



Caring for Someone with Cancer

Emotions
and cancer

Cancer Council Helpline

13 11 20

www.cancerwa.asn.au

Caring for Someone with Cancer

First published November 2006

Reprinted June 2007, October 2008, June 2010

Revised February 2009, November 2011

© The Cancer Council Australia 2011

ISBN 978 1 921619 52 6

Caring for Someone with Cancer is reviewed approximately every three years. Check the publication date above to ensure this copy of the booklet is up to date. To obtain a more recent copy, phone Cancer Council Helpline 13 11 20.

Acknowledgements

We thank the reviewers of this booklet: Jane Ussher, School of Psychology, University of Western Sydney, NSW; Piero Bassu, Consumer, NSW; Lindy Cohn, Cancer Information Consultant, Cancer Council NSW Helpline; Dr Mandy Goldman, Cancer Counsellor, Private Practice; Christine Harris, Consumer; Joanna Jarrald, Assistant Project Coordinator, Cancer Council NSW; and Colleen Sheen, Executive Manager, Policy, Strategy and Communication Unit, Carers NSW.

We would also like to thank the health professionals and consumers who have worked on previous editions of this title.

We acknowledge the School of Psychology, University of Western Sydney for permission to adapt parts of *Helping You to Care for a Person with Cancer: a self-help guide for partners, family and friends* for this booklet, which was funded by an ARC Linkage grant, in conjunction with Cancer Council. Thank you also to the NSW Government, Family and Community Services, Ageing, Disability and Home Care for their support of the Carers Grant Program.

Editor: Laura Wuellner

Designer: Paula Marchant

Printer: SOS Print + Media Group

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 your doctor's or other health professional's advice. However, 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.

Cancer Council WA

Cancer Council is the leading cancer charity in WA. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of WA. To make a donation to help defeat cancer, visit Cancer Council's website at www.cancerwa.asn.au or phone the Cancer Council Helpline 13 11 20 for more information.



Cancer Council WA

46 Ventnor Avenue, West Perth WA 6005

Cancer Council Helpline 13 11 20

Telephone (08) 9212 4333 **Facsimile** (08) 9212 4334

Email questions@cancerwa.asn.au **Website** www.cancerwa.asn.au

ABN 15 190 821 561

Introduction

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

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

You may be questioning how you will manage the emotional and physical needs of the person you are caring for. Perhaps you have been providing care for some time and need some reassurance.

This booklet aims to support you in your role as a carer. You may relate to some of the emotions and feelings described here, and you might learn practical tips on how to balance the demands of caring, family, work and your own needs.

Your role as a carer is valuable. Although caring for someone with cancer can be difficult and stressful at times, many carers have said they are better people for the experience of caring. Some people find that caring can be rewarding and life-changing.

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

If you're reading this booklet for someone who doesn't understand English, tell them they can call Cancer Council Helpline **13 11 20** for services in different languages.



Contents

Who is a carer?	4
How will I feel?	6
Common reactions	6
Some ways to cope	13
Key points	14
What some carers do	15
Work with the health care team	15
Stay safe at home	18
Communicate with family and friends	19
Manage medications	19
Manage finances	21
Manage pain	23
Prepare food and drinks	24
Manage paperwork	25
Long-distance caring	26
Key points	27
Caring for yourself	28
Make time for yourself	28
Care for your body	29
Deal with uncertainty	30
Talk with family and friends	30
Organise your time	31
Focus on the value of caring	31
Key points	32
Asking others for help	33
Setting boundaries and limitations	34

How relationships change 36

Caring for your partner 36
Effect of cancer on sexuality 37
When your support is not wanted 39
If caring doesn't work out 40
If your caring role is no longer needed 40
Key points 42

Communication 43

Talking 43
Listening 44
Conflict and disagreements 45

Advanced cancer, death and grief 46

Palliative care 46
Discussing the person's wishes 47
Anticipatory grief 48
If the person you care for dies..... 49
What is grief like? 49
Living with grief 50
Ongoing grief..... 52
Key points 53

Support and information..... 54

Where to find help 54
Respite care 55
Learn more about cancer 57

Useful websites 58

Glossary 59



Who is a carer?

A carer is someone who helps and supports a person through a disease or disability such as cancer. Carers can provide support in different ways: practical, physical, emotional and spiritual.

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

You may provide care for a short time or over months or years. Care may be needed for a few hours once a week or on a 24-hour basis. Sometimes a carer lives interstate or overseas and helps by coordinating care by phone, email or the internet.

Indigenous carers

Thousands of Aboriginal and Torres Strait Islander people are carers. Although their needs are similar to other carers, Indigenous carers may not have as much access to support services. Some carers fear and mistrust mainstream services.

The information in this booklet should be helpful. Carers Australia also has specific resources for Aboriginal carers. Carers NSW's *Looking After*

Ourselves DVD discusses how Indigenous carers can take breaks and look after their own well-being. There is also a relaxation CD. For copies, call (02) 9280 4744.

Cancer Council has resources for people in Aboriginal communities who are affected by cancer. The booklet, *Aboriginal Cancer Journeys*, and eight fact sheets are available at www.cancercouncil.com.au.

You may not see yourself as a carer, rather someone simply taking care of a person who needs you. You may see becoming a carer as a natural extension of your relationship with the person with cancer. Some people accept the change in the relationship while others may feel they had no choice or it was something they felt they 'should' do.

Becoming a carer is probably a big change for you, and it may take some time to adjust to your new role. You may have to balance caring with conflicting demands such as work, family or study.

How many carers are there?

According to Carers Australia, there are more than 2.5 million unpaid family carers in Australia. More than 770,000 of these people are primary carers, meaning they provide the most care for the person

they are looking after. The average carer spends about 40 hours per week providing care. Women are slightly more likely to be carers than men.





How will I feel?

A carer often experiences a range of feelings about their role and responsibilities. It's common to feel as if you are on an emotional rollercoaster. It may help to know your feelings may be similar to those experienced by the person with cancer.

Research shows that carers often experience higher levels of distress than the person with cancer.

Common reactions

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

Fear

Caring for someone with cancer can be frightening. You may feel afraid of:

- how unwell the person you're caring for is feeling
- not knowing enough about the treatment and health professionals
- being responsible for giving medications
- feeling like everything is out of your control
- not knowing what the future holds
- the possibility that the person you're caring for could die.

Many carers say that learning more about the cancer helps them feel more in control, while others feel overwhelmed by the information available. You need to do what feels best for you.

If you are anxious about managing medications, the tips on page 19 may help you feel more confident.

Anger and frustration

Carers can feel angry or frustrated for many reasons, including:

- having to be the carer
- the extra responsibilities
- family and friends not doing more to help
- having future plans interrupted
- having little or no time for activities they used to enjoy
- feeling the person they're caring for does not seem to appreciate the hard work and sacrifices being made.

You may be able to learn strategies to deal with anger and frustration.

tips

- Take some deep breaths, and try to understand why you're angry. There are many reasons why people feel angry. You may be tired and need a break.
- Let the anger out – for example, go for a brisk walk around the block or talk about your feelings with a friend, relative or another carer.
- Recognise the situations that make you angry, and try to avoid them, minimise them or react differently. Talking to someone may help.
- Notice the warning signs in your body – tense jaw, heart pounding, gritting teeth, shaking – and try to calm yourself down before your anger gets out of control.
- Try to direct your anger positively. Use it to motivate you to make changes for yourself or to find out more about cancer and its treatment.
- Try relaxation or meditation.
- Talk to your GP or a counsellor about how to manage your feelings.

Loneliness

It is easy to become isolated as a carer. You may feel too busy to socialise or contact friends and family. People may visit you less often because they think you have too much to do or they don't know how to deal with the disease of the person you're caring for. Maybe you did a lot with the person who has cancer and you miss this special time together.

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

tips

- Keep in contact with family and friends. You could email or create a blog to let others know what is going on.
- Try to make contact with someone on a daily basis or ask a friend to ring you every few days.
- Accept assistance from others and ask for support when you need it. Although it can be hard to ask for and accept help, it will lessen your workload and make caring more manageable. If you pretend you can manage on your own, people may not offer help.
- Arrange for visitors to come to your house. Reassure others if they are frightened or upset by the signs of cancer, or if they don't know what to say.
- Join a local carers or cancer support group (see page 55). Sharing your feelings with somebody in a similar position may make you feel less lonely.

Stress

The demands, difficulties and limitations of looking after someone with cancer can be stressful.

Symptoms of stress include physical signs, such as trouble sleeping, constant headaches, high blood pressure and other heart problems. Emotional signs may include feeling tired, unwell and overly sensitive.

If stress continues for a long time, it could lead to exhaustion and burnout. Many carers say they feel out of control or under extreme pressure all day, every day.

tips

- Recognise signs of stress, and find a way to deal with how you are feeling.
- Exercise regularly, if you can, even if it's just a walk around the block.
- Meditate or practise deep breathing.
- Do something you find relaxing such as listening to music or reading.
- Talk to someone.
- Ask others for help.
- Try to rest and get enough sleep.
- Eat nourishing food to give you energy and keep you well. Ask your doctor if any vitamin or mineral supplements would be beneficial for you.
- Take time to care for yourself. Respite care may give you the break you need.

Depression

The word depression is used to describe a range of emotions.

Feeling down or sad is common and usually lasts a short time without severely affecting your life. However, depression is an emotional state that is more severe than feeling down or sad.


It may last a long time and can significantly affect your life.

Depression is common among carers, and is not just a mood you can snap out of. Research shows that about one in four carers suffers from depression.

Some of the symptoms of depression include:

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

There are many ways to deal with depression. What works for you may not work for someone else. Talk to your doctor about how you can cope.

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

tips

- Try to do something you enjoy every day.
- Get up as soon as you wake up rather than lying in bed.
- Catch up with friends – either in person or on the phone.
- Try to do some exercise; even a 30-minute walk every day can be beneficial.
- Make an appointment with your GP. Discuss what you are experiencing. Your doctor might be able to refer you to a counsellor or talk about other options. You may want to ask if medication would help in your case.
- Visit www.beyondblue.org.au to get more information about depression and anxiety.

Loss and grief

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

As a carer, you may feel that you have lost an enjoyable part of your relationship with the person you are caring for. You may be missing parts of your life, such as work, regular exercise, social events or intimacy. You may be dealing with an uncertain future and financial changes.

It can take time to adjust to the changes and challenges you are facing. It may help to talk to friends and family about your feelings, or you can contact Cancer Council Helpline 13 11 20.

Guilt

Guilt is one of the most common emotions carers experience.

Some carers have said they feel guilty about:

- feeling angry and resentful
- wanting a break from caring
- being well, while the person they are caring for is sick
- not doing a perfect job as a carer.

tips

- Talk about how you feel with the person you care for, a friend or family member. Keeping your feelings to yourself could add to the guilt you are already experiencing.
- Consider talking to a counsellor. This may help you to communicate your feelings and change the way you are thinking.
- Avoid using the words 'should' or 'must' – they can make you feel more guilt.

Satisfaction

Although it can be challenging at times, caring can also be very rewarding. One of the most fulfilling parts about caring for someone else may be your sense of satisfaction, achievement and personal growth.

Knowing that you are helping someone in their greatest time of need may make you feel good about yourself. Spending time with the person who is sick – even if it seems insignificant – can help build your relationship and create lasting memories.

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

Some ways to cope

Keep a diary

Some carers use a diary to:

- give them some perspective – for example, reading what you wrote yesterday may help you see that today is a better day
- release some of their worries or frustrations and see them in a different light
- acknowledge their feelings.

Don't expect to be perfect

Sometimes you may feel like you could have handled a situation better or done something differently. It's okay to make mistakes. Each new day gives you a chance to try again. You may expect too much from yourself, and you may need to learn not to be so hard on yourself. No one is perfect; you're doing the best you can.

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



Key points

- You may experience a range of emotions about your role as a carer. It is natural to have mixed feelings at times.
- Many carers feel afraid or anxious about the future.
- You may sometimes feel angry and frustrated due to your additional responsibilities.
- Some carers are lonely because they feel too busy to socialise or contact friends. Accepting offers of help and getting in touch with others may make you feel less isolated.
- If you have intense feelings of sadness or moodiness for long periods of time, you may be depressed. Depression may make it hard to function each day.
- You may feel a sense of loss. Some people grieve the missing parts of their life, such as work, social events, exercise or intimacy. It can take time to adjust to changes.
- Carers often feel a lot of pressure. Signs of stress include trouble sleeping, headaches or tiredness. It's important to recognise these signs, seek support and rest.
- Some carers feel guilty because they want or take a break. They may feel like they are failing, but everyone needs time out.
- Caring for someone who is sick can also be rewarding. Your role may give you a sense of fulfilment or achievement.
- Talking to friends, family members or health carers; keeping a diary; and allowing yourself to make mistakes can help you cope.
- Cancer Council's booklet about emotions and cancer may help. Call **13 11 20** for a copy.



What some carers do


Every caring situation is different. There are no specific responsibilities for a carer; your role will depend on the needs of the person you are caring for and what you are able to do. Your role and the level of care you provide may change over time.

Caring is often more than a one-person job. Consider sharing the responsibilities with family, friends, or various support services – see page 54.

Work with the health care team

As a carer you're part of a health care team made up of doctors, nurses and other health professionals who specialise in treating cancer. In some treatment centres these specialists work together closely – this is often referred to as a multidisciplinary team. The team will discuss the needs of the person with cancer and recommend the best treatment. They may also refer the person to other specialists to ensure all aspects of their care are covered.

Dealing with health professionals can be intimidating, especially if you haven't done it much before. You may feel overwhelmed with all the new and complex information. It can be frightening to go to a new clinic or treatment centre. Having one contact person in the multidisciplinary team may make you feel more comfortable.

“ Sometimes my extended family members would criticise and add further to the load. It was helpful for me to focus on the advice of the health care team. ”  Carer

Health care team

The health professionals and health workers you see may include:

Health professional	Role
General practitioner (GP)	responsible for general health and coordinates specialist treatment
Surgeon	surgically removes tumours
Medical oncologist	responsible for chemotherapy
Radiation oncologist	responsible for radiotherapy
Haematologist	diagnoses and treats diseases of the bone marrow, blood and lymphatic system
Nurses	provide support and help during all stages of treatment
Palliative care specialist and nurse consultant	responsible for control of symptoms such as pain, nausea, depression and anxiety
Pharmacist	responsible for dispensing medication
Dietitian	supports and educates patients about nutrition and diet during treatment and recovery
Physiotherapist and occupational therapist	help with movement and mobility, and assist in preparing the house to accommodate a patient's needs
Social worker, psychologist, counsellor, pastoral care worker	help provide emotional and spiritual support and advise on support services

Including carers in the health care team

According to national laws, carers should be considered part of a patient's care team. Try to find health professionals you feel comfortable with, as you may see them frequently.

Carers' experiences of working with health professionals varies – some people have good experiences, while others

may feel that their role is not acknowledged. If you feel you aren't being recognised as a carer, talk to the health care team about your role. For example, some young carers are not included in important conversations because the health professionals believe that the person is too young to be in the carer role.

Preparing for the doctor's appointment

Before the visit

- Talk to the person you care for, discuss any questions you both have and write them down beforehand so you don't forget anything. It may help to do some research at the library or on the internet, so you can ask informed questions. See *Learn more about cancer* on page 57.
- List all the drugs being taken and their doses, and note any side effects experienced.
- Check with the medical centre about what you need to bring, e.g. test results, scans, blood tests.
- Write down any change in the patient's condition.
- Ask for a longer appointment if you have a lot of questions.
- Call Cancer Council Helpline 13 11 20 if you need information and assistance with the types of questions to ask.

During the visit

- Take notes or record the discussion with the doctor.
- Write down any specific instructions.
- Check that your notes and understanding are correct.
- Ask the doctor if they can give you printed material or tell you where to find further information.

After the visit

- Review your notes.
- Record the next appointment.
- Call the doctor for any test results.
- Contact the doctor about changes in the patient's condition.

Stay safe at home

Depending on the needs of the person you are caring for, you may have to make some changes to their home.

tips

- Rearrange furniture to make access easier, and remove loose rugs and other tripping hazards.
- Talk to an occupational therapist about changes you can make or equipment you can hire or purchase. This may include putting handrails on the stairs or in the bathroom, or moving the main living area to an easily accessible part of the house.
- Look after your back if you have to lift the person you're caring for. Ask someone, such as a physiotherapist, to show you how to lift safely. You may be able to hire or purchase equipment to help you.

Communicate with family and friends

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

tips

- Use technology such as group text messages or emails to keep others up to date. You may want to start an online diary or blog.
- Ask a family member or friend to keep others up to date.
- Leave a message on the answering machine to reduce some of the time needed to answer calls. You could say something like, "Bill is doing okay with the chemo. He's mainly feeling tired. Thanks for your concern."
- If you are communicating with children, the *Talking to Kids About Cancer* booklet may help. Download a copy from www.cancercouncil.com.au.

Manage medications

The person with cancer may be taking prescription and non-prescription medications. Keeping a list of the names of these drugs, their purpose, dosage, when to take them and any side effects, will help you administer them safely. It can also save time and confusion when seeing health professionals.

You may want to use a Medi-List form available from your pharmacist or create your own log or spreadsheet.

tip

Keep the medication in its original packaging so you always know what type of drug it is.

You should also know the following information about the medication you are administering, or ask the doctor or chemist:

- How should it be given (with food, without food, orally, etc)?
- Is there anything, such as alcohol, that should be avoided while taking the medication?
- Does the drug interact with other drugs or vitamin supplements?
- Are there any possible side effects? What should I do if the person experiences side effects?
- How long will the medicine be needed?
- What should I do if a dose is missed?
- When is the use-by date?

Safety Net concession card

Many medicines cost much more than the price they're sold for. The Australian Government pays most of the cost through the Pharmaceutical Benefits Scheme (PBS).

To reduce the amount of money you spend on medicines each year, you can apply for a PBS Safety Net concession card. To be eligible you need to keep a record of what is spent on PBS medicines on a form available from your pharmacist. Once the threshold is reached, PBS medicine will be less expensive or free for the rest of the calendar year.

For more information, call 1800 020 613 or go to www.pbs.gov.au.

Manage finances

Caring for someone with cancer can be a difficult time financially. There may be a drop in your household income if you or your partner have reduced work hours or stop working. There may also be new expenses such as childcare, transport, medication and equipment.

Various organisations can help you with financial issues, such as budgeting, refinancing or counselling. In addition, you can talk to the hospital social worker about financial or practical assistance available, and apply for it as soon as possible. You may be eligible for financial assistance from volunteer bodies, church groups or your local council.

Centrelink is a government organisation that supports primary carers financially through various schemes:

- **Carer Payment (adult)** – allocated to carers who provide full-time assistance in the home of the ill person. This payment is income- and asset-tested.
- **Carer Allowance (adult)** – for carers who provide a significant amount of assistance, either in their own home or in the home of the sick person. The allowance is not means tested so you may be eligible for it if you are working or receiving another pension.
- **Carer Payment (child)** – for people who are not able to participate in the work force because they are caring full-time for an ill child. It is income- and asset-tested.

- **Carer Allowance (child)** – for people who provide a significant amount of care to a child under age 16 while living in the same home. A number of factors influence the rate of the allowance.

If the person with cancer travels for treatment, they may be entitled to financial assistance from their state or territory government.

You may be able to apply for partial reimbursement of travel costs so you can access treatment that isn't in your local area. Talk to your social worker or community health centre for information, or call Cancer Council Helpline 13 11 20.

tips

- Contact your local Carers Association on **1800 242 636** for help and information on financial assistance.
- Check if you're eligible for any Centrelink payments. Contact Centrelink's Carers Line on **13 27 17** or visit the website, **www.centrelink.gov.au**.
- Seek professional help to set up budgets and manage debt.
- Find out if you or the person you are looking after are eligible to access superannuation early. Get financial advice before accessing this money, as it may affect your retirement.

Enduring Power of Attorney

The person with cancer may appoint you as their Enduring Power of Attorney while they are undergoing treatment. This gives you power to act on their behalf on all financial matters, and it will also enable you to do things such as pay bills and manage bank accounts.

An Enduring Power of Attorney differs from a Power of Attorney because it means you can act on behalf of the person you care for even if they lose the capacity to make their own decisions.

Consult a solicitor for more detail about this and advice about how to make legal arrangements.

Manage pain

If the person is in pain, they may become irritable or even aggressive. In most cases, pain can be controlled throughout treatment with medications or other techniques. Talk to the health care team if the person is experiencing discomfort.

tips

- Use a pain scale to help you understand the intensity of the person's pain. This may help them communicate the need for extra doses of pain medication.
- Keep a diary of the patient's pain levels and symptoms. Let the health care team know how the medication has been working and notify them of any changes.
- You may be concerned if the person needs stronger pain relievers, but addiction is not an issue for people with cancer. Pain relief medication helps them stay as comfortable as possible.
- Try relieving pain and discomfort with hot-water bottles, ice packs or gentle massage.
- For more information about pain management and massage, contact Cancer Council Helpline **13 11 20**.

Prepare food and drinks

When the person you care for is having treatment you may notice their appetite changes or they have problems eating. They may not even be able to tolerate their favourite foods.

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

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

If the person with cancer refuses food you have prepared, try not to take it personally; they are unwell and the treatment has changed their taste and appetite. Nausea and poor appetite can last for several months after treatment has finished.

You may feel anxious because you want the person to eat well so they can cope with the side effects from the treatment and recover quickly. However, it's not necessary to follow a strict eating plan.

A dietitian, doctor or nurse can provide advice on a suitable eating plan. The tips on the opposite page will supplement their advice. Cancer Council has practical suggestions on eating well during and after cancer treatment. Call 13 11 20 for a free booklet about nutrition and cancer.

tips

- Cook extra food and freeze it for another day.
- If the person you're caring for was the main cook, ask them for recipes.
- Make meals a time when you can sit together and talk.
- If the person you care for is losing weight, talk to your doctor, dietitian or pharmacist about digestive aids or dietary supplements.
- Take extra care when preparing food because cancer and its treatment weaken the body's immune system. Always wash your hands before preparing food and take special care when handling raw meat, fish and chicken.
- Store ready-made supermarket meals in the freezer.
- If the person is nauseous due to radiotherapy or chemotherapy, ask the health care team if they can prescribe medication.
- Ask to try different nausea medication until you find one that works well for you. Nausea and poor appetite can last for several months after treatment has finished.
- Offer the person's favourite or well-tolerated foods often.

Manage paperwork

Paperwork can pile up. You may have to keep track of bills, receipts and letters from health professionals. It's easier if you have them all in one place such as a folder, expanding file or filing cabinet. Although it might take a bit of effort and time to set up initially, carers who have an organised system say it is worth the effort.

Long-distance caring

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

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

tips

- Try to create a support network of volunteer and paid carers, service providers, relatives and friends to regularly visit the patient. These people should be reliable in case of an accident or emergency.
- Create a contact list of the health professionals who are looking after the person with cancer, and keep this list handy in case you need to contact them.
- Use technology (such as email, blogging, text messaging and video conferencing) to stay in touch.
- Ask the person if their doctor will allow them to record consultations, so you can hear what was discussed.
- Look at the best possible telephone (landline and/or mobile) plan to reduce your costs.
- If you visit the person with cancer to take care of them, try to have a rest when you return home.



Key points

- There are no specific caring responsibilities. Your role will depend on the needs of the person you are caring for and what you can do.
- Carers are part of the patient's health care team. You may liaise with various health professionals, including the GP. Some carers help prepare for a doctor's appointment, attend the appointment and follow-up.
- Making some changes to your home can help ensure it's a safe environment.
- It may be helpful to use technology, such as blogging, to update friends and family about the condition of the person with cancer. A friend or family member can also help with this.
- You might give medication to the person with cancer. Your doctor or chemist can give you advice about managing medications.
- Carers often help manage finances. If you have an Enduring Power of Attorney, you can act on the person's behalf on all financial matters.
- You may be eligible for financial assistance through organisations such as Centrelink.
- Preparing food and drinks can be an important part of someone's care. For more information about food and cancer, call the Helpline.
- It may help to have a system to keep track of paperwork like bills, receipts and letters.
- Some carers do not live close to the person with cancer. Being a long-distance carer can be challenging, but there are ways that you can provide support from a distance.



Caring for yourself

Caring can be rewarding, but many carers also find it demanding, both physically and emotionally. If you have been caring for someone for some time, you may feel exhausted. You might feel guilty making time for yourself. However, looking after yourself can help relieve the stress and exhaustion of caring, and reduce feelings of frustration and isolation.

Make time for yourself

Some carers have said they felt like they lost their identity when caring. You may feel like your career, interests and health are no longer important or have to take second priority.

tips

- Take some time every day, even if it's just 10 minutes, to do something for yourself. You don't have to leave the house. For instance, you can take a nap, catch up on personal phone calls, emails and letters, do some gardening, read or simply relax.
- Plan in advance when you will take time for yourself, so you can fit it in with your caring responsibilities.
- Try to stay involved in activities you enjoy. It will give you something else to think and talk about outside of caring.
- Let friends or family know that you want to chat about things other than caring.
- Ask family and friends to help you so you can have regular breaks or arrange respite care (see page 55).

Care for your body

Carers can often forget to look after their own well-being. When they do notice that they're not feeling well, they tend to downplay their own health needs. You can acknowledge that you are not feeling well without comparing it with how the person with cancer is feeling.

tips

- Eat healthy meals and snacks. If the person you care for has long appointments or is in hospital, you may need to bring healthy food from home.
- Try to get enough rest. Tiredness often adds to the stress of caring and may make you feel irritable. Taking a warm bath or listening to relaxing music before bed may help you relax.
- Continue having checkups with your own doctor.
- Avoid using alcohol or cigarettes to deal with stress. These may make you feel better for a short time, but they contribute to other problems.
- Exercise for 15–30 minutes each day. This will make you feel more energetic, help you sleep better and improve your mood. If you can leave the house, a walk, run or swim may help. An exercise bike or a yoga/meditation mat will mean you can exercise at home.
- See a doctor if you notice changes in your health such as fatigue, sleep problems, weight changes and depression.
- If you are lifting, moving or physically supporting the patient, don't go beyond your capabilities and hurt yourself. Physiotherapy and occupational therapy teams can give you advice about the correct techniques. It is important to stay as fit and well as possible so you don't end up with an injury.

Deal with uncertainty

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

You may be able to schedule doctors' visits so you can attend with the person you're caring for. It may also help to learn more about cancer and possible treatment options, so you feel like you have more knowledge about what is happening.

Talk with family and friends

Talking about how you feel about caring, particularly if you are feeling angry (venting) may help you deal with these emotions.

You may feel uncomfortable talking to the person with cancer because you think they have a lot to deal with already and you are meant to be their support. It's understandable if you don't want to talk to the person with cancer, but try not to hold in all your feelings. You can share your feelings with friends or family members, or join a support group for carers (see page 55).

“ When my husband was first diagnosed with cancer, people were very supportive, but as the illness has continued people have gotten used to it and forget I still need help. ”

Carer

Organise your time

It may not be possible to do everything you want to do. You will need to manage your time.

tip

- Prioritise your weekly tasks and activities.
- Use a personal planner/diary to keep track of information and appointments.
- Ask for help from family, friends or support services. For instance, someone might be able to make dinner or drive the person with cancer to treatment. Asking for help is not a sign of failure and it may relieve some pressure.
- Concentrate on one task at a time, e.g. making dinner.
- Avoid multiple shopping trips, e.g. do one large shop rather than going daily.

Focus on the value of caring

Looking after someone with cancer is not always easy or satisfying. Many carers say they feel overburdened and resentful. However, many carers say focusing on the value they were adding through caring helped them to cope and made them feel better.

Some of the rewards of caring include:

- learning new skills
- strengthening your relationship as you demonstrate your love and commitment
- satisfaction from helping someone in need.



Key points

- Caring can be physically and emotionally demanding.
- Looking after your own well-being can relieve stress and tiredness, and reduce feelings of frustration and isolation.
- You may feel like your health and interests are second priority to the person with cancer. Try to take time for yourself, even if it is just 10 minutes daily.
- Carers often forget to look after their own health. Try to eat well, get some exercise, rest and keep up your regular checkups. Talk to your doctor about any health concerns, especially if you are feeling depressed.
- If you lift, move or physically support the person with cancer, get professional advice about correct lifting techniques so you don't end up with an injury.
- Life can seem unpredictable and uncertain at times. Learning more about cancer and treatment may help you feel more in control. You may also want to attend doctors' appointments with the patient.
- Talking to friends and family or joining a carers' support group can help you process your feelings and deal with them.
- Organise your time wisely and try to concentrate on one task at a time. Using a diary and getting help from others can relieve some of the pressure.
- Thinking positively and focusing on the value of your caring role can make you feel more satisfied.



Asking others for help

You may want to do all that is possible to help, especially at first. If the condition of the person you're caring for changes over time, you may have to take on more tasks, which can make it harder to cope.

Some carers say they feel as though they have failed if they can't manage all the responsibilities of caring by themselves. Others worry that asking for help will be interpreted as a sign that they are not coping with caring, and their role will be taken away. You may feel that everything should be provided by the family and that outside help is not necessary.

Asking for and accepting assistance is sometimes difficult. You may find it hard to let others know what help you need. If you seem to be coping with everything, family and friends may not realise you need help. They may be waiting for you to ask for help because they don't know how to offer or fear they will be intruding or disturbing you.

There are some ways you can determine what needs to be done and who could help:

- Write down everything that you do each day.
- Ask yourself what things the person you care for wants only you to do. For example, the person may be most comfortable with you assisting them with toileting or showering.
- Consider the tasks that are the easiest to delegate or share.
- Think about specific tasks you enjoy or are particularly good at. You may want to do these things and allocate other responsibilities.

You may want to hold a family meeting to discuss how everyone is going to help. Tasks that are often done by or shared with others include:

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

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

Setting boundaries and limitations

To establish a happy and long-lasting caring relationship, it may help to set boundaries. Outline what you are comfortable helping with, the level of workload you can manage, and what your own needs are. The help of family, friends or support services can be used to fill the gaps. For example, if you find it uncomfortable or are physically unable to wash or provide intimate care to the person you care for, talk to a community nurse about providing this care.

What about the person I care for?

Many people being cared for look forward to a change from their usual care arrangements as much as their carers do. However, sometimes the person with cancer may not want you to take a break, because they're worried about what it means for them. Explaining how a break will benefit both of you may help.



Christine's story

My husband Rick was diagnosed with a terminal brain tumour called a glioblastoma.

I cared for Rick at home over 15 months. For the first year – even after brain surgery – he was quite capable and self-sufficient. He was very fit before the diagnosis.

Rick was not allowed to drive and I drove him to all of his medical appointments. Our daughter Suzy and friend Peter helped out as well. Sometimes Peter would take Rick to blood tests and out for coffees. This was a nice break for me.

After a year, Rick deteriorated quickly. He lost his appetite so I made light, nourishing meals. The meals also helped me stay well, because I didn't want to get sick. As Rick became sicker, I got advice from occupational therapists about the right way to lift and move him.

Rick became paralysed and after a while, I couldn't provide care at home. We moved Rick to the palliative units in hospital and a nursing home. He was only there 10 days before he died. It was hard, but I know I did the best I could caring for Rick at home during his illness.



How relationships change

Caring for someone with cancer may affect your relationship with them. Most carers agree that the relationship is under greater stress during the diagnosis and treatment.

Facing challenges such as cancer together may strengthen some relationships, but others may be strained. The impact on your relationship may depend on what your relationship was like before the cancer diagnosis.

If you have a strained relationship with the person you care for, the pressure of cancer treatment and the demands of caring may add further tension. You may want to share the caring role with other people so you are not the full-time carer.

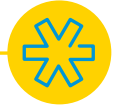
Caring for your partner

Cancer often changes family roles. If you are caring for your partner, you may have to take on many of their responsibilities.

Discuss with your partner how you feel about the change in your roles and how you will restructure your life during cancer treatment. Try to include your partner in household decisions and ask for their advice. Work together as a team. They will appreciate that they are still an important, contributing member of the family, despite the cancer. Talk to your children about these changes.

You may not want to take away all of your partner's jobs and responsibilities. Being able to do things may make them feel useful and help maintain their independence, dignity and sense of control.

When you have established your new roles and responsibilities it may be necessary to ask others for help. Discuss the various job allocations with your partner.



Gay, lesbian, bisexual, transgender or intersex (GLBTI) people may face extra challenges when caring for their partner. They may worry about their family accepting them, or wonder if support services are GLBTI-friendly. Carers Australia has resources for GLBTI carers – go to www.carerlifecourse.com.au.

Effect of cancer on sexuality

You and your partner may find the cancer and its treatment affects your sexual relationship. How it affects your sex life will depend on the type of cancer, the treatment and its side effects.

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

There are some ways you may be able to improve your intimate relationship with the person who has cancer.

tips

- Restore the intimacy in your relationship by spending time together. If your partner is well enough, you may be able to go to a movie or out to dinner. Otherwise watch a DVD together, give each other massages, read the newspaper together, look through old photo albums, or talk about how you first met.
- Tell your partner you care. Your partner may need reassurance that you love them and find them attractive despite the physical changes from cancer or treatment.
- Discuss any fears you have about being intimate with your partner. If you keep quiet, your partner may misinterpret your distance and think that they're no longer desirable. Many people feel embarrassed talking about their sexual needs, but being open can help you identify changes you need to make.
- Keep an open mind about ways to feel sexual pleasure. You may need to try different things if your usual ways of lovemaking are now uncomfortable or not possible. For a while you may need to focus on kissing and cuddling. Some people find lubricants or vibrators help.
- Take things slowly and spend time getting used to being naked together.
- Be patient. You will probably find that any sexual problems after cancer improve with time and practice.
- Talk to a counsellor who helps couples with intimacy and sexual issues.
- For more information call **13 11 20** for free information about sexuality and intimacy.

When your support is not wanted

There may be certain tasks that the person you are caring for does not want you to help with, such as having a bath or shower or going to the toilet.

It may be hard to step back and let the person with cancer do things for themselves, especially if you can see that they are finding the task tiring or painful.

If the person refuses your offers of help, you should respect their request. If you have concerns about the person's safety, place a bell nearby to ring if they need assistance. You may suggest that you will come back every 5–10 minutes and call out to make sure they are okay. You can also talk to your doctor or nurse to get some in-home help.

The person you are caring for may do something that you feel could be harmful, such as refusing medications or wound care. If this happens, try talking with them and discussing their feelings. Another family member or close friend may be also able to be a positive influence. If this doesn't work, you should seek support and advice from the medical team. They may be able to discuss it more objectively with the person with cancer.

“ Mum's been grumpy and difficult all her life and I realise that now she has cancer it won't change. Even though she doesn't want my help as her carer it won't mean that I'll stop caring about her.  Carer

Carer Life Course

Carer Life Course is a website with information about different stages a carer may go through. It covers information about how a carer may feel and how their relationship may change over time. It also has links to other useful web-based resources. Visit www.carerlifecourse.org.au.

If caring doesn't work out

You might try to be a carer and find it hard to manage. Sometimes the changes in your relationship make caring too difficult.

It might help to get professional counselling, either alone or with the person you are caring for. The counsellor may be able to discuss if there is a way to make the caring arrangements manageable. If not, you may be able to get advice about how to change to a different arrangement with the least amount of stress to you both.

Ask your GP or call Cancer Council Helpline for information on how to get a referral to a counsellor.

If your caring role is no longer needed

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

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

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

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



Key points

- Caring for someone with cancer may put your relationships under greater stress. However, some people say that facing cancer strengthens their relationships.
- If you have a strained relationship with the person you care for, the demands of caring may add further tension to the relationship.
- If you are caring for your partner, you may have to take on some of their responsibilities. Try to include your partner in your decision-making process.
- Gay, lesbian, bisexual, transgender or intersex people may face extra challenges when caring for their partner.
- Cancer may affect your sexual relationship. For example, you may feel too tired to have sex. You can improve your relationship by spending quality time together, discussing your feelings, and taking things slowly.
- The person with cancer may not want your help with some tasks, such as toileting or showering. It can be hard to step back, but you should respect their privacy. Seek in-home help if needed.
- You may find it too difficult to be a carer. If you want to stop being a carer, you can get advice about how to change to a different arrangement.
- There may come a time when your assistance is not needed as much or at all. This may make you feel redundant or hurt. It might be challenging or impossible to resume your life as it was before caring. Give yourself time to adjust to the situation and to find other activities that give you pleasure and a sense of worth.



Communication

When someone is diagnosed with cancer they may experience a range of emotions such as shock, fear, irritability and anger. You, as a carer, may also feel this way. This can affect communication, which is an important part of any relationship.

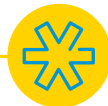
People who frequently share their feelings may be better able to talk about cancer. If you usually solve problems or make decisions alone, it may sometimes be more difficult to communicate.

Talking

It can be challenging to talk about cancer, its diagnosis and treatment. This may be because you:

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

However, many people find talking helps them cope better with the cancer diagnosis. It also helps couples know how one another is feeling and creates a bond between them.




Talking about cancer with children or young adults can be challenging. How you communicate with a young person will depend on their level of understanding. For more information, download a copy of *Talking to Kids About Cancer* at www.cancercouncil.com.au.

Listening

Listening is an important part of communication, and helps others talk about how they're feeling.

Ways to be a good listener

- Sit somewhere private where you will not be interrupted.
- Relax and show you are there for as long as needed.
- Signal that you don't want to be interrupted, e.g. switch off your mobile phone.
- Maintain eye contact.
- Ask if the other person feels like talking.
- Focus on the person and listen carefully. Try not to think about something else or plan what you will say next.
- Ask open questions to get the person with cancer talking.
- Don't interrupt or change the subject.
- Allow the person with cancer to be sad or upset. You don't have to keep them happy and in good spirits all the time.
- If the person interrupts you, ask them to wait until you've finished.
- Make sure you have understood what they've said, e.g. repeat back information or paraphrase.
- Try not to give advice, but prompt the person to think about their options. If you do give advice, don't give it too early.
- Respond to humour.
- If the person stops talking, give them some time to gather their thoughts rather than filling in the gap.

“ It is okay to show that you are upset too. Don't hide your feelings or put on a brave face all the time. ”  Carer

Conflict and disagreements

During your role as a carer, there may be times when you disagree with the person you are caring for. It's normal to have disagreements from time to time. Although dealing with conflict is stressful, it can also be a good way to get closer to the person you are caring for and understand their point of view.

If you can't resolve your differences or if the caring situation becomes too stressful, consider taking a break from your caring role or organising another caring arrangement.

tips

- Talk to the person you are caring for about your concerns. Let them know that you care about them and want to resolve your differences.
- If you disagree on something important, try to stay calm and talk through the issues involved. Hear each other out and try to make a decision together. Sometimes people disagree because there has been a misunderstanding.
- Compare your goals and expectations. For example, some people with advanced cancer choose to stop having treatment to cure the cancer. This may be difficult to accept if you want the person to keep having treatment.
- Choose your battles – it may help to focus your energy on the issues that really matter.
- Ask your family and friends for help and support.
- Talk to your GP or medical team. You might be able to get a referral to a counsellor or social worker who can talk to you about what you are going through.



Advanced cancer, death and grief

The person you are caring for may have been told that they have advanced cancer – cancer that won't go away and is unlikely to be cured. You may both be trying to come to terms with this and experiencing a range of strong emotions such as fear, sadness and grief.

Caring for someone with advanced cancer can be frightening. Some people can live with advanced cancer for many years. You may find that you try not to think about this very much and focus on the everyday practical matters.

As the illness progresses, the person's needs may change and a different type of care may be needed. You may have to reassess the type of care you can offer and who else can help. It may be necessary for the person with advanced cancer to be admitted to hospital or another type of care facility. Some carers feel guilty doing this but handing over the everyday care to somebody else will allow you to spend more time just being together. If you wish, you can assist the staff with caring duties.

Palliative care

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

Palliative care is tailored to an individual's case and involves the coordination of services to meet their medical, emotional, spiritual and social needs.



This chapter is intended to be helpful but it may stir up difficult feelings. Read it if you need to, when you feel ready.

A GP or community health nurse can coordinate palliative care but if the needs of the person with cancer change, they will be referred to a specialist palliative care team.

You may want to read Cancer Council's information about advanced cancer and palliative care. For free copies, call the Helpline on 13 11 20.

Discussing the person's wishes

A person with advanced cancer may wish to discuss their thoughts about dying with you. This may be more common if you are their partner or family member. Although it can be difficult to discuss, death is an important issue. Getting advice from a counsellor, social worker or pastoral care worker may help you with the discussion.

The place of death may be important to the person with cancer. Some people prefer to be in a hospital or hospice. Others wish to die at home in familiar surroundings and in the company of their family (see the following page).

One of you may have strong views, making the decision easier. If the person with cancer is not clear what they'd like, it may be good to discuss it now to avoid any regrets or feelings of guilt later.

Dying at home

Some people say that they want to die at home. The palliative care team can discuss whether this is possible for the person you are caring for. You may also contact an organisation that helps people with a terminal illness die at home. Call LifeCircle on **1300 364 673**.

Anticipatory grief

Many carers experience anticipatory grief. This is the grief you feel when you are expecting a loss such as death.

Anticipatory grief feels similar to grief after a loss (see opposite). You may experience depression and extreme concern for the person. Some people start preparing for the death and beginning to think about what life is going to be like without the person with cancer.

Anticipatory grief can give family and friends time to slowly get used to the death, and to say what they want to say or tell the person what they have meant in your life. For example, some people write a page about what the person with cancer has meant to them and read it aloud to them.

This type of grief may not always occur, and it can be different to the grief a carer experiences when the person dies. The grief experienced before a death does not make the grief after the death last a shorter amount of time.

If the person you care for dies

If the person you have been caring for dies, you may feel a range of emotions, including:

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

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

What is grief like?

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

- physical symptoms such as breathlessness, loss of appetite, crying and sleep problems
- confusion, trouble concentrating or hallucinations
- a sense of disbelief.

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

Carer

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

Some people are critical of themselves for not coping as well as they think they should or for not reacting in the way others may expect them to grieve. Try to be kind to yourself.

Living with grief

- **Find someone to talk to** – This may be a family member, friend, professional counsellor or bereavement support group. If you're feeling very anxious, have trouble looking after yourself or think about hurting yourself, get professional help from a doctor, counsellor or a psychologist immediately.
- **Take time to reflect on your feelings** – Find a way to express your feelings, e.g. cry or write a diary. If you didn't tell the person who passed away all the things you wanted to say, it might help to write them a letter expressing how you feel.
- **When you can, talk about the person you have lost** – Acknowledge how they have contributed to your life.
- **Remember their life in a way that is meaningful to you** – e.g. plant a memorial tree or put together a special photo album.
- **Give yourself time** – Some days you will just exist until better days come along.

- **Don't make big decisions too soon** – If you make decisions in a hurry you may find, later on, that you regret them. For instance, you might want to wait until your grief lessens before moving from the house you shared.
- **Avoid using cigarettes, alcohol or drugs** – Dealing with your grief this way may help delay or numb the grief for a while but can cause health problems.
- **Contact Carers Australia** – Call 1800 242 636 for a referral to the National Carer Counselling Program. Counsellors may be able to talk to you about your feelings and discuss ways you can cope with them.
- **Look after yourself** – It is common for a bereaved person to not eat well and to sleep poorly. Having set mealtimes and establishing a regular bedtime may help.
- **When you feel the time is right, explore a new interest** – You may feel guilty doing this, but it's okay to rebuild your life.

Carers often say that gradually they are able to cope and enjoy life in a new way again.

“ Changing the answering machine message was really difficult for me. I didn't want to do it but my sister said it was hard for family members to leave a message after hearing my husband's voice. ” *Carer*

Ongoing grief

Coping with grief is an ongoing process. The feelings of loss don't go away but the intensity eases.

Most people will continue to grieve in subtle ways for the rest of their lives. You may find little incidents, memories or anniversaries like birthdays or the day the person died bring back an intense sense of loss. It may help for you to arrange to be with family or friends at these difficult times. Support groups or counselling can also help you get through times when your grief seems overwhelming.

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

Experts say most people grieve for 6–12 months before they are able to carry on without thinking of their loss most of the time. However, if your sadness is ongoing and affects your day-to-day life, you may be clinically depressed. Talk to your GP about your feelings.



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



Key points

- Caring for a person with advanced cancer can be frightening or upsetting.
- As a person becomes sicker, their needs may change and different care may be needed. Some people are admitted to hospital or a hospice.
- Palliative care can help the person with cancer manage symptoms and stay as comfortable as possible.
- A person with advanced cancer may want to discuss their wishes about care at the end of life. For instance, some people wish to die at home.
- You may experience anticipatory grief if you are expecting the person to die. You may think about what life will be like when the person is gone.
- If the person you care for dies, you may feel a range of emotions, such as sadness, numbness or anger. Even if you were expecting the person to die, it may still be shocking when it happens.
- Everyone grieves in a different way. You may feel physically unwell or have mental symptoms such as confusion or a sense of disbelief.
- It is very challenging to live with grief. You can try to speak to loved ones, reflect on your feelings and look after yourself. When you feel ready, explore new interests.
- Coping with grief is an ongoing process. Some days are better than others. Memories and anniversaries can cause strong feelings to rush back.
- Carers' and bereavement support groups and counselling may help you. Seek professional help if you think you are depressed.



Support and information

Carers sometimes need help and support to keep going. You may think you can cope on your own, but many carers have found that getting help made their lives easier.

The availability of services may vary depending on where you live. Some services are free but others may have a cost.

Where to find help

Carers Associations

Carers Associations in each state and territory provide carers with information and advice. They can help carers with referrals, counselling and support. They also provide resources on a wide range of topics including support groups, home help, financial entitlements and respite. Contact your local Carers Association on 1800 242 636.

National Carer Counselling Program

The National Carer Counselling Program (NCCP) provides a short-term counselling program for carers to help reduce stress, and improve carer coping skills. The program is delivered by qualified, professional counsellors either in person, by telephone, one-on-one or in a group. The NCCP service is run by your local Carers Association.

Home help

Home care services can help with practical tasks in the home such as cleaning, shopping, laundry and helping with bathing, dressing and toileting.

Home nursing

A trained nurse may visit people with cancer in their homes to assist with personal care, administer medication, give injections or change dressings. Care may be provided regularly or when needed.

Support groups

Getting in touch with other people who have been through a similar experience can be beneficial. In these support settings, most people feel they can speak openly, share tips with others, and just be themselves.

Support services are available for patients, carers and family members. They include:

- face-to-face support groups, which are often held in community centres or hospitals
- telephone support groups for certain situations or types of cancer, which trained counsellors facilitate
- an online support forum to connect with carers at any time – see www.cancerconnections.com.au.

Ask your nurse or social worker to tell you about support groups in your area. Cancer Council Helpline nurses can also talk to you about suitable support groups or peer support programs.

Respite care

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



You may be eligible for up to 63 days of residential respite care per year. For information, call **1800 052 222**.

Respite care can be for a couple of hours, overnight or a few days. You can access respite care for any reason. For example, you may have respite care to:

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

Some carers don't access respite care because they feel guilty or concerned about leaving the person they are caring for. However, the service is there because caring can be a very difficult role and can challenge your own sense of well-being. By taking a break, you will probably find that you can continue your caring role more effectively.

Commonwealth Respite and Carelink Centres are experienced in finding respite options for people of all ages and conditions. Call 1800 052 222.

““ I cannot speak highly enough of the Commonwealth Carers emergency respite services. They played a very important role in my case. ●● Carer

Learn more about cancer

You may find it helpful to learn more about cancer. This may give you a better understanding of what to expect during treatment. It may also reassure you and the person you care for, and allow both of you to speak to health care professionals with more confidence.

You can call Cancer Council Helpline 13 11 20 for support and information, or visit the Cancer Council website. You may want to read information about a particular type of cancer or download a range of publications.

The hospital, treatment centre or Cancer Council may also run workshops or discussions about cancer, treatments and side effects.

Cancer Council library*

Following a cancer diagnosis, many people look for information about new types of treatment, the latest research findings and stories about how other people have coped.

Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you. Your local library may also have some relevant resources.

**This service is not available in Victoria and Queensland*



Useful websites

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

Australian

Cancer Council Australia.....	www.cancer.org.au
Cancer Institute NSW.....	www.cancerinstitute.org.au
Carers Australia.....	www.carersaustralia.com.au
Carer Life Course.....	www.carerlifecourse.com.au
Young Carers Australia.....	www.youngcarers.net.au
Commonwealth Department of Health and Ageing.....	www.health.gov.au
Commonwealth Respite and Carelink Centres.....	www.commcarelink.health.gov.au
Health Insite.....	www.healthinsite.gov.au
beyondblue.....	www.beyondblue.org.au
Palliative Care Australia.....	www.palliativecare.org.au
Australian Centre for Grief and Bereavement.....	www.grief.org.au
Centrelink.....	www.centrelink.gov.au
Pharmaceutical Benefits Scheme.....	www.pbs.gov.au

International

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



Glossary

You may come across new terms when reading this booklet or talking to health professionals. You can check the meaning of other health-related words at www.cancercouncil.com.au/words or www.cancervic.org.au/glossary.

carer

A person who helps someone through a disease or disability such as cancer.

empathise

To understand the feelings of someone else.

Enduring Power of Attorney

The ability for a person to act on behalf of the person they are caring for on all financial matters.

health care team

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

Medi-list

A list of names, dosages and times of a patient's medications. Available from pharmacies.

palliative care

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

pharmaceutical benefits scheme (PBS)

A government-funded scheme that subsidises some prescription medicines.

respite care

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



How you can help

At Cancer Council we're dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer-smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

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

Make a donation: Any donation, whether large or small, will make a meaningful contribution to our fight to defeat cancer.

Buy sun protection products from our website or retail stores: Every purchase helps you prevent cancer and contributes financially to our work.

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 cancer issues and help us defeat cancer by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council does research to investigate the causes, management, outcomes and impacts of different cancer types.

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



Cancer Council Helpline 13 11 20

The Cancer Council Helpline is a telephone information service provided by Cancer Council WA for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk about any concerns confidentially with oncology health professionals. Helpline Cancer Nurses can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 8am to 6pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au). This service will help you to communicate with a Cancer Council Helpline Nurse.

Regional offices

Goldfields

Kalgoorlie
Ph: (08) 9080 8200
Esperance
Ph (08) 9071 0400

Great Southern

Albany
Ph: (08)9842 7536

Hills

Guildford
Ph: (08) 6278 1048

Midwest

Geraldton
Ph: (08) 9956 2408

Peel Rockingham

Mandurah
Ph: (08) 9581 4059

South West

Bunbury
Ph (08) 9791 1464
Busselton
Ph: (08) 9751 2762

Wheatbelt

Northam
Ph: (08) 9690 1603



Cancer Council
Helpline

13 11 20

For support and information on cancer and cancer-related issues, call the Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancerwa.asn.au