



# Caring for someone with cancer

For family and friends



### **Caring for Someone with Cancer**

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# Introduction

**This booklet is for people who are looking after someone with cancer.** You may have only recently found out that the person has cancer and you will be their carer. Or you may have been caring for someone for a while. You may not even think of yourself as a carer – you may think that what you are doing is just part of your relationship with the person.

Whichever situation you are in, you may be trying to come to terms with the news that someone you know has cancer and that you will play a big part in the journey through their illness.

You may have questions about what caring for someone with cancer means. How will you cope with your emotions and theirs? How will you manage their physical needs? Perhaps you are worried about how it may affect your day-to-day life, your relationship with that person and others in your life. You may be looking for extra information, tips and strategies or reassurance about your feelings and how you are coping.

Cancer is a very difficult and stressful experience for everyone involved. Many people say that it can also be a rewarding and life-changing time. In this booklet we want to especially acknowledge the difficulties and rewards for you, the carer.

The term ‘carer’ doesn’t sit well with everyone. You may find it strange to be ‘labelled’ in this way. But for many people it is a positive way of explaining their situation and the significance of what they are doing. However you feel about this term we hope that you will find this booklet useful. We aim to guide and support you in your role as a carer and provide you with information that will help you better understand your emotions. We discuss ways of caring for and supporting the person with cancer as well as looking after your own important needs and commitments along the way.

Everyone is unique and will experience and do things slightly differently. Your role as a carer will depend on many factors, such as the stage of the person’s cancer. We suggest you use this booklet as a

general guide. Read the sections that you feel will be helpful for you. Your family and friends may also find it helpful to read this booklet. It can help them understand what being a carer involves and how their love and support will help you.

★ **You can telephone the Cancer Council Helpline on 13 11 20, Monday to Friday 8.30 am to 8 pm.**

If you would like to talk to someone about your role as a carer or receive further information, call the Cancer Council Helpline. The Helpline nurses are qualified, experienced cancer nurses who are specially trained to listen and provide information and support. They can also tell you about Family Cancer Connect, through which you can talk to someone who has had a similar experience. Refer also to the section on support services and resources at the end of this booklet.

The words in **bold** are explained in the list at the back of this booklet.

★ **Are you reading this for someone who does not understand English? Tell them about the Multilingual Cancer Information Line. See the inside back cover for details.**

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# Being a carer



**A carer is someone who provides physical and emotional support to a person who is ill or disabled.** You might be the partner (husband, wife, girlfriend or boyfriend), son, daughter, relative, friend or neighbour of a person with cancer.

## Who is a carer?

You are someone who is sharing that person's experience of cancer. You may live with the person and provide care 24 hours a day or visit a few hours a week to help. Or you may be a long distance carer and coordinate most of the care over the phone, only visiting occasionally.

Some carers may not have chosen their role. It can come about due to changing and unplanned circumstances. You may have felt pressured into your caring role by expectations or a sense of duty. You might not even feel that close to the person. Some carers have other commitments, such as young children, or a demanding job or studies. Carers can be young or elderly. However many hours you care and whatever your age or circumstances, caring can be a difficult but very important role.

## What does being a carer mean?

Caring may involve helping with practical jobs such as cooking meals, shopping, transport, hygiene needs, paying bills or organising and attending medical appointments. It can also mean giving emotional and spiritual support.

Knowing how to listen, when to talk and sensing when ‘being there’ is all that the person with cancer needs, are a few of the greatest skills a carer can have.

Most carers will be providing all of these things without realising it. But we feel it is still important to acknowledge your valuable work as a carer.

It can take time to adjust to becoming a carer. Your role can be full of rewarding, yet challenging, times for you and the person you are caring for. You may have strong, conflicting emotions, feel confused and wonder if you will cope. Many carers find it hard to focus on their own feelings so they put all their energy into the person with cancer. This may be necessary sometimes but there are going to be times when it will be extremely important to take care of your own needs. You may not feel you have time to do this. It is only natural to worry that taking time out for yourself may impact on the quality of care you can give. But if you don't, eventually, your overall health and wellbeing may suffer, which may make it difficult to look after the person.

**‘I realise that looking after my needs while caring for my husband with cancer is so important; it’s like being on the plane when the safety announcement tells you to put the oxygen mask on yourself first before helping others.’**

**– Carole, age 66**

## Carers with medical problems of their own

Not everyone who cares for someone with cancer is fit and well themselves. Some carers have their own medical problems; these could include chronic pain, mobility problems, diabetes or **depression**. Some problems may have happened since you became a carer. You may be elderly and frail or even have cancer yourself.

If you are ill or disabled, being a carer can bring up different emotions and challenges than if you have good health. You may neglect your own health needs, believing that they are not as important now in comparison to the person you are caring for. You may do things that you wouldn't normally do, such as help lift the person, forget to take your own medication or not eat or rest when you usually do. If you have just been diagnosed with cancer, you may feel pressure to recover more quickly so you can get back to your caring role. You may make decisions about your own care and treatment that you are not completely happy with so that you can finish treatment sooner.

We hope this booklet will reassure you that your needs are just as important as those of the person with cancer. You can still care for them well but you may need to modify how you do this to ensure that your health problems don't worsen. See the section titled 'Caring for yourself'.

*'I was told I had cancer and my first reaction was to think, "I don't have cancer, I can't have cancer. Who will look after Bill?"' – Lesley, age 72*

## Young carers

A significant number of young carers are 25 years or younger. Even some children under the age of 12 are playing a caring role for someone with cancer. Young carers often have a lot of emotional and practical responsibilities compared to other people their age – for example,

helping a parent shower, get dressed, take their medication or eat their meals.

As well as caring for the person with cancer you may also be helping care for your younger brothers or sisters. Trying to study, attend school or fit into your peers' social life can be very difficult for a young person to cope with along with everything you do as a carer.

If you are a young carer you may have different types of questions:

- How do I tell my friends that I am a carer?
- Do I let my teacher know that I am a carer?
- How do I keep my friends?
- I feel very frightened and don't know where to get help. I want to go out with friends or move out of home but I don't feel that I can. Who can I talk to about this?

We provide some information in this booklet but there are support services and resources specifically for young carers. Call the Cancer Council Helpline on 13 11 20 or Carers Victoria on 1800 242 636 to find out more. Ask them about respite centres that have young carer funding and programs.

## Indigenous carers

Very few Indigenous people would think of themselves as carers; however, many have significant care-giving responsibilities, including looking after their elders and other family members with an illness, including cancer. As an Indigenous carer you may have fear and mistrust of mainstream services. You may not be linked to carer support services. If you are an Indigenous person, please use this booklet. You may also find it helpful to call Carers Victoria on 1800 242 636 for specific information to suit your needs and those of the person you are caring for.

## Caring from a distance

It can be very difficult to care for someone when you don't live nearby. You may feel that you don't have the full picture about what is happening with their treatment and care. At times you may feel that you are being left out of helping make important decisions or that you are finding things out later than you would like.

This can be hurtful and hard to cope with, especially if you are very close to the person with cancer. You may feel guilty that you cannot be there more often or worry that you are not providing the right kind of support. However, you may be doing more than you think. Caring from a distance may mean that you can be more objective about things and solve problems that other close friends or family members are unable to solve. Sometimes, people with cancer feel stifled by people being around all the time. Your distance may allow them to speak more freely or express emotions they would otherwise keep to themselves.

If you are unsure about how to best care for someone from a distance, think about the following tips and strategies.

- Use the phone, email and text messages as much as possible to keep in touch.
- Try to organise a roster of friends, family and paid services to visit the person with cancer regularly.
- Make sure there is a list of emergency contact numbers by the phone for anyone who is visiting or helping care for the person with cancer.
- Keep a contact list close by of all the health care providers involved. Let them know who you are.
- Look for ways to reduce your costs: for example, travel in off peak times and get the cheapest phone plan for your needs. (If you are overseas, Skype or international phone cards can make calls very cheap.)

Remember to also allow yourself to relax and not worry all the time about the person with cancer. You cannot do everything from a distance. There will be times when you will just have to trust that others have things under control.

## Caring for a young child

Caring for a child with cancer can be quite different from caring for an adult; parents and relatives report that it is very emotionally demanding. Along with the anxiety that might occur throughout the decision-making and treatment process, there are normal parenting issues: making sure the child is doing normal things for their age, such as having play time, and keeping up with school work. Parents try to ensure siblings don't feel isolated and left out of family life; this may be very difficult when most of the attention needs to be on the sick child.

Some of the information in this booklet will be helpful for carers of young children. For more specific information, call the Cancer Council Helpline on 13 11 20. You can also ask for further information from the medical team at the hospital caring for the child.

# Different stages, different people, different caring



**Becoming a carer of someone with cancer can happen at different stages of the illness.** It may happen suddenly or very gradually over a long period of time. Your role may begin when the person is in the early stages of cancer and cure is the aim. You may take on the role when the cancer is advanced and cure is not possible. You may have cared for someone whose cancer was treated many years ago and now the cancer has come back and you need to take on that role again.

When you first begin to care for someone with cancer they may not ask much of you. But as time goes on and their treatment affects them, you may feel they place more and more demands on you. The needs of the person with cancer will vary depending on their age, the stage of their cancer, their cultural and religious background and the type of treatment they are having.

Certain times may be more challenging or traumatic than others. The demands on you and how you feel will vary depending on what is going on. For example, caring for your mother in the early stages of cancer will bring up different emotions for you than if you were caring for her in the advanced stage of the disease. Caring for a young child will have its own unique difficulties. Cultural differences can be

challenging as well. For example, for some people, the causes of cancer are set in beliefs about the spiritual world of curses and being 'paid back' for supposed misdeeds. Such beliefs may influence how you discuss cancer and its treatment. Sometimes strong family values and cultural beliefs affect how people wish to be cared for or how you want to care for someone, placing strong expectations upon you as the carer.

Care for the person with cancer as best you can. Ask for help if you have any questions or difficulties. Everyone will do it in their own way. The important thing is to recognise that everyone's needs (both the carer's and the person with cancer's) may differ at different stages of the disease. Respecting the needs of all involved is very important.

# Your feelings and emotions



**Carers report that they go through a range of conflicting emotions when they are caring for someone with cancer.** Many have described their role as an ‘emotional roller coaster’. At times, some carers feel more distress than the person they are caring for. This is a normal reaction to the change in life associated with becoming a carer.

Some days you may feel very positive, loving and happy to be caring for the person. Other days you may feel resentful, fed up, angry and depressed by what you have to do, then feel very guilty for having those feelings. If you have already had someone close to you die from cancer, this could have a big impact on your day-to-day feelings. There is no right or wrong way to feel, everyone is different. Whatever you are feeling, be reassured that it is perfectly natural to feel as you do.

The important thing is to know when to ask for help. You may need time to come to terms with your role as a carer. It is okay to let the person you are caring for know that even if sometimes you feel anxious and worried, you are still there to support them.

Caring brings up many different feelings. Sometimes you’ll feel satisfied and positive. You then may go through other, more difficult

emotions, some of which are interlinked. They won't happen in any particular order and you may not experience all of them.

## Satisfaction

Caring for someone can be very positive. It can be very satisfying to know that you are making a difference for someone during such a difficult time in their life. You may feel surprised and pleased with the way you have handled the situation and the new skills you have acquired as a carer. Serious illness often brings people closer together. It can make you reassess your life and priorities. You may share things that you wouldn't normally have felt able to or do things together that you had been putting off. Some carers say they have been surprised by their personal strength and growth. You may become more aware and thankful for all the good times you have shared and make it a priority to enjoy more happy times together.

*'It was a great honour to care for my mother. There were days I felt despair but then sometimes I would feel so thankful and happy to be able to do this for Mum. She had worked so hard all her life for us kids – I now wanted to give something back when she most needed us.'* – Geoff, age 33

## Loneliness and isolation

Being a carer can be extremely lonely at times. Even if there are a lot of other people around offering help, you may still feel as though nobody else truly understands what you are going through. Unless they have been a carer themselves, they probably don't. This can be very isolating.

Good friends may not be there as much as you would like them to be. Other family members may not be helping as much as you thought they would. You may feel overwhelmed with your responsibilities

and not feel there is anyone you can turn to for support. You may be concerned that people are tired of hearing you talk about what is happening or that they expect you to be positive or strong.

If you shared a lot of leisure time with the person you are caring for, you may miss these times. You may feel at a loss now that your role within the relationship has changed. The time taken up being a carer may mean that you have less time to spend with other friends and family.

It may help to join a local support group or contact Cancer Connect. Cancer Connect is a telephone peer support service that puts people in touch with others who have had a similar cancer experience, including family members of people with cancer. Call 13 11 20 for more information.

Although not for everyone, many carers say that being part of a support group is a ‘sanity saver’. The other carers can offer friendship, fun and advocacy in a way that other close friends and family are unable to do. See the section titled ‘Help and support’.

## Frustration

We feel frustration when we perceive an obstacle blocking satisfaction of a need or goal. Typically, we feel anxiety as well. Your frustration may be related to many things: lack of time to do your own thing, not being able to change the situation for the person with cancer, or feeling you can never please them. Wanting to do more than your time allows or you are physically able to can cause frustration. Although it’s a very normal feeling for carers, frustration can make you feel anxious, upset or even angry at times.

**‘When you talk about being a carer, frustration should be written in capital letters as every part of my life and the family’s has gone into a “holding pattern.”’ – Nick, age 38**

## Fear and anxiety

Watching someone go through cancer and its treatment can be frightening. Fear can be one of the hardest emotions to deal with. You may be fearful that the sick person won't get better or of the side effects that may occur from their treatment. You may be frightened of the future, that you are not going to support them in the right way or that you won't cope with the situation. The person with cancer may have their own fears, which may make it difficult to talk to them and share experiences. Fear can make you feel that you have no control over the situation.

Most people find a way of coping with their fears.

Sometimes when someone is under a lot of stress they can become so fearful or anxious that they have what is called a 'panic attack'. This can include physical symptoms such as increased heart rate, breathlessness and sweating. During a panic attack, some people even fear that they will die. You may feel afraid to leave home in case you have an attack. You may feel you are experiencing similar symptoms to those of the person you are caring for. Panic attacks can come on very suddenly and can be extremely frightening but are generally not dangerous. As hard as it will be at the time, the best thing you can do is to try to talk yourself out of a panic attack. Keep telling yourself that you are safe, nothing bad is going to happen and in time you will feel calm again. Remember to slow your breathing down and use any relaxation techniques that you know may help. If possible, let someone know that you are feeling this way so that they can stay with you and support you.

If you have concerns that your anxiety is affecting your quality of life or if you are having regular panic attacks see your GP for support and advice.

## Stress

Looking after someone with cancer will be different for everyone. However, it is likely to bring a lot of stress into your life as you both try to deal with the demands of the treatment and its side effects or other changes the illness brings. Feeling tired, upset, angry or anxious can only add to your stress. You may not think that you are stressed but others may see it clearly. Some symptoms of stress can include:

- feeling very tired but having difficulty sleeping
- becoming easily upset
- feeling anxious all the time or having panic attacks
- regular headaches
- aches and pains
- high blood pressure
- increased heart rate.

If you think you are stressed it can help to talk to someone about how you are feeling. Take some time out and try to relax. Some people benefit from doing some strenuous physical exercise while others prefer to take a gentler approach and do some deep breathing and meditation.

## Sadness and depression

Feeling down and sad is very normal when you are caring for someone with cancer. You may feel sad about what the person has to cope with or what they have had to give up because of their **diagnosis**. If you are partners then you may also feel sad about not being able to enjoy things together as you used to. Feeling down can also be due to lack of sleep, not eating properly and stress – all of which you may have to deal with as a carer. These down times usually only last a few days and then you gather strength to keep going with the routine of your role.

For some people though, the sadness may not go away. You may begin to feel down all the time and not able to pull yourself out of it. If this is the case then you may be suffering from **depression**. Other

symptoms of depression can include changes in your appetite or weight, sleeping problems and feelings of hopelessness.

Depression is very different from sadness. Depression is an illness that may need treatment with counselling or medication. If you think you might be depressed talk to your GP. The Beyondblue website ([www.beyondblue.org.au](http://www.beyondblue.org.au)) has a 'depression checklist' that you may find helpful.

## Guilt

Many carers say they feel guilty. You may feel guilty for not doing enough for the sick person or for feeling resentful, angry or lonely in your situation. Knowing you are well and the person you are caring for is ill can also cause feelings of guilt.

It can be difficult to get rid of these feelings but try not to beat yourself up. Perfection is impossible and it is likely that you are being a very supportive and thoughtful carer. It may help to talk with the person you are caring for about how you feel. If you think this might cause conflict, speak to a close friend or relative. Professional counselling may also be an option. Call the Cancer Council Helpline on 13 11 20 for more information or to ask to speak to a Family Cancer Connect volunteer.

**'I found it very difficult to cope with the fact that my health was so good. I used to feel so guilty every time Ben had chemotherapy and felt so sick afterwards. I used to wish so much that it was me that had the cancer and not him.'**

**– Belinda, age 55, mother of Ben, age 25**

## Anger

Most of the time, you may be happy in your role as a carer. But there may be other times when you feel angry about what you have to do or

how the person with cancer treats you. You may feel that they don't appreciate everything that you are doing, or that they are only thinking about themselves. Carers often say that they feel angry about their circumstance and what they are giving up to be a carer. They no longer have much freedom, time or energy to enjoy life the way they once did.

**'One day I felt so angry I threw my hairbrush at the bathroom wall. I wish someone had come along and said to me that it is okay to be angry and it was okay to let that anger out, without harming anyone, sometimes.'**

**– Bev, age 66**

Dealing with anger may not be easy and could make you feel guilty. But the following tips may help:

- In the heat of the moment, take a deep breath and walk away from the situation for a few minutes – try to work out what is causing your anger.
- Try to rest when you can, eat well and do some exercise each day – tiredness, hunger and lethargy can all set off anger.
- Don't hold your anger in – there are lots of positive ways to help you deal with anger such as listening to music (with earphones if necessary), going for a walk or run, writing your feelings down or talking to a friend or relative.
- Avoid using alcohol and other drugs to relieve anger – they may help in the short term to relax you but overall they will make you feel worse and may make you do or say things you regret.

## Resentment

It is very normal for carers to sometimes feel resentful. This may be towards the person you are caring for. They are taking up time that you could be using to do things you enjoy. You may feel other family

members, friends or even medical staff could be doing more to ease your burden. People may stop asking about you and only ask about the person you are caring for. People you once thought were friends may even have stopped visiting or being in contact. You may begin to resent this and wish that someone would ask how you are feeling. Loving someone doesn't always protect you from resentment.

**'I just wish once, someone would ask how I am before asking about Mum's cancer.' – Erin, age 19**

If your relationship with the person you are caring for was 'rocky' or had ended before they became ill, you may now be struggling with feelings of resentment for having to care for them.

**'I feel so upset and resentful about being their carer as we had been separated for years before the cancer.'**  
– Chris, age 46

Don't feel bad about feeling resentful. This doesn't mean that you care any less or are a bad person. You have had a lot to deal with and may have given up a lot to become a carer.

**'Jack was improving and I was proud to be part of that but I also had feelings of "What about me?"'** – Mary, age 44

If things become too hard and you are finding that you feel resentful all the time, you may consider other options for care for the person with cancer. It is okay to think like this. Sometimes you have to make a decision that is right for you.

## Helplessness

There may be times when you feel that there is nothing you can do to help. You can't take away the cancer or the pain. All you can do is be there. Many carers say this makes them feel helpless. But feel reassured

that just by being there you are doing a lot and it is greatly appreciated. Even health professionals caring for someone with cancer, especially when it is in the advanced stages, sometimes feel at a loss to know how to best support them.

## Loss and grief

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

Many changes and losses occur with cancer. You may be grieving for how your life was before you became a carer. You may feel that you have lost the enjoyable part of your relationship with the person you are caring for. You may be missing work, people, regular exercise or an active and fun social life. Perhaps you are grieving over the loss of dreams and friendships. Certain family and friends may be staying away because they are not sure how to deal with illness. You may be dealing with an uncertain future and financial changes.

It can take time to adjust to the changes and challenges you are now facing, so be kind to yourself. If you feel you would like to talk to someone about your feelings contact the Cancer Council Helpline on 13 11 20.

*'So much has changed in our lives from the cancer which others can't see, unlike a death there are no funerals for the death of our dreams.' – Brian, age 47*

## How can I cope with my emotions?

We are all unique and have our own ways of coping during good and bad times. However, nearly all carers say they have times when they are not just 'fed up' but really don't think they can deal with the situation

any longer. They have had enough! While not magical solutions, the following may help you 'hang in there' and feel more in control.

- Try to read the signs of stress and do something before it gets too serious – if you are waking up every night at 3 am and can't get back to sleep it may be stress. Don't just lie there thinking – get up and have a cuppa (decaffeinated is best), listen to your favourite music, try to relax. Talk to your GP if it continues.
- Acknowledge your feelings and allow yourself the time to feel and work through your emotions.
- Don't be afraid to ask for help.
- It is okay to feel angry, to cry and to let people see how you are feeling – even the person you are caring for. You can't be cheerful all the time.
- Talk your feelings through with a close friend or relative or seek help from a professional counsellor.
- Some people use their religious and spiritual beliefs to help them cope with their emotions. Cancer may challenge your beliefs but it can also make them stronger.
- Keep a pen and paper close by to write your thoughts down. Even keep them by your bed in case you wake and feel anxious and restless. Many people say writing things down helps a lot.
- Know that we all make mistakes – none of us is perfect. Accept yourself for who you are. Know that you are doing the best job you can.
- You can't do everything so don't expect to – there may be days when you need to leave certain things like the washing or cleaning. Just focus on those things that are really worth your time and energy.
- Remember – some things you just can't change!
- Read the section titled 'Caring for yourself' to find out more about how to cope with your emotions and ask for help.

# Practical issues caring for someone with cancer



**Being a carer can mean juggling many different jobs each day.** It will be different for everyone, depending on who you are caring for and how sick they are. Keeping a daily calendar of all your commitments can help to remind you about important times of the day for medications, appointments or jobs you need to do on time.

You may find you are regularly faced with new challenges that will become part of your role as a carer. At first some things may seem too hard to do. For example, you may not feel comfortable talking with health professionals or helping with medications. This can be very difficult, but with time, most carers say they are surprised by their new abilities. They gain a sense of satisfaction from realising the difference they are making.

Following are a number of responsibilities that you may have to fulfil as a carer.

## Working with the health care team

You may be the only person who knows about everything that is going on with the person you are caring for, particularly if you have

known the person prior to their illness. This knowledge can be a huge responsibility but it will be invaluable to the **health care team**.

*'I've been with my husband so long that I can tell when he's not well just by the bat of his eyelids.'* – Marion, age 72

Along with finding out information for you and the person you are caring for you may also be responsible for passing on information from the health care team to family and friends. Getting accurate information from the right people will help you do this well. If you are going to communicate with the medical team away from the person you are caring for, the team will need the patient's consent to do this. There may be information that the person you are caring for doesn't want passed on to other people.

The health care team may include doctors and nurses as well as others who specialise in cancer care (dietitians, social workers, radiographers, psychologists, occupational therapists, physiotherapists, pastoral care workers, etc.). These people often work very closely together and are known as a 'multidisciplinary team'. They will have regular meetings to discuss the best treatment and care for the person you are looking after. There may be times when you and other family members are asked to come along to one of these meetings.

Knowing that you have the support of a group of people who specialise in cancer can be very reassuring. But it may be confusing and daunting at first. Make sure you ask about anyone you are not sure about. Find out their roles, how you contact people and when it is okay to do so.

Overall, these people are there for you and the person with cancer. They want to help, so where possible, lean on them. Sometimes you may meet someone in the health care team that you don't get along with. This can make life difficult for you and possibly the person you are caring for. If this is a real issue and begins to cause a breakdown in communication, it may help to discuss your feelings and get some

advice from someone such as a professional counsellor. See the section titled ‘Help and support’.

‘So often as a carer you don’t know what you don’t know about cancer.’ – George, age 67

## Preparing for appointments

Going to doctors’ visits, treatment sessions and investigations can require a lot of concentration and patience. The person you are caring for may rely on you to do the listening and ask the questions. Some information can sound complex and confusing. You may worry that you won’t understand what is being said or miss something that you need to do to help care for the person, such as giving medication on time or changing a wound dressing. It is important to ask if you are unsure.

Before going to an appointment talk with the person you care for and find out what you would both like to know. Many carers say that it helps to find out more about the type of cancer and treatment the person is having. Call the Cancer Council Helpline on 13 11 20 and ask one of the nurses for more information, where to access other reliable sources of information or to speak to a Family Cancer Connect volunteer.

The nurses on the Helpline can also help you write a list of questions to take to the appointment. Take along with you a pen and paper to write the answers. Take lots of notes. That way you can refer back if necessary. Some people may prefer to record the conversation and listen back to it once home. Speak with the **health care team** to see if this is possible. If you are not given it, ask for written information to back up what the doctor has said so you can read this at home as well.

‘Take plenty of notes! My wife filled up a couple of notebooks and it made life much easier.’ – Lawrie, age 52

## Managing family and friends

This can include communicating with small and adult children, siblings, grandparents, friends and colleagues. A huge task for anyone! Most carers say this can be very tricky and exhausting. People will see you as the key person to contact to get an update on the person you are caring for. You may find yourself constantly on the phone, making calls, answering the door or emails. It can be very time-consuming, frustrating, tiring and sometimes painful to have to go over and over the same information with different people. There is also the issue of communicating with different sorts of people at different ages. Read the section titled 'Carers need to communicate' for tips on how you can save yourself some time and energy as well as communicate effectively.

There may be past and long-term conflicts within the family that cause difficulties and make it hard for you to manage. These problems are likely to intensify now that someone in the family has cancer. There may be even more resentment, difficulties and anger.

Whatever the situation, it is very important that you get some time away to rest from your caring duties. While they may not suit everyone, the following tips and strategies may be useful in certain situations.

- Ask someone else to take on the role as 'information provider'. They can do a regular group email or text message to keep the majority of people informed.
- If people need to phone, ask them to do so between certain times so that you are ready for the calls. Explain that you can only talk for a few minutes.
- Leave a detailed message on your answer phone letting people know how things are going – you can change this regularly to keep them up to date.
- For those who prefer to use the Internet you may like to set up a 'Blog' and write a regular update. Many people say this can also be a great way of getting support as well, as people can post messages on the site.

- Take the phone off the hook if necessary.
- Be honest. If you don't feel like talking or you are busy, just let people know – they will usually understand. If they don't then maybe you don't need to keep in touch for now.
- While the needs of family and friends are important, try to find the best way to satisfy everyone's needs with the least amount of stress for you.
- Write a 'wish list' of things that others could do if they offer their help.
- Have a 'coffee/tea station' area set up where visitors can serve themselves rather than you having to wait on them (you could even suggest that they also make you and the person with cancer a cuppa!)

Organise a family forum to discuss needs and expectations. You may find it helpful to ask a health care professional to assist with this meeting to ensure that any past family differences don't get in the way of finding the best way to support you and the person with cancer.

## Looking after the home

This may sound simple but it can be quite a challenge if the home needs modifying to allow the person with cancer to get around better. If mobility is a problem you may need to move their bedroom from upstairs to downstairs or install railings around the house to help them get around safely. Talk with the occupational therapist at the hospital, who can help organise these changes.

Shopping, cooking, cleaning and caring for children can all take up time and be very tiring along with everything else you may need to do. Don't expect too much from yourself – leave the things that are not so important, or get help.

You may be eligible for help with childcare costs and home duties. Call the Family Assistance Office on 13 61 50. Local councils provide a range of community and home services such as meals on wheels,

foster care for children, housekeepers and **respite care**. Telephone your council (listed by council in the White Pages).

## Problems with eating and drinking

Many carers say that the eating and drinking habits of the person they are caring for can be a major cause of concern. People with cancer often suffer from diet problems. This is because the cancer or its treatment can affect the body and how it functions, causing problems such as:

- loss of appetite
- feeling and being sick
- tiredness (fatigue)
- mouth problems (soreness, ulcers)
- taste changes
- bowel problems – diarrhoea or constipation.

Most of these problems are temporary and will disappear once treatment finishes. However, for some people there may be permanent changes to the way they can eat and drink. This can be very difficult for them to cope with and hard for the carer to know how to best support them.

If you are doing the cooking you may become worried that the person you are caring for is not eating enough or that you can't seem to please them no matter what you cook. You may feel very frustrated or at a loss to know how to make something nutritious and tasty or how to encourage them to eat. If your efforts to cook nice meals don't seem to be appreciated you may begin to feel rejected.

Remember, uneaten meals are unlikely to have anything to do with your cooking but be about how the person you are caring for is feeling. They may feel sick or bloated, or have a sore mouth, making it too painful to eat. Someone with breathing difficulties will often refuse food because they become too tired and puffed when they have to chew and swallow.

People in the advanced stages of cancer may eat very little or some days nothing at all. They may not be able to eat or have an appetite. This may mean that they no longer enjoy eating so they avoid meal times. Read Cancer Council's booklet *When Cancer Won't Go Away: For Carers of People with Cancer* for information about caring for someone with **advanced cancer**.

## Tips to cope with diet problems

Even knowing why someone is not eating doesn't always help. You may continue to feel anxious about the effect of this on treatment. You may worry about weight loss and its effects. Talk to the medical team (doctor, nurse or dietitian) about how you can help manage a suitable eating plan. The following tips may also help.

- Offer three small meals with snacks in between rather than three large ones – large amounts of food are not appealing to someone who feels unwell.
- Plan meals with the person you are caring for – involving them may help you prepare food that they want.
- Find snacks and small meals that are easy to prepare. You don't need to be in the kitchen cooking for hours – you probably have enough to do right now.
- Boost calories and protein in foods by adding butter, honey or milk.
- Don't worry if the person you are caring for doesn't feel like eating for a few days after treatment – drinking is very important, but they can make up for lost calories between treatments.
- Keep a handy stock of snack foods that you know the person likes – offer them throughout the day.
- Serve cold or slightly warm food if the smell of cooking is a problem.
- Be sure that the person you are caring for is comfortable at meal times – not in pain, not too tired and sitting upright to help with digestion and breathing problems.

- Let the person eat when and what they want – you don't need to stick to set meal times.
- A soft diet will help someone who has a sore mouth.
- Encourage good mouth care – a person is more likely to feel like eating if their mouth is clean and fresh.
- High calorie drinks may help reverse weight loss problems – ask your medical team about these.
- Get help with cooking if it is getting you down – ask friends and relatives to do a few meals a week to take the strain off you.
- If food tastes metallic to the person you are caring for, use plastic utensils.
- Increase flavour in foods by adding spices, relish, chutney or herbs.
- Encourage the person to eat more fibre if constipation is a problem, and low fibre, starchy foods to help with diarrhoea. Encourage drinking plenty of water for both problems.
- If feeling sick is a problem then ask the doctors for some medication to help prevent this.
- Finally – make sure that you eat regularly, even if the person you are caring for isn't.

There is more about 'Caring for yourself' further on in this booklet.

**\* Cancer Council's booklets *Coping with Chemotherapy and Coping with Radiotherapy* discuss ways of managing side effects. The booklet *Nutrition and Exercise* also contains useful information. Visit [www.cancervic.org.au](http://www.cancervic.org.au) or telephone 13 11 20.**

## Managing symptoms and side effects

Most people with cancer will suffer symptoms and side effects from their cancer and its treatment during some stage of their illness. The medical team will guide you and the person with cancer about how

to best manage these. However, it can still be very frightening and upsetting to see someone suffering from side effects such as pain, ongoing fatigue, feeling or being sick or having trouble breathing. You may worry that they won't get better or that you won't be able to support them.

There are usually ways of effectively managing most symptoms. If you feel that the person you are caring for isn't comfortable or there have been changes in their condition, contact their medical team. They may need to reassess the person and alter their treatment or care. Symptoms can change depending on the stage of the cancer, treatment side effects and what the person is doing. The important thing is that you don't feel alone. You can't do everything – most carers will need help along the way. The following tips may help you feel better able to support someone through many types of symptoms.

- Keep a diary of symptoms and side effects to show the doctor if necessary – for example, monitor the person's pain, sickness, bowel habits, eating habits, mobility or problems with confusion, anxiety or memory.
- Keep a list of medications – write down when they take them and whether or not they helped.
- Try relieving symptoms in practical ways such as using a hot water bottle or heat pack for pain, pillows for comfort and breathing problems, or music or candles to create a calm environment to help relieve anxiety.
- If the person needs strong pain-relieving drugs, try not to worry that they will become addicted or take too much. Addiction is unlikely to happen when these drugs are taken for pain relief. Regular pain relief is very important for someone in pain.
- Use a 'pain scale' with the person you are caring for to find out how much pain they are in and to help decide when extra pain-relieving drugs are needed. This means rating their pain from 1 to 10 with 1 meaning no pain and 10 being the worst pain

imaginable. This can help keep pain under control. These scales could be applied to measure other symptoms as well such as sickness or even feelings of sadness or anxiety.

- Read the information under 'Problems with eating and drinking' to find ways to manage problems with diet and sickness.

The person you are caring for may also be having difficulties with sexual function due to their cancer and treatment. This can be difficult to cope with, especially if you are in an intimate relationship. Read the section 'How caring affects relationships'.

You or the person you are caring for may think about unproven cancer therapy to help with symptoms and side effects from treatment. Friends may also mention unconventional treatments that they have read about helping to treat or cure cancer. There is a big difference between **complementary therapies** and **alternative cancer therapies**. Cancer Council supports people in wanting to explore different treatment choices. However, we want to ensure people have the right information to make choices that give them the best outcome for treating their cancer.

★ **Cancer Council's booklet *Complementary and Alternative Cancer Therapies* is an informative discussion of alternative treatments for cancer. Visit [www.cancervic.org.au](http://www.cancervic.org.au) or telephone 13 11 20.**

## Work and money

These issues will vary depending on your relationship with the person you are caring for. If you are partners, it may mean that you have had to leave your work or go part time to manage your role as a carer. Some employers will let you take annual leave, long service leave or leave without pay. The person with cancer may have been the main income earner or be self-employed. Either way, it can place a lot of financial

pressure on you and the rest of the family. Caring can also add many extra financial costs, some of which may be ‘hidden’.

The person you are caring for may ask you to become their **enduring power of attorney** during their treatment for cancer. This will allow you to act on their behalf for all their financial matters. It can be very daunting to have to take on roles you may not be used to such as:

- paying bills
- managing bank accounts
- dealing with tax or debt issues
- budgeting for the household.

Get professional help with difficult issues. You may be able to get financial assistance such as a carer payment or concession cards from Centrelink. Many people don’t seek assistance thinking they would not be eligible for help or they may be put off by the paperwork! Don’t avoid finding out because you feel embarrassed about getting financial assistance. This is money that you may be entitled to and has been specifically allocated by the government to help sick people and their carers. You are saving the government money by caring for someone at home. Contact the following organisations for more information.

- Commonwealth Carer Resource Centre: 1800 242 636
- Centrelink: 13 27 17 – the Centrelink Multilingual Service is on 13 12 02
- Cancer Council Helpline: 13 11 20 – for a *Financial Assistance Fact Sheet*.

## Paperwork

Many carers say that the amount of paperwork they need to fill in, for example to apply for the carers benefit or to get a disability parking permit, can be very complex, off-putting, time-consuming and even demoralising. With so much on your plate already, where are you supposed to find the time and energy to fill in pages of information on forms? For others, language difficulties may be a barrier. While some paperwork is hard to avoid it can help to ask the social worker at the hospital or Centrelink for help and advice. They can suggest ways to make things easier on you.

# Coping with other people's reactions



**Generally people will be very supportive of you in your role as a carer.** But be prepared for mixed reactions towards the person with cancer and you as their carer. Some may have expectations of how you should be caring for the person with cancer. Even close friends may not react in a way you were expecting – some may even disappear!

Some friends and family members may find it difficult to accept that you can no longer give them the time and attention you once could. Others may give advice or negative comments on how you are doing things, which can be hurtful and discouraging. Others will make you feel at ease very quickly and reassure you that you are doing a great job. People you thought would be there to help and support may avoid you and those you did not think would help may surprise you by being very supportive.

You may also have to cope with people's reactions to the person with cancer, for example, to changes in the way they look, act or talk due to their cancer and its treatment. This can be very difficult for the person you are caring for and for you as well. Most people will not mean to upset you but if they do and you need to maintain contact with them, try to talk to them about it. Let them know why you are upset and how

they could better support you. Also, there may be times when saying nothing is the best way to handle things! Don't feel you always have to explain – some things are very personal and only need to be discussed between you and the person you are caring for.

## **Carers need to communicate**

Communicating with the person you are caring for and others involved in their care is likely to be a large part of your role. There may be times when you feel reluctant to talk for fear of saying the wrong thing and upsetting yourself or the person you are caring for.

You may not be used to having to communicate with so many different people at once (family, friends, finance people and health care professionals). Ensuring that all the right people know what is going on can be very daunting and exhausting. The next few sections focus on how you can best communicate with the person you are caring for.

## **Choosing the right times to talk**

This may not be possible all the time but if you can create a calm and comfortable environment to talk, it will help. Pick a time when you both feel rested. Get rid of any background noise or potential interruptions (TV, radio, washing machine and mobile phones) and close doors to rooms where other people might be. It can also help to set aside a regular time each day for you to sit and chat. This doesn't mean that you have to have a deep and meaningful conversation each time, but it gives you both a time to touch base and discuss any concerns, despite everything else that has to be done.

## **Being a good listener**

As much as you may want to listen, it can sometimes be hard to do this well when you are under stress. There are things that you and others close to the person you are caring for can do to improve your listening skills.

Focus on the person you are caring for. Give them your full attention and let them see that you are really there and wanting to hear what they have to say. Face them and make eye-to-eye contact. In certain situations it may help to hold their hand. Try not to look at the time, fiddle with your clothing or tidy around the person when they are talking – it can be tempting to try getting two things done at once, but it won't help encourage the person you are caring for to talk about what's important. Don't change the subject, even if you have something you would rather talk about.

Don't interrupt – wait until they have finished talking and then speak. If they interrupt you, explain that you would like to finish what you have to say because it would be helpful for them to understand your feelings and thoughts.

## Encouraging the person to talk

Encourage the person to talk by nodding your head where necessary, or simply answering 'Yes', 'Okay', or 'I see'. Use short sentences to prompt them to keep talking: 'And then how did you feel?' or 'What happened next?' Acknowledging that you have understood by repeating what they have said can make them feel that you are there with them and really listening. For example, say 'Ah, I see, so you thought ...', 'What you are saying is ...', or 'That must have been very upsetting for you'.

Don't feel you have to fill silent gaps by talking. A few minutes' pause between speaking might be necessary to help them think what it is they really want to say. It isn't always necessary, but it may help during these times to sit closer, place a hand on their shoulder or give them a cuddle.

## It's okay to be upset

It is sometimes very natural to want to stop someone crying or getting angry. You may want to fix things and make people feel happy. But it isn't always the best or most helpful thing to do.

People affected by cancer have a lot to cope with. Feeling sad and upset is very understandable for both you and the person being cared for. They sometimes don't know how to express their feelings and may try to hold them in for fear of getting out of control if they let their guard down. If the person you are caring for gets very emotional when they are talking to you, just let them. Try not to say things like 'Oh, don't worry, everything will be fine.' Stopping them expressing their true feelings might actually cause more harm than good. Saying things like 'You are really feeling sad today' or 'It's okay to feel angry, you have good reason to' can be far more supportive and caring than trying to pretend everything is fine. This also applies to how you are feeling and what people say to you.

## Involving the person you are caring for in their care

It can be very tempting to try and do everything for the person you are caring for. Or you may think you are bothering them so you don't ask their opinion about how they might like something done. At times it may be difficult for the person with cancer to get involved in planning their daily routine or treatment and doctors' visits. They may feel unwell, tired or too emotional to do these things. However, it is important to ask them and involve them as much as you can. They need to feel that they are contributing to their care and not burdening you with everything.

Here are some ways to help.

- Let them know that you are there to do whatever you can to support them but you would also like them to be involved as much as they can or want to be. Don't take over doing something if you see that they might be struggling – for example, drying themselves after a shower. It may be important to them to have this independence. Just let them know you are there if necessary.

- Try not to answer questions that are directed at them from medical staff, friends and family. There may be times they want you to but wait for this cue.
- Don't push conversation if the person does not want to talk about an issue even if you do. Leave it and try again another time.
- Encourage them to share their feelings and let you know if you are doing things that upset or annoy them. Let them know you are not perfect and you are also trying to find your way during this difficult time – so you may get some things wrong.
- Don't stop certain people visiting without first checking with the person you are caring for – someone you don't get along with may be very important to them.
- Some people are happy to have information about their cancer and its treatment available to all family and friends, while others are very private. Check whether the person you are caring for is happy to have information discussed with other people.
- You don't always have to communicate by talking – writing a letter or just giving a cuddle can also let someone know that you are thinking about them and wanting to involve them in decisions.
- Respect their need to be alone sometimes – we all need this!

## Your reactions

How you react or respond to certain things can make a big difference to how the person you are caring for will feel and cope. Trying to understand what and how they feel can be difficult at times, but your empathy will go a long way to helping them feel more able to talk with you and express their true feelings. The following tips may help.

- If the person you are caring for is frightened, angry, upset or worried about the future, listen and offer them reassurance where you can.

- If sexual difficulties are an issue, acknowledge them if appropriate and listen carefully to how the person feels. If you are partners you need to work together on this one. Discuss ways of improving any problems. Some people may benefit from getting help through counselling or prescribed medications.
- Educate yourself about their type of cancer, treatment and side effects. Your interest and knowledge will help them feel more at ease about discussing their concerns.
- If the cancer or its treatment has changed the way they look, such as causing scars from surgery, hair loss, weight loss or gain, let them talk to you about the changes. This can help them feel less anxious. If wanted, suggest ways of hiding or camouflaging the changes using hats, scarves, clothing or make up.

## Problem solving

You may not see yourself as a problem solver, but being a caregiver is likely to involve quite a few problems that need solving. Not all problems can be solved but with good communication many can. Be sure to ask the person with cancer their opinion. It is important for you both to understand the problem, talk about it, and then remain realistic but positive about solutions. This will help you both feel less anxious and more in control of the situation. You may need to be more assertive than you normally are when dealing with certain difficult problems.

## Communicating with young children

Young children need to be kept informed about what is going on. What you tell them will depend on their relationship with the person you are caring for. A child's reaction to hearing that someone close to them has cancer will very much depend on their age and maturity. But for most children it can be difficult to adjust to someone in the family having

cancer, especially if it is someone very close, like a parent or sibling. Having that person in hospital all the time or trying to cope with any changes to the way the person looks can be very hard for children. Such changes can be very frightening for children but if they are told calmly and sensitively what is going on it may lessen their fears.

Every child is different so it isn't always easy to know what to tell them or how they are going to react. The natural desire is to protect children from upsetting news. However, honesty is usually best. This doesn't mean you have to go into great detail about what is happening or might happen. But if you don't give some explanation, children usually pick up that something isn't right, whether it is from body language or hearing bits of conversations. By not telling them the truth you risk them thinking things may be worse than what they really are. They may be little and appear not to understand but they still feel and worry like all of us. Call the Cancer Council Helpline on 13 11 20 for more information about how to talk to children about cancer, or to speak to a Family Cancer Connect volunteer.

# Effects on relationships



**There may be times when your relationship with the person you are caring for changes.** This is very natural considering all the challenges cancer and its treatment can throw at you both. For some people these changes are very positive. You feel closer and stronger together. For others the relationship weakens. You no longer feel able to communicate or support each other as well as you used to.

A lot will depend on what your relationship was like before the cancer **diagnosis**. Different relationships will face different challenges. If there were problems within the relationship before the cancer diagnosis then these problems are likely to become more intense now.

## Caring for your partner

Caring for your partner during their cancer and treatment may be the most difficult challenge you ever face as a couple. There is likely to be a huge shift in responsibilities within the relationship. You may find yourself doing a task that you never dreamt you would have to do or could do, for example, giving an injection, mowing a lawn or doing most of the cooking. You may do these things differently from your partner, which might cause conflict within the relationship.

The person you are caring for may now be dependent on you. It is not uncommon for people in this situation to feel they have lost control of their life. Despite loving them, you may also feel resentful, angry or overwhelmed by your new responsibilities. Adjusting to these changes can take time.

There may also be times when your partner wants to do something a certain way and you are not sure you can cope with it. For example, they may want to have their treatment and care at home rather than in hospital. While you want to support them as much as you can, you may not feel comfortable with this. It can be very hard to know what you should do in these situations. You may go along with their wishes for fear of upsetting them. In the long run this may build up bad feelings between you.

Your partner may become moody and uncooperative towards you due to the symptoms and side effects of the cancer and its treatment. It can come as quite a shock when your once placid and patient partner becomes impatient and short tempered with you. This can make you feel sad, afraid and unsure about asking their opinion about certain things.

It can help to talk to each other about the changes in your roles and look for ways to cope with them. Honesty is often the best solution. It may be tempting to spare your partner the worry and make household decisions without first asking their advice. This may cause more harm than good! Working as a team and making your partner feel their input and help is still valued is very important. Let them know that you are there if necessary but let them continue with jobs that they can still do.

## Intimacy within the relationship

Cancer and its treatment can affect a person's sexuality. Symptoms and side effects such as pain, sickness, tiredness and changes to the body can make someone less able or feel less confident about having sex. As their carer you may feel too tired and emotional to want sex. Or you

may be reluctant to initiate sex because you are afraid of causing your partner discomfort. Some people with cancer believe that they are no longer attractive to their partner because of the changes it has caused to their body image. Fatigue is also a very common reason why people with cancer don't feel able to have sex.

Sometimes the things you have to do for your partner, such as help them on and off the toilet, clean up after they have been sick and attend to their daily hygiene needs, don't help to create a very sensual atmosphere for either of you.

**‘There’s nothing erotic for either person about having to help your partner change their pants because they have had an accident.’ – Bill, age 64**

Because of these issues you and your partner may find that your usual sexual habits change. These changes may be temporary or long lasting.

Whatever changes you both face, you can still remain close even if you don't have sex. Intimacy is more than sexual intercourse. Finding other ways to be intimate can be difficult at first. You may feel awkward or unsure. You need to be prepared to put some time and effort in to making things intimate and fun again. But it will be worth it for the rewards. The following suggestions may help you feel closer.

- Talk to your partner about your sexual needs and concerns and about how they might be feeling. This can be difficult but worthwhile.
- Let your partner know that even though you may not be able to have sex you still want to be near them – cuddling, kissing and just being together!

- If possible, make time each day to do something intimate together – lie on the bed and cuddle, give each other a massage, play a game, watch a movie or just sit quietly together, chat, hold hands, spend time together in the garden. Anything that will keep your spirits alive!
- Reminisce about the good times you have had, when you first met, the mad things you did together and how much fun it was. This often makes couples feel alive and close again.
- Sometimes people avoid intimacy for fear of it having to lead to sexual intercourse. If you or your partner has these feelings try to discuss them and set some boundaries – tell each other what you feel comfortable doing.
- Remind your partner that it is not just their body that you find attractive – you love their humour, kind heart, honesty or calm nature.
- If you both do feel like having sex, but penetrative sex is difficult, try oral sex, explore other parts of the body and don't be afraid to let each other know what makes you feel good.
- Take your time and don't rush each other – remain open minded and allow a new intimacy to evolve. You may be surprised by what pleasures you can give each other. You can have a deep, rich and emotional time once again.
- Fantasise – it can do wonders for bringing back some energy and joy!
- Go away for a night together. If finances allow, find somewhere with a spa bath, have a glass of wine and enjoy some time splashing and playing together. Look in our 'Help and support' section for information about respite and holiday programs available to cancer patients and their carers free of charge.
- Acknowledge each other's losses and the changes the cancer has brought into your lives – let each other know that you may need time to adapt but you do want to make the relationship work.

- Above all remember that this person is your best mate. You need to talk, talk and talk some more – you are both going through a hard time and need to give each other some extra personal attention.
- Some couples may benefit from having sexual counselling. Contact the Cancer Council Helpline to find out about counsellors who deal with these issues. You can also ask your GP for a referral to a psychologist, which may allow you to have six to 12 sessions at a reduced rate.

**★ For Cancer Council information on sexuality and cancer or to obtain our booklet *Sexuality and Cancer*, visit [www.cancervic.org.au](http://www.cancervic.org.au) or telephone 13 11 20. Although this information is written for people who are having cancer treatment it may also help you as a carer.**

## **Caring for a friend, close family member or child**

Caring for a good friend or close family member other than your partner can have its own difficulties. You may get on very well with the person. But for some, caring may mean having to put aside past problems so that you can support and care for the person in the best way. Knowing that they may be dependent on you for some time can cause disruption to your daily life. Juggling your work and home responsibilities along with caring for someone may be very tiring and difficult.

Children over the age of 16 can legally make their own decisions about their treatment and care, but parents caring for them may find it very difficult to accept that they may not be involved in these decisions. If you are caring for a good friend, you may find it very draining having to try to please your family and theirs. Things may not always run smoothly and you may have to deal with people getting upset with you for not doing things when and how they would have liked.

Caring for a young child with cancer can have its own unique set of problems. Giving a sick child the emotional support they need as well as attending to the needs of other children in the family can be exhausting at the very least. A young child with cancer will become even more dependent than usual on their main caregivers.

The demands on a mother and father caregiver can greatly differ. Mothers may have to deal more with the 'hands on' care of the child as well as managing any behavioural changes the child develops as a result of the cancer and treatment. They may also be expected to plan activities for the rest of the family. Fathers may find it difficult to manage work, organise help to care for other siblings, and also support the mother. Sometimes these traditional mother/father roles are reversed and that poses more problems.

Parents who are separated may have to put aside their differences as a couple. Their main focus now must be finding the best way to support their child through their cancer and its treatment.

## When your help and support is not wanted

When this happens it can be difficult to know how to cope. There may be certain tasks that the person you are caring for does not want you to help with, for example, having a bath or shower or going to the toilet. It may be very hard to step back and let them do these things for themselves, especially if you can see that they are finding the task tiring or painful. Offer your help but if they refuse and want their privacy you will need to respect their needs. If you have concerns about their safety, suggest that they have a bell nearby to ring if they need help. You may suggest that you will come back every five to 10 minutes and call out to make sure they are okay.

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 to them and working through things together. If

this doesn't work, another family member or close friend may be able to influence them. If not, you will need to seek support and advice from the medical team, but let the person you are caring for know this is what you are going to do.

**'Mum's been grumpy and difficult all her life and I realise that now she has cancer that 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."' – Thelma, age 68**

## **Coping with changes in your relationship**

Some changes may be positive. Others may put more strain on the relationship. Knowing how to cope can be very difficult. The following suggestions may help.

- Talk to the person you are caring for about your concerns. Let them know that you do care and want to sort out any difficulties between you.
- Some people may find it helps to have professional counselling. This can help sort out many relationship problems, for example, about intimacy, communication, coping with your emotions and dealing with practical issues such as finance.
- Learn more about the person's cancer and treatment. Being aware of what might happen and what they are going through can help you better understand their reactions and emotions. It may prevent problems and help the relationship grow. Call the Cancer Council Helpline on 13 11 20 and ask for information.
- As hard as it may be, try to accept changes that you know may be permanent, such as sexual difficulties. Look for new ways to enjoy being intimate with the person rather than focusing on what isn't possible. (See the section titled 'Intimacy within the relationship'.)

- Where possible seek support from family and friends – because they are less involved they may be able to see solutions that you can't.
- If you disagree on something important, try to stay calm and talk through the issues involved. Hear each other out and then make a decision together. Suggest trying both ways and see which works best. For example, 'Why don't you try taking your pain-relieving drugs every four hours rather than only when you are in a lot of pain? If it doesn't help then we will speak with your doctor for further advice.'
- Set some boundaries! This may not seem necessary at first but if your caring role continues for months or years then you both need to know what your limitations are. You can't do everything all the time. You need to care for yourself to ensure you can continue to create a happy and supportive environment for the person you are caring for.
- 'Choose your battles'. Try to only focus your energy on the issues that really matter.
- Remember – you can always talk to your medical team about any important treatment issues that may be causing problems, for example, if the person is refusing to take their medications. Your treatment team (for example, social worker or cancer nurse) may also be able to support you to deal with the emotional impact of caring for someone with cancer.

Read the next section, 'Caring for yourself' for further tips on how to help with any changes in your relationship.

# Caring for yourself



**Reports have shown that as many as 8 out of 10 people (80%) caring for someone with cancer don't get the help they need.** Many carers struggle emotionally, physically and financially. Some carers do not have anyone to talk to about their feelings and needs. Often carers don't ask for help or think their needs are not as important as the person with cancer.

Caring for yourself is extremely important. It's something most of us are aware of but find hard to do. You may not think you have time with everything else that is going on in your role as a carer. Many carers feel guilty about taking time out for themselves but if you can, both you and the person being cared for will benefit. It will go a long way to helping you last the distance and avoid resentment, exhaustion, anger and **depression**.

*'A nurse sat down beside me at the hospital and said, "And how are you feeling Chrissy?" I said, "Oh, it's not me that has cancer, it is my husband." "Yes, I know that," she said. "So how are you feeling?" I suddenly realised that I never really thought about myself, it was Jim that was sick. But it was nice to be asked.' – Chrissy, age 75*

Caring for yourself is one of the most important things that you can do, but many carers say they find this difficult. Here are some suggestions to help.

## Asking for help

This doesn't come easily to everyone. For some, giving help comes more naturally than receiving it. You may feel you should be able to cope alone and that asking for help is a sign of failure. This simply isn't true. It is very hard to do everything alone. Most carers benefit from some help. People might not offer help because you appear to be coping so well alone. However, this doesn't mean that they don't want to help. Many people will be very happy to help if asked.

Getting some help may allow you as a carer to stay healthier, give more and allow the person you are caring for to worry less about how much you are doing for them. It can help to stop for a moment and put yourself in their situation – you would probably want them to get as much help as possible if they were caring for you.

Ask yourself what you need most:

- help with shopping, cooking or cleaning
- someone to do the driving to medical appointments or the school run
- someone to take over the role of letting friends and family know what is going on
- having time to meet a friend for lunch one afternoon a week just to chat about your feelings and concerns.

Be prepared for some people to say no – even those you thought you could depend on. This can be very hurtful but may be because they have their own worries right now and don't feel able to commit to helping someone else. Or they may be afraid of how they will cope with seeing someone they know sick. So try not to take it too personally. Many people tell us that they often receive support from people they

least expected it from and have been disappointed by the friends they thought they could count on.

If you would like to talk to someone about the support available, call the Cancer Council Helpline on 13 11 20 and speak with a cancer nurse. You may be eligible for help with cleaning, shopping, meals on wheels and other kinds of support.

## Coping with exhaustion

Many carers say that the hardest thing about caring is tiredness or fatigue – absolute exhaustion. There is no relief and you never feel able to completely rest and relax. Even when you are sleeping you may still feel your mind is working. You feel that you need to be alert all the time in case the person needs you. Recognising when you feel tired is important. Even if you only sit down for a few minutes every hour, it will help. Pushing yourself to the limit is likely to end up affecting your health.

Use the tips in this section, which may help to prevent exhaustion.

## Planning time for you

Put aside regular times each day (several five to 10-minute sessions and possibly one longer session) when you know you can do what you like. Just have a cuppa, read the paper or go outside and get the post. Organise other people to sit with the person you are caring for if necessary. Try not to feel guilty about doing this. You really do need the time to renew your mind, body and spirit. Don't use this time to pay bills, do shopping or clean – you need to get away from all your jobs.

Make a list of 10 things you love to do and plan a different activity each or every other day. Catch up with a friend or family member for lunch and a chat. Talk about things other than your caring role. Research has shown that having support from those close to you is extremely important to the carer as well as the person with cancer. Do

something physical – take a walk or drive, swim, do a yoga class or some work in the shed. Use the time to relax in whatever way you most enjoy: watch a movie or sports, read a book or listen to music.

Discuss with the person you are caring for when might be the best time for you to do something for yourself. It may be when they nap in the afternoon, or when visitors are around to help.

As hard as it will be at times, try to really involve yourself in whatever activity you have chosen for your time out. If you keep thinking about what you could be doing to help the person you are caring for, your mind is not getting the rest it needs. You may need to look at putting some joy back into your life. The following tips may not be possible in all situations but they could be helpful for some carers:

- Plan a holiday for when the person you are caring for feels better. Research it together, plan what you will do and how much fun it will be.
- Take up a new hobby, something you have always dreamt of doing – it will give a real boost to your self-esteem and wellbeing.
- Plan a weekly massage (if your budget allows) or ask a friend to give you one for free! Also, ask if these services are available at the hospital.
- Ask a few close friends to come on a regular weekly or monthly outing together. It could be to an art gallery, the museum or a movie.
- Set aside time with the person you are caring for to do an activity together. Make a rule that you try not to talk about their cancer or treatment during this time. For example, watch a movie, try doing a crossword together, play cards or read the same book.
- Go for a drive or take a walk to your favorite spot.
- If you have grandchildren, nieces, nephews or your own young children, spend some time with them and get some cuddles: they are sure to make you laugh and feel good!

- Watch a funny movie, reread one of your favorite books or listen to some of your favorite music.

**'At 59 I became a fitness instructor as it had always interested me. I now go out in the morning at 5.30 am and am back by 9.30 am to help Max through his morning routine. I do a workout for myself as well as instructing others about their fitness and health. I love it.' – Jess, age 61**

## Staying fit and healthy

With the added stress of caring for someone with cancer you can easily become run down. It is very important to stay aware and listen to your body's needs. If you are someone who has past or present medical problems you need to be extra careful that you don't neglect what is needed to keep you well. Don't be tempted to ignore symptoms because you are afraid of what they might be and it may take you away from your caring role. You need to feel strong in both mind and body to carry out all the demands on you as a carer. This means:

- Eating a regular well balanced diet – many carers say that they forget to eat because they are too busy doing other things. You may need to carry some healthy snacks with you if the person is in hospital.
- Take regular exercise – whatever appeals to you and is possible. Walking, running and swimming are good if you can leave the house. If not, try an exercise DVD at home (yoga, tai chi or Pilates). It doesn't have to be for long (15 to 30 minutes) but it can help you feel more relaxed.
- Try to get enough sleep. You may be able to nap during the day at the same time the person you are caring for does. If you are having trouble sleeping, take a warm bath, or read or listen to some relaxing music before bedtime.

- Find a GP who you trust and can maintain good contact with if you need help.
- Build in a proper health check program for yourself. For example, you may need regular blood pressure checks or blood sugar checks. Also, don't forget to have your regular screening tests such as Pap test, mammogram and bowel checks.
- Limit the amount of alcohol you drink and avoid drugs that are not prescribed by your doctor. Although they may help you sleep or feel better at the time, long term, too much alcohol and recreational drugs can affect your health.
- See your doctor if you notice any changes in your health. Weight changes, aches and pains, bowel and urinary problems, sleep changes and feeling tired and low in mood all the time are all possible when you are using up a lot of energy caring for another person.

If you are someone who has medical problems or cancer, you may need to get some extra support so that you can properly care for yourself. The person you are caring for also needs to be made aware that you must take time to attend to your own medical problems. If you don't, your health is going to suffer and you will not be able to help them.

*'I ignored my pain and other symptoms for quite a while because I was worried about who would look after Jen. Even when I got help and had to go into hospital for a short time I was still worrying about what will happen to her, will she eat well if I am not there and what if she falls. Caring never ends. I had to learn to think a little more about me.'*

*– Frank, age 62*

## Leaning on close family and friends

Most close family and friends will want you to ask them for help and support. There may be times they just don't know how to best help you, so if you can guide them it will help a lot. The more help you have, the less stress you feel. It will allow you to focus on those tasks that you feel will support the person with cancer the most.

- Make a list of the things that will help you most – help with cooking, cleaning, shopping or school runs. Ask family and friends what they can help out with.
- You or a friend can make a 'book of vouchers' to hand out to friends and family. Each voucher has a task on it for them to do such as 'Cook meal Thursday', 'Cleaning Friday', 'Shopping Tuesday', 'Sit with Bill Thursday morning' or 'Mow the lawn at the weekend'. Each person can take a voucher and carry out that task for the week. People can swap their vouchers if necessary.
- Don't be afraid to call people at short notice for help. If they are busy they will let you know and may suggest someone else.
- Talk to friends and family about how you feel. Being a carer can make you feel very isolated and lonely at times. Others may not realise how much you are doing or how you feel.
- Organise a family meeting to discuss your needs and expectations.

## Finding support outside close friends and family

Not everyone feels comfortable looking for support from people they don't know. However, many carers find it a great help to talk with someone outside close friends and family. You may express feelings and thoughts that you don't feel able to with those so close to you.

There are several types of support available to both the person with cancer and their carer. Cancer Council Victoria offers telephone and Internet support groups and can help you find a local support group in

your area. We also offer Family Cancer Connect, where you can speak to a trained volunteer who has been in a similar situation.

For more information, visit our website [www.cancervic.org.au](http://www.cancervic.org.au) or call the Cancer Council Helpline on 13 11 20. Also read the section titled 'Help and support'.

## Allowing for bad days and looking for the good

Some days you may feel so upset, stressed, sad, angry or frustrated that you don't know how you will get through the next hour. Bad days will happen! And there may be a run of a few days or sometimes weeks when everything seems to be going wrong.

The person you are caring for may be suffering severe side effects from treatment and you feel you do not know what is going on. There may be more bad news about their **diagnosis** or they may feel very negative and low in mood, which rubs off on you. Problems within the family may crop up, adding to your stress. During times like this you are likely to become exhausted and anxious about everything. You may even feel unwell. You could be wondering if things will ever improve.

Even on days when nothing major goes wrong you may still feel very down. Looking after someone with cancer is difficult. It can often be very hard to find something positive in your life. However, many carers say by trying to look at things differently you can sometimes see a positive side. Finding positives can help you feel better and be more able to cope with the bad days. The following suggestions may help you to focus on things in a different way.

- Try to focus on what can be done rather than what can't be done.
- Feel a sense of satisfaction and pride in how you have coped with the caring role.
- Small improvements in the person you are caring for can become the source of major happiness some days.

- You may have grown closer to the person you are caring for and discovered things about each other that have given you both a lot of joy.
- You may feel fortunate to have your close family and friends provide you with the love and support you need.

## Feeling like you are being taken for granted

Some carers say that they have days when they feel they are not appreciated and are being taken for granted. The person you are caring for may not realise that they are making you feel like this.

They may become used to you doing everything for them. Once they are more able, they may continue to let you tidy their mess, ensure medications are taken on time or organise social events. It is important to find out the person's self-care abilities during their illness. Ask your **health care team** for their input at your next appointment. These abilities can change daily, so it can be hard to know whether or how much to push! However, encourage them to do as much as possible for themselves.

If they are struggling with a task, let them know you are there to help. You want to create an environment where they feel safe and independent, but able to ask for help.

# What happens afterwards?



**Carers reach the end of their caring role at some point.** Some people decide they can no longer be a carer and opt out. The person you are caring for may recover, which will affect both of your lives. Sometimes, the caring role ends when a person dies.

## When caring doesn't work out

Sadly this can occasionally happen. Your role as a carer may become too difficult to cope with. Past problems in the relationship may now seem even more difficult to change.

Before making a decision about ceasing to care for someone, it may help to get some professional counselling either alone or with the person you are caring for. Over time there may be a way to work things out. If not, then you will still be able to get some advice on how to best make the move with the least amount of stress to you both. Ask your GP or call your local Cancer Council Helpline for information on how to get a referral to a counsellor.

## When your role as a carer is no longer needed

There will come a time when you are not needed so much in your caring role. Hopefully, this means that the person you are caring for is getting better. Their treatment has worked and they are now trying to resume their 'normal' life. This means you will need to return to an active and full life. For some people this can be very hard. The less you are needed to help, the more you may start to feel a bit lost and 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 they are unlikely to be aware that you are feeling hurt. They may only see that the more they can do for themselves, the more it frees you up to do your own thing again.

You may think that you can slip back into your day-to-day life as it was before you became a carer. However, it isn't always this simple and many people say that you never get back to the 'normal' daily living they had before. You find a new way of living, as does the person who had cancer. It is a 'new normal'! You may have to return to work or resume other responsibilities that you had put on hold while you were in your caring role. It can feel a bit overwhelming.

Other people may think that all is okay now that the person has finished treatment: you must be so happy and excited about getting your life back. But it may not feel like this at all. You may feel you are still 'on call' for the next setback. It can be very difficult to just pick up where you left off before you began your role as a carer.

*'After my carer role was over I saw my whole world through a different lens.' – Jenny, age 58*

## Give yourself time

It is important to give yourself time to adjust once the person you are caring for is getting back into their life again. Don't expect too much

from yourself. Do things at your own pace and not at everyone else's. Everyone's situation will differ.

You may have moved from your own home to care for the person. Even though you may be pleased to have your own space back at first, it may feel strange and lonely to go back to your own home.

If you were caring for your partner you will both be facing new challenges as you create a different life together. You may be reluctant to share your feelings of uncertainty and loss with your partner. You may worry it will upset them or worry things will get worse again down the track. But you could be surprised about how much they are struggling to feel good about moving on. Chatting together can ease anxieties and help the transition into another way of life.

You may find it helps to read Cancer Council's booklet, *Life after Cancer – A Guide for Cancer Survivors*. Although this booklet is written for the person who had cancer, the information will help many carers as well.

## If the person you are caring for dies

Sadly for some people, the person you are caring for may have a cancer that is too advanced to cure. This is usually devastating for everyone involved. You may have been caring for the person for a very short time before they die. Others may have been in their caring role for some weeks, months or even years. No matter how long you have been caring for the person when they die, most people will feel a huge sense of loss and grief. You may also feel a sense of relief. Don't feel guilty about this. It is very natural to feel like this, especially when you may have watched them suffer for some time.

For some people, trying to adapt to life without the person you were caring for can be almost too much to cope with. Losing your partner, a child or good friend is devastating and will change your world. You may feel like you no longer fit into society or even want to. Everywhere

you go, whoever you speak with, is a reminder of what you have lost and the things you have missed out on.

If it is your partner who has died, seeing other couples going out to dinner, talking about going on holiday or planning for the future will hurt. You are no longer seen as part of a 'couple'. People may even refer to you as single. This can feel very strange and be extremely upsetting.

If you have lost a child, seeing other children enjoying their lives at the age your child would be now can be very painful.

If you would like more information and support, call the Cancer Council Helpline on 13 11 20.

# Help and support



**This section provides some useful ideas and sources of information for carers.**

## Questions to ask the health care team

You may like to take all or some of these questions when you meet with the health care team.

- Who do I contact for support for carers?
- Are there support groups for carers?
- How do I find out about financial assistance for carers?
- Where can I access counselling services?
- Where can I find information about sexual problems my partner and I are having?
- Where can I find information about complementary and alternative therapies?

## Bereavement support

GriefLine offers support to people who are experiencing grief as a consequence of a significant loss in their lives. Telephone 9596 7799.

Palliative care services provide voluntary support workers who will visit regularly throughout the illness and immediately after the death. Telephone 9662 9644

Centrelink has produced a useful booklet titled *What to Do When Someone Dies*. For a free copy, visit your local Centrelink office or telephone 13 23 00.

## Cancer Council Helpline

This is a confidential Cancer Council service where you can talk about your concerns and needs with a cancer nurse. The cancer nurse can send information and put you in touch with services in your area. Telephone 13 11 20 Monday, Friday, 8.30 am – 8 pm.

## Cancer Connect and Family Cancer Connect

This is a Cancer Council peer support program. It connects people who have had cancer, or who are caring for someone with cancer, with volunteers who have been in a similar situation. It is free and confidential. You will be able to talk to someone who understands what you are going through. They know what it is like to have cared for a loved one with cancer and how it affects your life. All volunteers are trained and are supported by a program coordinator and cancer nurses from our Cancer Council Helpline. Telephone 13 11 20.

## Carers Advice Line / Carers Victoria

Carers Victoria is the statewide voice for family carers, representing and providing support to carers in the community. Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail.

The Carers Advice Line provides information and support for people caring for people with illness and disability. They also have information for young carers. Telephone 1800 242 636.

## Centrelink

Carer allowance and carer payment income support may be available for people who provide daily care to people with a severe medical condition. Call 13 27 17 or visit [www.centrelink.gov.au](http://www.centrelink.gov.au) for more details.

## Chronic Illness Alliance

The Chronic Illness Alliance has information about work, welfare and wills to help people deal with legal issues around health and life changes. It also has information about 'Utilitease' so people can find out how to access energy concessions, relief grants and other assistance. Visit [www.chronicillness.org.au](http://www.chronicillness.org.au) or telephone 9882 4654.

## Counselling

Talk to your GP about specific concerns, for example, your feelings about being a carer, sexuality and sex life, and relationship problems. They may suggest that you get a referral to a professional counsellor. You may be able to get some help with paying for between six and 12 counselling sessions through Medicare, but you need to discuss this with your GP first. You can also call the Cancer Council Helpline on 13 11 20 or visit [www.carersvic.org.au](http://www.carersvic.org.au) to find out more.

## Financial Assistance

Centrelink can provide information on Commonwealth Government disability, sickness and carers' payments. Telephone 13 27 17.

The Cancer Council's Financial Assistance Program can provide one-off financial assistance for people with cancer. Telephone 13 11 20.

## Funerals

The Australian Funeral Directors Association can provide a list of funeral directors and estimates of funeral costs. Telephone 9859 9571.

## Your general practitioner (GP)

If you don't have a GP, call your local health centre for information about GPs in your area. Your GP can play an important role in helping support you as a carer.

## Home help

Local councils provide a range of community and in-home services, including foster care for children, meals on wheels, housekeepers and **respite care**. Telephone your council (listed by council name in the White Pages).

## Home visitors

DoCare (see the White Pages for the service in your region) and the Australian Red Cross Society (9685 9999) can organise home visitors. Other charitable organisations may be able to help, as may a local Cancer Support Group. Telephone 13 11 20.

## Legal advice and information

See your solicitor or call the Cancer Council Helpline for a list of community legal centres. If you do not have a solicitor, contact the Law Institute of Victoria's Legal Referral Service on 9607 9550.

## Lifeline

Lifeline can provide information, over the telephone counselling and referral for people with health and family-related problems. Telephone 13 11 14 (24 hours, seven days).

## Living with Cancer Education Program

This is a course for people with cancer and their families and friends, held at hospitals and community organisations throughout Victoria. Ask your hospital's social worker for details or contact the Cancer Council Helpline on 13 11 20.

## Multilingual Cancer Information Line

The Multilingual Cancer Information Line is a free and confidential Cancer Council service. You can call and speak to a specially trained nurse with the help of an interpreter. It is for people with cancer, and people who are close to them. People who speak any language can use the service. For more details see the inside back cover.

## Palliative care services

Palliative Care Victoria provides information about palliative care and **hospice** facilities and services. Telephone 9662 9644.

## Respite and holiday programs

Call the Cancer Council Helpline on 13 11 20 for information about holiday and respite homes. Your local council can also tell you about services available in your area. Telephone your council (listed by council name in the White Pages). Your local palliative care group or hospital social worker will also be able to advise you.

## Social and pastoral care workers

For information, support and advice, contact your hospital and ask for the social worker or patient services unit. Your local community health centre may also have a social worker on staff, or be able to refer you to a social work service. Pastoral care workers are able to discuss practical and spiritual concerns (from all religious and non-religious viewpoints).

## Support groups

The Cancer Council Helpline can refer you to a support group in your area. Telephone 13 11 20.

## Other useful contacts

Disability Discrimination Legal Service: 9602 4877; 1800 651 275

Equal Opportunity Commission of Victoria: 9281 7111

Human Rights and Equal Opportunity Commission: (02) 9284 9600

# Useful websites



The following websites will be useful for carers who want to find out more about specific types of cancer and carers issues.

## Carers Victoria

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

## Young Carers Victoria

[www.carersvic.org.au/AboutCarers/About\\_Young\\_Carers.html](http://www.carersvic.org.au/AboutCarers/About_Young_Carers.html)

## The US National Cancer Institute

When someone you love has advanced cancer: <http://www.cancer.gov/cancertopics/When-Someone-You-Love-Has-Advanced-Cancer>

When someone you love is being treated for cancer: <http://www.cancer.gov/cancertopics/When-Someone-You-Love-Has-Advanced-Cancer>

Caring for the caregiver: [www.cancer.gov/cancertopics/caring-for-the-caregiver](http://www.cancer.gov/cancertopics/caring-for-the-caregiver)

## The American Cancer Society

How to care for a loved one with cancer – and yourself: [www.cancer.org/docroot/MLT/content/MLT\\_3\\_1x\\_Caregiving\\_-\\_How\\_to\\_Care\\_for\\_a\\_Loved\\_One\\_With\\_Cancer\\_-\\_And\\_Yourself.asp](http://www.cancer.org/docroot/MLT/content/MLT_3_1x_Caregiving_-_How_to_Care_for_a_Loved_One_With_Cancer_-_And_Yourself.asp)

# Glossary: what does that word mean?

This explains some of the words listed in this booklet.

**advanced cancer** Cancer that has spread (metastasised) and/or is unlikely to be cured.

**alternative cancer therapy** Approaches to cancer treatment, often unproven and sometimes harmful, used instead of conventional medical cancer treatments.

**carer** A person who provides physical and emotional support to someone who is ill or disabled.

**chemotherapy** The use of special drugs to treat cancer by destroying cancer cells or slowing their growth. Chemotherapy can also harm normal cells, but they are usually able to repair themselves.

**complementary therapy** Therapy used alongside medical treatment to help manage symptoms and side effects.

**diagnosis** The process of finding out about a person's illness by considering their signs and symptoms, medical background and results of diagnostic tests.

**depression** Continuous very low mood. Other symptoms of depression can include changes in your appetite or weight, sleeping problems and feelings of hopelessness. Depression is different from sadness; it is an illness that may need treatment with counselling or medication.

**enduring power of attorney** A person with legal authority to act on behalf of the person they are caring for on all financial matters.

**health care team** A group of health professionals who may be responsible for managing the person you care for (doctors, nurses, dietitians, physiotherapists, social workers, etc.).

**hospice** A centre that provides comprehensive care for people with incurable disease. This includes inpatient medical care, symptom management at any stage of the cancer, respite care and care of the dying person if they are not able to die at home. Hospices also offer day-care facilities and home visiting teams.

**radiotherapy** The use of radiation, usually x-rays or gamma rays, to destroy cancer cells or injure them so that they cannot grow or multiply. Radiotherapy can also harm normal cells, but they are usually able to repair themselves.

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

# Your comments

We would appreciate your feedback on the information in this booklet. Please complete and return to:

Cancer Information and Support Service  
Cancer Council Victoria  
Carlton Vic 3053  
or contact [ciss@cancervic.org.au](mailto:ciss@cancervic.org.au) or call the Cancer Council Helpline on 13 11 20

Are you caring for someone with cancer or a cancer patient or survivor?

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Was the information helpful?

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If yes, what was most helpful? If no, what else would you have liked to know about?

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Any further comments

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# Cancer information in other languages

خط معلومات السرطان باللغة العربية

إتصلوا بالخط  
للتحدث الى ممرضة عن مرض السرطان  
باللغة العربية على لرقم **9209 0160**

Polskojęzyczna Infolinia na Temat Raka

Aby móc porozmawiać z pielęgniarką na temat raka w języku polskim należy dzwonić pod numer **9209 0165**

廣東話癌症信息專線

用廣東話與護士談論癌症  
請致電 **9209 0161**

Информационная линия по раковым заболеваниям на русском языкеЕсли вы хотите поговорить по-русски с медсестрой о раковых заболеваниях, то позвоните по номеру **9209 0166**

Ελληνική Γραμμή Πληροφοριών για τον Καρκίνο

Για να μιλήσετε σε μια νοσοκόμα σχετικά με τον καρκίνο στα Ελληνικά, τηλεφωνήστε στο **9209 0162**

Línea telefónica de Información sobre el Cáncer en el Idioma Español

Para hablar con un(una) enfermero(a) en español llame al **9209 0167**

Linea Informazioni sul cancro in italiano

Per parlare del cancro con un infermiere in italiano chiama il **9209 0163**

Đường dây Chỉ dẫn về bệnh Ung thư bằng tiếng Việt

Nói chuyện với y tá về bệnh ung thư bằng tiếng Việt, gọi số **9209 0168**

普通话癌症信息专线

若要用普通话与护士讨论癌症  
请电 **9209 0164**

For other languages please call 9209 0169. Tell us which language you speak and an interpreter will help you talk to a nurse. To speak to a nurse in English, call 13 11 20.

INTERNET: For information in a range of languages please visit our multilingual website at: [www.cancervic.org.au/other\\_languages](http://www.cancervic.org.au/other_languages)



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