks, especially if you have other responsibilities such as a job or looking after children, or if you have your own health issues. Talk with family and friends about ways they can help.	• Carer Gateway 1800 422 737 • My Aged Care 1800 200 422 • social worker

Emotional support	Who can help
Dealing with emotions 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 for you to function or enjoy some aspects of life. ▸ See pages 21–22, 28–33 and 61–63 of this booklet, and our *Emotions and Cancer* and *Understanding Grief* booklets.	• GP or palliative care team • social worker • psychologist, counsellor or psychiatrist • support groups (page 69) • Cancer Connect 13 11 20 • Carer Gateway Counselling Service 1800 422 737 • Beyond Blue 1300 22 4636 • Lifeline 13 11 14 • church or religious group
Communicating with family and friends The carer is often the main point of contact for family and friends. It can be challenging to cope with people's reactions when you are struggling with your own. Giving constant updates as the disease progresses can also be draining and time-consuming. It is important to make sure children in your family are included and supported in discussions about advanced cancer and end-of-life issues. ▸ See our *Talking to Kids About Cancer* booklet.	• social worker • Cancer Connect 13 11 20 • family members or friends who can share updates • social media apps to connect with family and friends (see page 23)
Maintaining hope 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.	• social worker • psychologist or counsellor • spiritual care practitioner (pastoral carer) • religious leader • family and friends

Emotional support (continued)	Who can help
Exploring the meaning of the person's life This may be a time when the person wants to reflect on their life and make sense of their experience. They may appreciate help recording their memories and insights in some way (see page 62). Some people also want to explore spirituality, even if they have never been religious. ▸ Listen to Cancer Council's podcasts at cancercouncil.com.au/podcasts.	• social worker • psychologist or counsellor (ask the treatment team or GP for a referral) • spiritual care practitioner (pastoral carer, may be available at your treatment centre) • religious leader
Support with legal and financial matters	**Who can help**
Organising finances You may need to find additional financial support and possibly help the person you are caring for access their superannuation and insurance. Seek professional advice before changing any financial arrangements. ▸ See pages 24–25 of this booklet, and our *Cancer and Your Finances* booklet.	• social worker • financial counsellor or financial adviser • National Debt Helpline 1800 007 007 • Services Australia Financial Information Service 132 300 • Cancer Connect 13 11 20
Making legal arrangements If the person hasn't already done so, it is important to make sure their wishes for the future have been documented. This can include preparing a will, appointing a substitute decision-maker and preparing an advance care directive. ▸ See pages 56–59 of this booklet, and our *Getting your affairs in order* fact sheet.	• social worker • National Advance Care Planning Support Service 1300 208 582 • lawyer (contact your state or territory Law Society) • Community Legal Centres • Cancer Connect 13 11 20

Advance care planning

Advance care planning is when a person thinks about their future health care and discusses their preferences with their carer, family, friends and healthcare team. It may take several discussions and involve:

- talking with the person with cancer about what is important to them for quality of life and what matters most when making treatment decisions
- discussing the treatments the person with cancer may or may not want
- preparing legal documents, including appointing a substitute decision-maker and making an advance care directive.

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.

Starting the conversation – Although advance care planning is often done when people are first diagnosed with cancer, it can be started at any time, whether the person is healthy or ill. Discussing the person's wishes does not mean they have given up hope or will die soon – their needs may change over time and it is a good idea to regularly review the plan.

If you need some tips on starting the conversation, you might like to use one of Palliative Care Australia's discussion starters at dyingtotalk.org.au/discussion-starters or Advance Care Planning Australia's conversation starters at advancecareplanning.org.au.

How you might feel – It can be confronting as a carer if the person you are caring for decides they do not want any more 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 treatment, even if it may not benefit them. You may find it helpful to talk to the palliative care team about how you are feeling.

Different laws

Each state and territory has different laws about what capacity means, making advance care directives and appointing substitute decision-makers. For details, talk to a lawyer, call Advance Care Planning Australia on 1300 208 582 or visit advancecareplanning.org.au.

When preparing legal documents, it is important to seek legal advice. Cancer Council may be able to connect the person you are caring for with a lawyer. Call Cancer Connect on 13 11 20 to find out more.

▸ See our *Getting your affairs in order* fact sheet.

Preparing legal documents

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 the person's wishes are recorded.

For these documents to be legally binding, the person needs to have decision-making capacity at the time of making the document. In general, this means the person can understand and remember information about the available choices, understand the consequences of their decisions, and communicate their decisions. For more information, talk to your lawyer and doctor, or visit end-of-life.qut.edu.au/capacity.

Appointing a substitute decision-maker

The person with cancer can appoint someone to make medical decisions on their behalf if they become too unwell (lose capacity) to make their own decisions. This person is called a substitute decision-maker, and they may be a person's spouse or family member, or someone else the person trusts. Depending on your state or territory, the documents used to appoint a substitute decision-maker may be called by different names, such as enduring power of attorney or appointment of enduring guardian.

If the person has not appointed a substitute decision-maker, the law in each state or territory outlines who may make medical treatment decisions on their behalf. This is usually someone close to them, such as a spouse or partner, family member or close friend. If you are unsure if you have the right to make treatment decisions on the person's behalf, talk to the treatment team or a lawyer.

Making an advance care directive

An advance care directive is a written record of a person's values and preferences for any future medical care. It is ideal if the advance care directive can be as detailed as possible so that their preferences are clear. An advance care directive is legally binding and can be used by doctors, family members and carers to guide their decision-making. Depending on where you live, the advance care directive may be called an advance health directive, advance personal plan or similar.

Once the document has been signed, dated and witnessed, the person you are caring for may ask you to share copies with the substitute decision-maker (if that is not you) and the treatment team, so it can be placed on the person's medical record. A copy can also be saved to the person's My Health Record – find out more at digitalhealth.gov.au. You may also want to take witnessed copies with you to appointments.

Preparing a will

A will is a legal document that sets out what a person wants to happen to their assets after they die. These assets, called an estate, may include a house, land, savings or investments. A will can also record the person's wishes regarding who will look after their children (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 advise you or contact the Public Trustee in your state or territory.

Voluntary assisted dying

Voluntary assisted dying (VAD) is when a person with an incurable, life-limiting condition or illness chooses to end their life with the assistance of a doctor or health practitioner – using specially prescribed medicines from a doctor.

As of August 2026, VAD is operating in all 6 Australian states and the ACT. In the Northern Territory, VAD laws have been passed and VAD is likely to begin in 2028.

For information and updates on VAD for your state or territory, visit Queensland University of Technology's End of Life Law in Australia website at end-of-life.qut.edu.au/assisteddying.

VAD may be an option for some people who meet all the strict conditions and follow certain steps as required by the laws in their state or territory. "Voluntary" means it is the choice of the unwell person to end their life. You cannot ask for VAD on their behalf or pressure them to ask for it; only they can ask for it and they must have decision-making capacity.

You may have a range of emotional responses if the person you are caring for chooses to investigate VAD. You may find it confronting if they choose to proceed with VAD, and it is important that you look after your own emotional wellbeing.

The person may also ask you to be present when they end their life, and it is important to think about how you might feel. It is your choice whether to be involved in the VAD process. You may find it helpful to get support from your GP or a counsellor.

- For more details, visit the Health Department website in your state or territory.

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 want to 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. Although dying is a natural process, few people have experience or knowledge of looking after someone who is dying.

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. It can be helpful to have a backup plan ready in case the person's medical needs increase and they need to move to a palliative care unit or hospital near the end.

Not everyone wants to die at home, and some people change their minds as their illness progresses or their medical needs increase. People may choose to receive end-of-life care in a hospital, palliative care unit (hospice) or 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 tasks.

▸ 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 symptoms such as pain, nausea or breathlessness are not well controlled. Others may experience emotional distress, anxiety or depression. If the person you are caring for is becoming distressed, encourage them to discuss how they're feeling with a doctor or counsellor.

Health professionals can offer treatment and other ways to help manage pain, depression and other symptoms. It is important that you talk to the healthcare team about any emotional or physical symptoms that are causing the person with cancer distress, 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 emotional distress, call Lifeline on 13 11 14 at any time.

Ways to say goodbye

A life-limiting illness offers you the opportunity 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 – 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 may be the way they cope with the unknown or it might be because they prefer to focus on the present moment. If you find their response upsetting, it may help to share how you feel with a social worker on the treatment team or call Cancer Connect on 13 11 20.

You can ask the person with advanced cancer if they want to visit a special place, see particular family or friends, contact someone they've lost touch with, or see a spiritual care practitioner. 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. You can help the person with all these tasks. They are all part of the process of saying goodbye, for all of you.

The person with advanced cancer may find comfort in planning their own funeral so that family and friends don't have to guess what they would have wanted. If you find it confronting to be involved in the planning, family and friends may be able to help, or talk to a spiritual care practitioner, funeral celebrant or end-of-life doula for assistance.

Anticipatory grief

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

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.

"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

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 loss 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. These responses and thoughts are natural.

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.

After someone dies

The response you have when someone dies is called grief. Coping with grief doesn't mean getting over the person's death. It's about finding ways to live with the loss. The sorrow may never go away completely, but most people gradually adapt.

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 with the person, which can also increase your grief.

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 for the loss
- sadness
- anger towards the doctors or the hospital, your god or the person who died

- relief that the person is no longer in pain
- guilt that you feel relieved to be free of the burden of caring and can now make plans for your future
- pride in how you supported someone as they were dying
- 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
- regret 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 you will do or how you will manage.

All these reactions are common. These emotions may come and go and change over time. Be kind to yourself. You do not need to rush to make decisions about your life.

There is no right or wrong way to grieve and everyone mourns in their own way. If your grief seems overwhelming, you can reach out to your GP, a bereavement counsellor on the palliative care team, call Griefline on 1300 845 745 or call Cancer Connect on 13 11 20. Support groups or bereavement counselling can help you get through tough times.

▸ See our *Facing End of Life* and *Understanding Grief* booklets and listen to our "Life After Loss" podcast episode.

"At times the sadness and pain I feel is all consuming and hard to bear, while at other times these feelings are just in the background of my day-to-day activities." ANNE

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 care 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.

Advance care planning

- 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

Useful contacts

Aboriginal resources

Carer Gateway 1800 422 737 **carergateway.gov.au/first-nations**	Resources to support First Nations carers and communities.

Cancer information

Cancer Council 13 11 20 **cancerconnect.org.au**	Cancer Council produces easy-to-read booklets and fact sheets on many 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 specific episodes for carers; a separate series about advanced cancer; and a standalone relaxation and meditation podcast.
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 the Australian Government cancer control agency.
Cancer Research UK **cancerresearchuk.org**	Information about cancer prevention, diagnosis and treatment from a leading UK cancer charity.

Carer services	
Carer Gateway 1800 422 737 **carergateway.gov.au**	Practical information, support services and useful resources for carers.
Carers Australia **carersaustralia.com.au**	Provides information and advocacy for carers.
Services Australia **servicesaustralia.gov.au**	Provides government payments and services for carers; includes Centrelink and Medicare.
Young Carers Network **youngcarersnetwork.com.au**	Support for young people aged under 25 caring for a family member or friend.
Counselling	
Cancer Connect 13 11 20 **cancerconnect.org.au**	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 psychologist in your area.
Beyond Blue 1300 22 4636 **beyondblue.org.au**	24-hour telephone counselling service; online and email counselling also available.
Carer Gateway Counselling Service 1800 422 737 **counselling.carergateway.gov.au**	Free counselling service for carers aged 18 and over; available Monday–Friday, 8 am–6 pm.
General practitioner (GP)	Can offer support and prepare a mental health treatment plan so eligible people can get up to 10 Medicare-subsidised sessions with a psychologist.
Griefline 1300 845 745 **griefline.org.au**	Telephone and online counselling service and support groups for all Australians who have experienced a loss.

Counselling (continued)	
Kids Helpline 1800 55 1800 **kidshelpline.com.au**	Telephone and online counselling service and crisis support for young people aged 5–25.
Lifeline 13 11 14 **lifeline.org.au**	24-hour telephone and online crisis support and suicide prevention service.
QLife 1800 184 527 **qlife.org.au**	Provides an LGBTIQ+ peer support and referral service over the phone and online. Available 3 pm–midnight.
Suicide Call Back Service 1300 659 467 **suicidecallbackservice.org.au**	24-hour telephone and online counselling for people affected by suicide.
Home help	
Call your local council, talk to your palliative care team or call Cancer Connect on 13 11 20	Availability of home help services may vary depending on where you live. Some services are free, but others may have a cost.
Carer Gateway 1800 422 737 **carergateway.gov.au**	Practical information, support services and useful resources for carers.
My Aged Care 1800 200 422 **myagedcare.gov.au**	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 or there are private services.
Legal and financial information	
Cancer Council 13 11 20	Depending on where you live and if you meet the eligibility criteria, Cancer Council may be able to provide some financial support or refer you to a qualified legal or financial professional for assistance. Advice may be free if you can't afford to pay.

Legal and financial information (continued)	
Advance Care Planning Australia 1300 208 582 **advancecareplanning.org.au**	Information about planning for future healthcare, including making advance care directives.
Centrelink 132 717 **servicesaustralia.gov.au**	Offers financial support for people with a long-term illness and for carers.
National Debt Helpline 1800 007 007 **ndh.org.au**	Help with debt problems and finding a financial counsellor.
Palliative and respite care	
Carer Gateway 1800 422 737 **carergateway.gov.au**	Provides information about respite services, including emergency respite care.
CareSearch **caresearch.com.au**	Website providing evidence-based palliative care information and links to services for people affected by cancer.
Palliative Care Australia **palliativecare.org.au**	Information and resources; includes links to local palliative care organisations.
Support groups	
Cancer Council Online Community **cancercouncil.com.au/OC**	An online discussion forum where people can connect with each other at any time, and ask or answer questions. Includes a forum for carers.
Face-to-face groups Call Cancer Connect on 13 11 20 or contact a hospital social worker to help you find a support group	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 Connect on 13 11 20	Includes groups for people with advanced cancer, for carers and for the bereaved.

Glossary

active treatment
Treatment that aims to control or cure the cancer. Does not include maintenance treatments given long term to reduce the chance of the cancer coming back or palliative treatment.

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

advance care planning
When a person thinks about their future healthcare and discusses their preferences with their family, friends and healthcare team. The written record of these wishes may be known by different names such as an advance care directive, advance care plan or "living will".

advanced cancer
Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

allied health professional
A university-qualified professional who works with others in a healthcare team to support a person's medical care. Examples include psychologists, social workers, occupational therapists, physiotherapists and dietitians.

anticipatory grief
Grief that occurs before an expected loss. Also known as pre-loss grief.

carer
A person providing ongoing unpaid care and support to someone who needs this assistance because of a medical condition, disability, mental illness or ageing.

complementary therapy
Any of a range of therapies used alongside conventional treatment to improve general health, wellbeing and quality of life.

depression
Very low mood and loss of interest in life, lasting for more than 2 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.

healthcare team
A group of health professionals who are responsible for treating a person who is sick. Also called the multidisciplinary team (MDT).

hospice
See palliative care unit.

LGBTIQA+
A commonly used acronym referring to those who identify as lesbian, gay, bisexual, transgender, queer or questioning, asexual or other sexualities (such as pansexual), as well as intersex.

life-limiting illness
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 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 team (MDT)
A team of health professionals who work together to discuss a patient's physical and emotional needs. The team meets to review cases and decide on which treatment to recommend.

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.

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 visits. May be called a hospice.

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

quality of life
A person's comfort and satisfaction, based on how well their physical, emotional, spiritual, sexual, social and financial needs are met within the limitations of their 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. The care can be given in a range of settings.

substitute decision-maker
A person who makes decisions on someone's behalf if they become incapable of making them. The documents to appoint this person may be called an enduring power of attorney, an enduring power of guardianship, or appointment of medical treatment decision-maker.

voluntary assisted dying (VAD)
When a person with an incurable, life-limiting condition or illness chooses to end their own life with the assistance of a doctor or health practitioner – using medicines specially prescribed by a doctor.

Can't find a word here?

For more cancer-related words, visit connect.cancer.org.au/glossary.

References

1. Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings*, 2022, viewed 22 June 2026, available from: abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release.
2. The *Carer Recognition Act 2010* (Commonwealth), Schedule 1–The Statement for Australia's Carers.

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.

The right support.

cancer connect
Cancer Council

Cancer is never one story. Every diagnosis, every person, and every path is different. You don't have to figure it out alone.

Cancer Connect can help you find the information and support that are right for you.

You can explore trusted information on our Cancer Connect website at your own pace, or call 13 11 20 to talk to our qualified professionals. We will listen to your concerns, answer your questions, and connect you with support.

Wherever you are on your path, Cancer Connect can help make the next step feel clearer.

Right when you need it.

Call 13 11 20

Visit cancerconnect.org.au

TIS TRANSLATING AND INTERPRETING SERVICE

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

National Relay Service

If you are Deaf or find it hard to hear or speak to hearing people on the phone, you can contact us through the National Relay Service (NRS). accesshub.gov.au

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

cancer connect

Cancer Council

For information & support,
call **Cancer Connect 13 11 20**
or visit **cancerconnect.org.au**

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To support Cancer Council, call 13 11 20 or visit cancerconnect.org.au.