



# Emotions and Cancer

A guide for people with cancer,  
their families and friends

Coping  
with cancer

Cancer Council Helpline

**13 11 20**



## Emotions and Cancer

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First published July 2002. This edition April 2013.

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ISBN 978 1 921619 76 2

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

### Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Publications Working Group initiative.

We thank the reviewers of this booklet: Dr Lisbeth Lane, Senior Clinical Psychologist, University of Wollongong, Wollongong Hospital, NSW; Kim Hobbs, Social Worker, Gynaecological Oncology, Westmead Hospital, NSW; Dr Megan Best, Palliative Care Physician, Greenwich Hospital, NSW; Deborah Ball, Coordinator of Direct Support Services, Cancer Council SA; Sandy Hutchison, Executive Manager, Cancer Counselling Service, Cancer Council QLD; Jill Adams, RN, Helpline, Cancer Council WA; and Ksenia Savin, Cancer Connect Volunteer and Consumer.

We would also like to thank Cancer Council Queensland for kindly permitting its booklet *Coping with Cancer* to be used as source material for this edition.

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### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professional's advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

### Cancer Council Australia

Cancer Council Australia is the nation's peak non-government cancer control organisation. Together with the eight state and territory Cancer Councils, it coordinates a network of cancer support groups, services and programs to help improve the quality of life of people living with cancer, their families and carers. This booklet is funded through the generosity of the people of Australia. To make a donation and help us beat cancer, visit Cancer Council's website at [www.cancer.org.au](http://www.cancer.org.au) or call your local Cancer Council.



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# Introduction

Everyone with cancer copes in their own way. The diagnosis may cause you to feel a range of strong emotions, such as fear, anger, disbelief, sadness, guilt, loneliness, loss of control or distress. Each person has their own way of coping, and these are all natural reactions to such significant life-changing news.

A cancer diagnosis can also affect relationships with family, friends and carers, so this booklet provides practical tips about how to talk to others about your diagnosis, your treatment and how you're feeling. You'll find some suggestions for working together to adjust to these challenges.

There is also information for people caring for someone with cancer, with details on available support services.

It is important to remember that there is no right or wrong way to feel when you are faced with cancer – just as there is no one right way to cope. Use this booklet to remind yourself of the things you are doing well and to give yourself some fresh ideas for facing the future.

You don't need to read this booklet from cover to cover – just read the parts that are useful to you.

Cancer Council Helpline **13 11 20** can arrange telephone support in different languages for non-English speakers. You can also call the Translating and Interpreting Service (TIS) direct on **13 14 50**.



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# Dealing with the diagnosis

You may feel shocked when you are told you have cancer.

It is often difficult to take in the diagnosis immediately – you might hear the words but not believe them. There are many reasons for this shock: cancer is a serious disease, and most people feel afraid and unsure about treatment, side effects and the likely impact on family and work.

Cancer can also feel like a threat to your way of life. You may wonder if you will be the same person as before, if you will be able to do the things you usually do and if your relationships will change.

Having these thoughts and feelings is a natural reaction to a difficult situation. Knowing this can help you find ways to manage these feelings.

Over time, you may find that your strong feelings about cancer fade. Although your life has changed in some ways, in other ways it goes back to a more regular pattern and you feel more or less like your usual self. However, this may not happen, instead you may continue to feel worried and upset and these feelings can interfere with your life.

## Common reactions

For many people, the first few weeks after they are diagnosed with cancer are very stressful. You may have trouble thinking clearly, eating or sleeping. This can last from several days to several weeks. It's common to feel that you are on an emotional rollercoaster.

## Feelings you may experience

<b>fear</b>	It's frightening to hear you have cancer. Most people cope better when they know what to expect.
<b>anger</b>	You may feel angry with health care professionals, your God, or even yourself if you think you may have contributed to the cancer or a delay in diagnosis.
<b>disbelief</b>	You may have trouble accepting that you have cancer, especially if you don't feel sick. It may take time to accept the diagnosis.
<b>sadness</b>	It is natural for a person with cancer to feel sad. If you have continual feelings of sadness, and feel sleepy and unmotivated – talk to your doctor – you may be clinically depressed.
<b>guilt</b>	It is common to look for a cause of cancer. While some people blame themselves, no-one deserves to get cancer.
<b>loneliness</b>	It's natural to feel that nobody understands what you're going through. You might feel lonely and isolated if your family and friends have trouble dealing with cancer, or if you are too sick to work or socialise with others and enjoy your usual activities.
<b>loss of control</b>	Being told you have cancer can be overwhelming and make you feel as though you are losing control of your life.
<b>distress</b>	Many people, including carers and family members, experience high levels of emotional suffering as a direct result of a cancer diagnosis.

## tip

If you are having trouble dealing with any of your emotions, consider talking to family and friends, seeking professional help through a counsellor, psychologist or psychiatrist, or joining a support group (see page 38).

## Worry

After diagnosis the next step is likely to be treatment – which could be one event, such as surgery, or a series of events such as surgery, chemotherapy and radiotherapy. Each of these will have its own demands, including medical appointments, tests, physical and emotional side effects, and changed routines.

While it can be useful to plan for what lies ahead, worrying about the future can make you feel even more distressed. Instead, try to focus on the most immediate concern, directing your effort where it is needed right now. After you have dealt with what is happening now, you can then face the next step.

Try to take advantage of the breaks between treatments, tests or appointments, or when you are less troubled by the effects of your treatment. These breaks give you a chance to recharge, both physically and emotionally.

“Some mornings I would wake up feeling like I didn’t even want to get out of bed, that real ‘down in the dumps’ feeling. But once I got started, that feeling would kind of lift and things would seem okay.”  *Elisa*

## Finding hope

Having cancer doesn't mean you have to lose hope. The outlook for many cancers is improving constantly. Some cancers can be treated successfully, while others can be controlled. If the cancer can't be controlled, symptoms can be relieved to make life more comfortable. It is still possible to live well.

Often the first thing people ask when they are told they have cancer is, 'Am I going to die?'. Talk to your doctor about what the diagnosis means for you and what the future may hold. Knowing more about your illness may help ease this fear.

### Feeling down or depressed

Many people feel low or depressed after a cancer diagnosis, during treatment or when they are recovering. Don't be surprised if you feel unhappy at times.

But there is a difference between feeling unhappy and being depressed. You may be depressed if you are in a low mood for most of the time, or have lost interest and pleasure in most things for more than two weeks.

Depression often won't go away by itself, but tackling it early may mean that you can deal with problems quickly and avoid symptoms becoming worse.

There are also many effective treatments for depression, including both medication and non-medication options.



# Physical effects

The physical effects of cancer and cancer treatments may affect your emotions in different ways. People who experience physical symptoms, such as fatigue, nausea and pain, are often more likely to have emotional distress. How long these physical effects last varies from person to person.

## Fatigue

Feeling exhausted and lacking energy for day-to-day activities (fatigue), is the most common side effect of cancer treatment. It can be caused by the physical and emotional effects of diagnosis and treatment. Fatigue differs from normal tiredness as it often doesn't go away with rest or sleep. Fatigue can also be linked to low moods or depression, so it may help to talk to a health professional about available treatments.

### tips

- Plan to do things at the time of day when your tiredness is least severe. Keeping a journal may help you keep track of your 'good times'.
- Research shows that gentle exercise reduces tiredness, helps preserve muscle strength and gives a sense of normality.
- Let your doctors or nurses know if you are having trouble sleeping.
- Have a short rest during the day. Naps can refresh you without making it hard for you to sleep at night.
- Try to spend some time outside in the fresh air each day.

## Pain

People can experience pain from cancer and its treatment. If you are feeling anxious, this can make pain more difficult to handle.

If you are in pain, discuss it with your doctor. There are many treatments now available to help relieve pain.

“ I found the decision to take morphine regularly difficult. Having made it, I have been taking the slow-release tablets for 18 months with no appreciable side effects. Without the morphine, the pain would be too debilitating for me to continue doing all the things I do now. ” *Pete*

## Loss of appetite

You may not feel like eating if you are unwell, stressed or experiencing the physical effects of cancer treatment. You may also lose your appetite if you're anxious or depressed. This may make you lose weight and strength.

Good nutrition, or giving your body the food it needs to keep working properly, can help you cope better with the effects of cancer and treatments. It can give you more energy, make you feel less tired, and maintain your wellbeing.

Contact Cancer Council Helpline **13 11 20** for information and ideas on managing fatigue and cancer pain or finding new ways to improve your nutrition.



## Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not.

Give yourself time to adapt. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

For practical suggestions about hair loss and other physical changes, call Cancer Council Helpline.

### Look Good...Feel Better program

Cancer treatments, such as chemotherapy and radiotherapy, can sometimes cause side effects such as hair loss and skin irritation. These changes can make you feel self-conscious.

Look Good...Feel Better is a free two-hour program for both

men and women to teach them techniques using skin care, hats and wigs to help restore appearance and self-esteem during and after treatment.

Call **1800 650 960** or visit [www.lgfb.org.au](http://www.lgfb.org.au) for more information and to book into a workshop.

“ I did the Look Good...Feel Better program before treatment. It helped me prepare mentally for losing my hair during chemotherapy. ” *Ann*

## Sexuality, intimacy and cancer

Sexuality is about who you are and how you feel as a man or woman. It is the feelings and characteristics that make up your sexual identity. This means different things to different people.

This information has been written to be inclusive of all sexual orientations, whether you have a partner, are between partners or have chosen to be single.

Having cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, the way you and your partner communicate, the way you see your changed body, and your self-confidence. Knowing the potential challenges and addressing them may help you adjust to these changes.

While sexual intercourse may not always be possible during and immediately after treatment, closeness and sharing can still be part of your relationship. If sex is painful, or you have doubts about the safety of sexual activity, check with your doctor. Counselling, either individually or together, can provide ways to discuss cancer and how it affects your relationship with your partner.

Intimacy isn't all about sex. Sexual intercourse (or penetrative sex) is not the only way of showing love and affection or expressing sexual feelings. Holding, cuddling, kissing and caressing are also important ways of being intimate.





# Your coping toolbox

Most of us have different ways of coping with difficult situations that we have learned over a lifetime.

These could include:

- seeking more information
- trying to fix the problem
- having a laugh to feel better
- distracting yourself from unhelpful thoughts and feelings
- talking things through to try and make sense of what is happening
- denying the circumstances.

How you cope depends on the type of situation you are facing, your personality, upbringing, role models and what has worked in the past. You might find your usual ways of coping are not enough to handle the different challenges caused by cancer. There is no single best or right way of coping, but having a few different ways may help you feel a greater sense of control and confidence.

Think of ways of coping as being tools in your toolbox. Different jobs generally need different tools. If one tool doesn't fit the job, you need to try another one. It's helpful to consider several strategies or 'tools' for coping with a cancer diagnosis and treatment.



Some strategies are generally unhelpful for any situation if used too much, such as, avoiding the problem entirely, self-blame, alcohol or drug use, overeating, or gambling.

## Tools to help you cope



### Gathering information

What to do with all the information you are given and how to organise it so that you can find it when needed.



### Looking after yourself

Ideas to nurture yourself and reduce the stress that cancer can cause physically and emotionally.



### Complementary therapies

Different ways to cope with treatment side effects that may help to increase your sense of control over what is happening and help maintain your wellbeing.



### Helpful thinking

How to deal with difficult, unbalanced or unrealistic thoughts, which often occur in stressful situations.



### Making decisions

Suggests different ideas to try when you are faced with making difficult choices in a stressful situation.



## Gathering information

Once diagnosed, there is a lot of information to take in – and well-meaning family and friends may give you even more. Too much information may leave you confused about what to do. Instead, you may need more accurate information or a way of dealing with what you already have.



### Get organised

Start a filing system for all your test results, information and records.



### Keep a diary

This may help you to keep track of events and highlight where information may be missing. This will also be a useful, accurate record in the future (especially if you are seeing different professionals in different locations).



### Take time to work out what specific information you need

It may help to write down your questions and to put them in order of how important they are right now. For example, you may know what treatments are available to you but you may not know the specific pros and cons of each treatment for your situation.



### Involve other people

Consider asking people you trust to help gather and make sense of new information.



### Consider different sources of information

Look at websites, books and different organisations. Take care with cancer information from the internet as some of it is unregulated and poor quality. See page 44 for useful and reliable websites.



### **Talk to your doctor – specialist or general practitioner (GP)**

If you are unsure or confused about certain information, it can help to talk to your doctor. Doctors are usually happy to explain things and point you in the right direction. Consider writing your questions down beforehand so you remember what you want to ask when you see your health care professionals. You can also direct questions you have to the Helpline.



### **Organise and update your affairs**

Many people with cancer review their insurance policies and update their will. This doesn't mean you have given up. Everyone needs to do these things and once done you will have less to worry about.

## **Cancer Council library\***

Following a cancer diagnosis many people look for information about new types of treatment, the latest research findings and stories about how other people have coped. Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you. Call the Helpline on 13 11 20 for more information.

*\* Not available in Victoria and Queensland*

**tip**

It can help to take a close family member or friend to consultations with your doctor to take notes, ask questions and to help you remember the information you are given.



## Looking after yourself

Cancer can cause physical and emotional strain. Some days you may feel better than others. Nurturing yourself can enhance your wellbeing and reduce stress during this time.



### **Eat well**

Eating well gives your body better fuel to help it cope with the stress of illness and treatment.



### **Be active**

Physical activity has been shown to lift mood, lower blood pressure, improve sleep and reduce stress. It is also an important way to manage fatigue – helping you to feel more energetic and less tired. Even a short walk daily can help.



### **Make time for yourself**

Even though life may be very busy, it is important to make time each day just for relaxation and enjoyment. Think about things you do (or have done in the past) that help you to relax and feel good.



### **Deal with feelings**

Blocking out or avoiding your emotions may create extra pressure, leading to increased frustration and anxiety. Talking about the problem with your partner, friends, or members of your cancer care team may be more effective and less tiring, helping to make sense of your feelings as well as lighten your load. You can also call the Helpline on 13 11 20 to talk about your issues confidentially.



### **Sort out issues**

A cancer diagnosis may happen in the context of other life stresses such as financial problems, work-related issues, relationship concerns and family stresses. Dealing with other sources of stress in your life may help you cope better with the additional burden of cancer treatment.



### **Stay connected**

Staying connected with the world through work, hobbies, or time spent with family and friends, may help you see a life outside of cancer and provide time out from your worries.



### **Tap into spiritual beliefs**

Some people find meaning and comfort from their faith and spiritual practices, such as meditation or prayer. Others may experience spirituality more generally. For some people the experience of cancer challenges their beliefs. It may help to talk to a spiritual leader or pastoral care worker about your feelings.

## **Recognising signs of stress and anxiety**

Your body releases adrenaline, your heart beats faster, your blood pressure goes up, your breathing is shallow and fast, your hands get sweaty, and your mouth gets dry. These are natural responses and

useful when dealing with emergencies, but not very helpful in dealing with cancer. For ideas on how to learn to reduce these reactions, see complementary therapies, page 18.



## Complementary therapies

Complementary therapies are treatments that may help you cope better with side effects such as pain. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.



### Relaxation and meditation

Both of these therapies can help reduce anxiety, stress, pain and depression. Studies on meditation have shown it enhances wellbeing and can reduce anxiety. Relaxation usually includes slow breathing and muscle-loosening exercises to physically and mentally relax the body.



### Counselling

Through discussions with a counsellor or psychologist, you can identify problems and explore ways of resolving negative thoughts and feelings that impact on your health and day-to-day life. Counselling allows you to express your emotions in a safe, objective environment and learn new coping skills.



### Hypnotherapy

Involves deep relaxation and is used to help people become more aware of their inner thoughts. This may help you to overcome mental blocks.



### Art therapy

Is a way of using visual art to express feelings. An art therapist helps you explore the images you have created to encourage understanding of your emotions and concerns.

Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your medical treatment. Some may even cause harm.

Contact Cancer Council Helpline 13 11 20 for more information about complementary therapies and alternative therapies or for a free copy of the meditation and relaxation audio CDs. These are also available to stream from [www.cancercouncil.com.au](http://www.cancercouncil.com.au).

## The mind-body connection

Mind-body techniques are based on the belief that what we think and feel can affect your physical and mental wellbeing.

When your emotions or mental state are under pressure, your physical body can be affected. Similarly, physical symptoms can have a negative impact on your mood and mental wellbeing.

Many complementary therapies focus on the mind-body connection in different ways.

Examples include counselling, support groups, hypnotherapy, relaxation, meditation, visualisation, art therapy and music therapy.

Studies show that mind-body techniques may reduce the symptoms and side effects of cancer, which can all affect mood and overall wellbeing.

They have also been shown to help people feel more in control of their situation, more relaxed and less fearful of the future.



## Helpful thinking

In highly stressful situations, thoughts happen very quickly and you may not even be aware of them. Your thoughts at this time can be unbalanced and unrealistic – that is, they may be overly negative, exaggerate your problems and underestimate your ability to manage your emotions. This can leave you feeling more upset and finding it even harder to cope.



### Notice your thinking

This is not always easy because thoughts are often quick and automatic. When you are feeling upset, it may help to stop and take note of the thoughts going through your mind.



### Write down your thoughts

Writing down your thoughts is helpful because it slows down your thinking and makes it easier to focus.



### Check your thoughts

If your thoughts are making you feel upset, ask yourself if the thoughts are correct, realistic or helpful at this time.



### Find helpful alternatives

If the thought isn't based on the facts, or realistic or helpful, try replacing it with a more helpful one. This may help you feel calmer and less worried.



### Coach yourself

For thoughts to be helpful they need to be balanced and believable. Encourage yourself through difficulties, rather than undermining yourself. Learn to be kind to yourself. Counsellors can teach you these techniques.

## Be realistic

A common belief is that the most important thing in coping with cancer is staying positive.

While it can help to be optimistic, this doesn't mean denying the reality that cancer is serious or frightening. Trying to put on a brave face all the time and avoiding anything negative is hard work, drains energy, and generally doesn't work well because the negative thoughts just keep coming back.

Pressure to be positive all the time can lead to people being afraid to discuss fears and feelings, which can make problems worse.

Try to be realistic about what is happening and talk to someone about your fears and concerns so you can better deal with them. Explaining your fears and concerns to those around you may also help you get the support you need.

## Dealing with recurring difficult thoughts

It is natural for people affected by cancer to find themselves going over and over the same distressing thoughts about the past or future. Ignoring these thoughts or trying to distract yourself may work well at first, but they will often return once you are no longer distracted – for example, in bed at night or early in the morning.

- **Identify where the thoughts come from** – When you notice unwanted thoughts check if they are the result of an underlying belief, such as 'I must do things perfectly at all times', 'the world should be a fair and just place', 'if I can't do everything I used to do I am useless', 'I am a burden to my loved ones'.

- **Imagine what you would say to others** – Holding on to recurring thoughts can lead to sadness. One way to challenge them is to think of someone you love and imagine what you might say to them if they felt the same way.
- **Check the reality** – Having noticed your thoughts, ask yourself if you are jumping to conclusions or exaggerating the negatives. If so, is there something you can do to change the situation or improve it?
- **Acknowledge small achievements** – Check if you are focusing on the difficult things and ignoring the little achievements or happy events that may also be occurring. Sometimes we notice the bad things that happen and don't notice the good. Writing down three good things that have happened to you each day may help. They don't have to be major events – just the everyday things that often go unrecognised.
- **Practice letting your thoughts come and go** – Thoughts are fleeting. Some we notice and many we don't. Practice letting your thoughts come and go without getting caught up in them, just like clouds floating across the sky (the Cancer Council Mindfulness CD may help you practice this, contact Helpline 13 11 20 for a free copy).

**tip**

Believing that it is possible to do something, even in the worst situations, is the first step in tackling any problem.

## Types of health professionals you may see

**Counsellor** – A counsellor’s education may range from a vocational certificate in counselling through to university level studies in psychology or social work. There is no standard of qualifications required. Counsellors listen to clients’ problems, offer support and strategies for dealing with problems. Counsellors cannot prescribe medication.

**Social worker** – A social worker is often trained to provide emotional support as well as advocate for the patient, offer practical and financial assistance and help people access support services. Social workers cannot prescribe medication. Check if there is a social worker at your cancer treatment centre.

**Psychologist** – A registered psychologist in Australia must complete four years of psychology at undergraduate

level, followed by either postgraduate studies in psychology or two years of supervised clinical practice. Psychologists, who specialise in counselling, use their understanding of the mind to guide clients through issues with how they think, feel and learn. They cannot prescribe medication. Check if there is a psychologist at your cancer treatment centre or ask your GP about other options.

**Psychiatrist** – A psychiatrist is a trained medical doctor who specialises in the diagnosis, treatment and prevention of mental illness. As well as discussing issues with patients, a psychiatrist may prescribe medication to help a range of emotional conditions. For example, if you are severely depressed, a psychiatrist can work through coping strategies with you and may prescribe antidepressants. You will need a referral from your GP.



## Making decisions

During cancer and treatment you are likely to be faced with the challenge of making difficult decisions. These could include the choice of treatment, how to involve or care for your family, returning to work, and what to do about finances.



### Take your time

Even with a cancer diagnosis, there is often time to consider your treatment choices. Generally, people make better decisions – and have fewer regrets later – if they have taken time to make sure they have enough information and considered all the possible consequences.

Ask your health care professionals to provide you with details about your treatment choices and the benefits and side effects of each treatment option.

Social workers can give you information about financial assistance and community supports that are available.



### Write it down

Organising your thoughts on paper can be easier than trying to do it in your head. Consider every option available to you. Make sure you have all of the options written down, for example:

**Option 1** – only surgery

**Option 2** – surgery plus other treatment(s)

**Option 3** – only radiation therapy

**Option 4** – active surveillance.



### List what is important to you

Write down all the pros and cons of each option and consider how important each of these are to you. You could rate how important each point is on a scale of 1–5, with five being very important and one being least important. To determine how important a point is, look at how it affects you and others in both the short and long term. Consider the burdens and the benefits of each option.



### Talk it over

Talk through the options with someone close to you, like your partner or a close friend. As most decisions will affect others in your life, it's also important to talk it through with people who will be affected so that their opinions are considered.



### Get expert advice

Find out all the facts first, then review your options and the points for and against each one with specialists in that area, for example, someone in your treatment team, a financial or legal advisor or a counsellor. Being certain of the facts may make the decision and consequences less overwhelming.



### Expect to experience doubts

Being unsure does not mean you have taken the wrong path. Reassure yourself that you made the best decision you could with the information you had at the time. Also, decisions are not always final – it may be possible to change your mind even after you have already started down a particular path.

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## A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. Alternatively, you may decide you would prefer to be treated by the doctor who provided the second opinion.



# The others in your life

Sharing news of your diagnosis can be difficult. You may feel uncomfortable talking about personal matters, or unsure how family and friends will react. You might want to protect your loved ones, but sharing the news can bring you closer together. Sharing your anxiety and fear may also help you feel stronger.

If you already communicate well with certain family members or friends, develop this bond. You may find that talking about cancer is not as difficult as you had first thought. Sometimes you may feel that nobody understands what you're going through. At a time when you need support, try not to shut others out.

## Should I tell others?

You will need to decide who you want to tell about the cancer diagnosis. It's up to you how much detail you give, but hiding your diagnosis probably won't work. Sooner or later, family and friends will learn that you have cancer either through changes in your appearance or by hearing it from others.

Telling others can also help prevent misunderstandings, put you in control of what information is given out and allow those who care about you to support you.

**tip**

Telling different people repeatedly about a cancer diagnosis can be emotionally draining. It may help to ask a trusted friend or family member to pass on the information and then provide regular updates via weekly phone calls or emails.



## Ksenia's story

Personally, I feel guilty if I vent or put my problems onto other people.

But it's important to know that you are going through an extremely difficult time and that your real friends and the people that love you are strong enough to take on your negativity and feelings of worthlessness.

My friends provided an emotional support guarantee.

Often when I had appointments, a friend would say, "I'll call you this evening to see how you went". That one line kept me going all day.

My other friend sent me a card every round of chemo with an inspirational quote, so every three weeks I would get a card in the mail. I began to look forward to getting them and it made my cancer journey a whole lot more manageable.

## How do I tell others?

Telling others about a cancer diagnosis can be difficult but a little preparation can help:

- When you feel ready, decide who to tell and what you want to say.
- Think of answers to possible questions but only answer if you feel comfortable. You don't have to share every detail.
- Choose a quiet time and place.
- Accept that the person you are telling may get upset. You may find yourself comforting them, even though you are the sick one.
- Call the Helpline if you find the prospect of telling people too overwhelming. You may just need to find the right words.
- Ask for help – family or friends could tell others if you can't.

## Other people's reactions

Sometimes you may come up against reactions from family and friends that seem insensitive or uncaring. Some people may avoid or withdraw from you, some may appear too positive or make light of your situation. These reactions may make you feel hurt, angry or frustrated. Try not to take their reactions as a sign that they don't care. It may be that they need more time to take in your diagnosis before they are ready to face it.

“ People usually don't mean to make things worse. Their reactions are likely to come from their own difficulties in handling feelings such as fear and anxiety, or from uncertainty about what to do or say. ” *Dani*

## Helping your family adjust

Cancer is difficult for everyone it affects. Your family also needs to adjust to the diagnosis. Family members may deal with their feelings in a different way to you.

Your family may experience similar anxieties and need as much information, support and advice as you. Family members might express their own fear about the diagnosis, at the possibility of losing you, and at their inability to do anything about the disease. They may also worry about how the illness will change their lives.

It might help family members having difficulty dealing with your diagnosis to contact a counsellor. Cancer Council Helpline 13 11 20 can help you find a counsellor or psychologist.

## When friends stay away

Cancer can change friendships. Some friends handle it well; others cut off all contact. Friends stay away for different reasons. They may not be able to cope with their feelings or they may not know how to respond to changes in your appearance. Your friends may still care for you, even if they stay away.

If you think that awkwardness rather than fear is keeping a friend from visiting, call them to ease the way. Remember that you can't always know or understand all the reasons why some people avoid you. You may find that talking about your illness helps everyone cope with it better.

### tips

- Make time to talk. Don't wait for the 'right' time – it may never come.
- Don't fall into the trap of thinking, 'if they really cared they would know what I need'. They are not mind-readers.
- Be honest about your thoughts and feelings even if it is upsetting.
- Focus on understanding each other, as this is more important, at least initially, than trying to solve the problem.
- Really listen to what the other person has to say, putting aside your own thoughts and judgments, to try to understand where they are coming from.
- Talk openly about what is happening and what you need, and make some specific suggestions. For example, you may like someone to drive you or keep you company at the doctors.

## How do I talk to kids about cancer?

When you are diagnosed with cancer, one of your concerns might be telling your children, grandchildren or other young people in your life. Some parents avoid telling their children they have cancer. Children usually sense that something is wrong even if they don't know what it is. When not told what is going on, children may imagine the worst. They may also find out from someone else, leaving them feeling angry and confused.

Children often benefit from an open and honest approach. With planning, practice and support from family or health professionals, most people are able to talk to kids about cancer.

### tips

- Consider what you will say and how you will say it before the discussion.
- Talk to children in language they understand. Younger children need simpler explanations while teenagers and young adults might ask for more details.
- Encourage your children to tell you what they know about cancer and answer their questions honestly. This gives you the chance to clear up any misunderstandings.
- Children may also need reassurance that the diagnosis is not their fault.
- Tell other people close to your children (grandparents, friends and school teachers) about the diagnosis and the plan for talking to your children so that you all say similar things. Trusted friends can also talk to your children about cancer if you feel unable.
- Ask them if they want to tell anyone else about the diagnosis, e.g. their teacher.

## Helping children cope

Children might have difficulty coping with cancer in the family. Their parent or family member might look different, be in hospital, or confined to bed. And their own daily routines may be upset.

These changes can sometimes be frightening for children, and can affect their behaviour. Young children may become insecure and refuse to leave your side or behave badly to get attention. Older children may retreat or become much closer to the person with cancer. It is natural to wonder if behavioural changes are normal or a result of the cancer. Talk to a health professional if your child or teenager's behaviour changes significantly. Call Helpline for a free copy of *Talking to Kids About Cancer*.

### tips

- Tell children how you're feeling. Honesty and openness is important when talking about cancer.
- Listen and give children a chance to discuss their feelings.
- Answer questions simply and honestly. You may like to prepare answers to questions you think they may ask.
- Talk to their school teacher or school counsellor.
- Reassure them of your love. Do things together. Read them a story, help with their homework or watch television together. Ask a relative or friend to devote extra time and attention to them.
- Assure them that cancer is not contagious.
- Tell them they will be looked after throughout your cancer treatment even if you can't always do it yourself.

## It's okay to say no

Sometimes you will switch between wanting to talk about things and wanting to avoid difficult thoughts and feelings. It is okay to say no – whether it is discussing your personal concerns or an offer of help that you do not wish

to accept. At times when you don't feel up to taking phone calls or seeing visitors, it can be helpful for your partner or another family member to act as a gatekeeper and handle enquiries or rearrange calls or visits to more suitable times.

## Sharing without talking

Your own physical health and emotions could fluctuate during and after your treatment. Sometime it's hard to let your friends and family know how you're feeling and they may find it hard to ask.

If you are having trouble talking about how you feel, you can try sharing your feelings without talking by keeping a journal, or blog. Some people keep two journals, one private and one to share with others. You could be creative through making music, drawing or doing crafts.

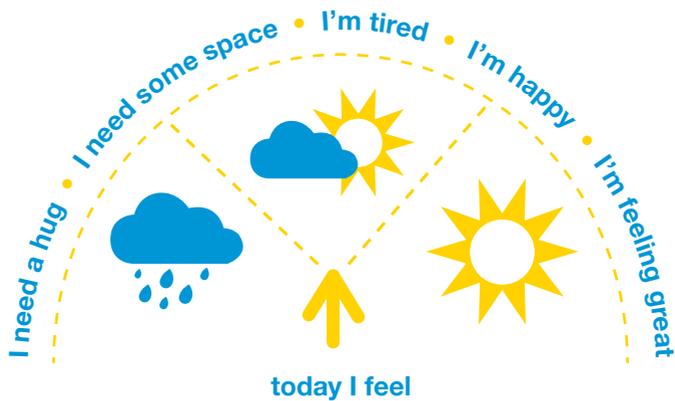
Use an emotions thermometer to show those close to you how you are feeling each day. See the next page for an example.

🗨️ Art therapy let me verbalise my inner thoughts. It's often easier to discuss something that you have created than to lay open your life and feel exposed. 🗨️ *Veronica*

## The emotions thermometer

An emotions thermometer is a simple tool that allows you to show how you're feeling every day. You can make one yourself and if you have kids, ask them to help. Decide on the feelings you want on the thermometer, for example,

stress, fear, anger or sadness. Put it up in a place where everyone can see it, such as the fridge. Attach a pointer, like a magnet that can be moved each day to indicate how you are feeling.





# Getting support

Even though family and friends can be there to help, many people still find it hard to ask for and accept support. When you are facing the extra demands of cancer, your support network can make an enormous difference. And family and friends can feel helpless and shut out if they are not allowed to provide support.

## Offers of help

Be aware that not everyone will be able to help in the same way. Some people will be comfortable talking about the cancer and comforting you if you are upset. However, other people may not be as good with words or strong feelings. They might prefer to support you in practical ways, such as helping with meals, transport or work around the home. Let people know what they can do to help and allow them to choose activities that match their abilities.

### Different ways people can help

- Giving practical help – for example, driving to appointments, sharing an after-school roster, providing company, shopping, making meals, helping you exercise.
- Having fun, getting you out and about, not talking about your worries.
- Keeping others informed, screening calls and emails, acting as a gatekeeper or support coordinator.
- Listening without trying to solve your problems.

## Getting help and support when you are alone

It's not unusual for people to find themselves alone sometimes in their lives. Having a serious illness when you feel that you have no close family or friends can be especially hard. But you don't have to tough it out by yourself. See the section below on Practical and financial help for ideas on the services that are available.

You may find that simply getting some help with practical things is all you need. For example, it might be useful to have your dog walked while you have treatment, get your lawn mowed or have your groceries or meals delivered.

“ I've met some amazing people along the way who have guided and helped me – some are likely to continue to brighten my future. ” *Tash*

## Practical and financial help

A serious illness can cause practical and financial difficulties.

Many services are available to help:

- Financial or legal assistance – through benefits, pensions and programs – may help pay for prescription medicines, transport costs to medical appointments, utility bills or basic legal advice.
- Meals on Wheels, home care services, aids and appliances can be arranged to help make life easier at home.

- Subsidised travel and accommodation may be available if you need to travel long distances for treatment.
- Home nursing care may be available through community nursing services or local palliative care services.
- Centrelink, Commonwealth Carelink Centres, home help, child-care assistance.

Contact the Cancer Council Helpline 13 11 20 or your hospital social worker, occupational therapist or physiotherapist to find out which services are available in your area and if you are eligible to receive them.

“Talking to a counsellor made me realise I don't have to go it alone. We have good friends and a great community who will support me and make sure the kids feel secure. I just needed to be able to step back and see the possibilities.”  *Kate*

## Community support

Letting others share in your care allows them to feel useful and supportive. It is also worth remembering that the more supporters you have, the smaller the load on any one person. Other sources of support could include formal or informal school-based assistance, such as the school counsellor or chaplain, outside school hours care, parent groups, and church and religious groups.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone. There are many ways for you and your family members to connect with others for mutual support and to share information.

In these support settings, people often feel they can speak openly and share tips with others. You may find that you are more comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears for the future.

Ask your nurse, social worker or Cancer Council Helpline about suitable support groups and peer support programs in your area.

### Types of support services\*

**Face-to-face support groups** – often held in community centres or hospitals

**Online discussion forums** – where people can connect with each other at any time – see [www.cancerconnections.com.au](http://www.cancerconnections.com.au)

**Telephone support groups** – for certain situations or types of cancer, which trained health professionals facilitate

**Peer support programs** – match you with a trained volunteer who has had a similar cancer experience, e.g. Cancer Connect.

*\* Not available in all areas*



# Life after treatment

Life after cancer treatment can present its own challenges. You may need to take some time to adjust to any physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious or vulnerable. You might worry about every ache and pain and wonder if the cancer is coming back.

Although you might feel pressure to return to normal life, you may find that you don't want your life to return to how it was before cancer.

You might find it helpful to:

- take time to adjust to physical and emotional changes
- re-establish a new daily routine at your own pace
- spend time on a leisure activity you enjoy
- maintain a healthy diet and lifestyle
- schedule regular check-ups with your doctor
- share your concerns with family and friends and tell them how they can support you.

Call Cancer Council Helpline 13 11 20 to connect with other people who have had cancer, or to request free information about life after cancer and any specific information you may require, for example, workplace rights.

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that

previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist or an accredited counsellor. Ask your doctor if you are eligible. Your cancer care centre may have a psychologist on site. Your local Cancer Council may provide access to a counselling program.

The organisation beyondblue has information about coping with depression and anxiety. Go to [www.beyondblue.org.au](http://www.beyondblue.org.au) or call 1300 224 636 to order a fact sheet.



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and some types of programs can offer valuable opportunities to share experiences and ways of coping.

Call 13 11 20 to find out more about different services and to request free information for carers.

There are many things you can do to help yourself and your loved one cope with their diagnosis and treatment:

- **Talk honestly about your feelings** – Try not to change the subject if it gets uncomfortable. Instead, share how you feel.
- **Chat about other things** – Dealing with cancer does not mean either of you have lost interest in your favourite sport or TV show.
- **Listen to their concerns** – Try to understand their feelings and perspective about treatment, side effects, finances and the future.
- **Don't be afraid to say nothing** – The silence might feel awkward, but simply being close to the person or holding their hand also shows you care and provides comfort.

- **Become informed** – Learn about the cancer and its treatment. This will help you understand what the person is facing. But be careful about offering advice.
- **Be around** – They’ll feel less isolated and know you care. If you are not there in person, check in by phone, text or email.
- **Offer to go with them to appointments** – You can take part in the discussion, take notes or simply listen.
- **Provide practical help** – Take the kids to school, provide a meal, help with the house or yard, or offer to drive them to appointments.
- **Try not to do too much or take over** – Give the person the opportunity to do things for themselves to maintain a sense of normality. They may appreciate the chance to be useful and connected to what is important, such as reading to the kids, even if they can’t do as much physically.
- **Keep them involved** – Even if your family member or friend is in hospital or home in bed, they can still take part in discussions and make decisions about day-to-day life, such as what is happening at school or work.
- **Look after yourself** – Give yourself time to rest as well as time away from the person with cancer. You need to look after your health if you’re going to give support. Don’t underestimate the emotional impact of supporting someone through cancer.

## Changing roles and routines

When someone is diagnosed with cancer, family roles and routines can change. Don't try to do everything you used to do.

These tips may help you cope:

- Relax housekeeping standards.
- Prepare simpler meals.
- Ask the children to help more around the house.
- Accept offers of help, for example, with cooking shopping, transport and other household tasks.
- Ask one person to coordinate help from family and friends.
- Think about joining a support group – everyone needs support and groups are available for children, spouses and carers.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Call 1800 242 636 or visit [www.carersaustralia.com.au](http://www.carersaustralia.com.au) or for more information.



## Useful websites

The internet has many useful resources, although not all websites are reliable. The websites below are good sources of support and information.

### Australian

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Cancer Council Australia.....	<a href="http://www.cancer.org.au">www.cancer.org.au</a>
Cancer Australia.....	<a href="http://www.canceraustralia.gov.au">www.canceraustralia.gov.au</a>
Cancer Connections.....	<a href="http://www.cancerconnections.com.au">www.cancerconnections.com.au</a>
beyondblue.....	<a href="http://www.beyondblue.org">www.beyondblue.org</a>
Breast Cancer Network Australia.....	<a href="http://www.bcna.org.au">www.bcna.org.au</a>
Carers Australia.....	<a href="http://www.carersaustralia.com.au">www.carersaustralia.com.au</a>
Commonwealth Respite and Carelink Centre.....	<a href="http://www.commcarelink.health.gov.au">www.commcarelink.health.gov.au</a>
Department of Health and Ageing.....	<a href="http://www.health.gov.au">www.health.gov.au</a>
Department of Human Services*.....	<a href="http://www.humanservices.gov.au">www.humanservices.gov.au</a>
Healthinsite.....	<a href="http://www.healthinsite.gov.au">www.healthinsite.gov.au</a>
Lifeline.....	<a href="http://www.lifeline.org.au">www.lifeline.org.au</a>
National Indigenous Cancer Network.....	<a href="http://www.nican.org.au">www.nican.org.au</a>
Relationships Australia.....	<a href="http://www.relationships.org.au">www.relationships.org.au</a>

*\*Contact for information on Centrelink and Medicare benefits*

### International

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American Cancer Society.....	<a href="http://www.cancer.org">www.cancer.org</a>
Macmillan Cancer Support.....	<a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>
National Cancer Institute.....	<a href="http://www.cancer.gov">www.cancer.gov</a>
Ottawa Hospital Research Institute.....	<a href="http://decisionaid.ohri.ca">decisionaid.ohri.ca</a>



## Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- How long do I have to decide about treatment?
- What will happen if I don't have treatment?
- What are the risks and possible side effects of each treatment?
- Will I be able to work during treatment?
- Will I have a lot of pain with the treatment? What can be done about this?
- Where can I get help for dealing with my feelings? Can you refer me to a professional counsellor or psychologist?
- Can you refer me to a social worker at my treatment hospital?
- Are there any complementary therapies that might help me?
- Who can I talk to about financial plans and legal matters?
- Where can my family get reliable information, help and advice?



# Glossary

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

## **active surveillance**

When a person does not receive treatment but instead has their health monitored regularly. Sometimes called watchful waiting.

## **advanced cancer**

Cancer that has spread from where it started (the primary site) to other parts of the body.

## **anxiety**

Strong feelings of fear, dread, worry or uneasiness.

## **biopsy**

The removal of a small sample of tissue from the body for examination under a microscope to diagnose a disease.

## **cancer**

A disease of the body's cells that starts in the genes. Damaged genes cause cells to behave

abnormally and they may grow into a lump called a tumour.

## **check-up**

A medical appointment after treatment has finished. Also known as a follow-up.

## **chemotherapy**

The use of drugs to treat cancer by killing cancer cells or slowing their growth. Chemotherapy can also be used to reduce the size of the cancer and help lessen pain.

## **complementary therapies**

Supportive treatments used in conjunction with conventional treatment to improve general health, wellbeing and quality of life.

## **depression**

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

**diagnosis**

The identification and naming of a disease.

**distress**

Emotional, mental, social, or spiritual suffering. Distress may range from feelings of vulnerability and sadness to stronger feelings of depression, anxiety, panic and isolation.

**fatigue**

Extreme tiredness and lack of energy that doesn't go away with rest.

**general practitioner**

A doctor in general practice. Commonly referred to as a GP.

**insomnia**

Inability to get to or stay asleep for a prolonged period of time.

**malignant**

Malignant cells can spread (metastasis) and eventually cause death if they cannot be treated.

**metastasis**

A cancer that has spread from another part of the body. Also known as secondary cancer.

**prognosis**

The predicted outcome of a person's disease.

**radiotherapy/radiation therapy**

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so that they cannot grow and multiply. Also used to control cancer pain.

**side effects**

Unintended effects of a drug or treatment.

**symptoms**

Changes in the body that are felt or seen by the patient that indicates there is something wrong, e.g. pain, headache.

**tumour**

A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.



## How you can help

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

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

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

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

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

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

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



# Cancer Council Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided throughout Australia for people affected by cancer.

For the cost of a local call (except from mobiles), you, your family, carers or friends can talk confidentially with oncology health professionals about any concerns you may have. Helpline consultants can send you information and put you in touch with services in your area. They can also assist with practical and emotional support.

You can call Cancer Council Helpline 13 11 20 from anywhere in Australia, Monday to Friday. If calling outside business hours, you can leave a message and your call will be returned the next business day.

## Visit your state or territory Cancer Council website

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

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

**Cancer Council Northern Territory**  
[www.cancercouncilnt.com.au](http://www.cancercouncilnt.com.au)

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

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

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

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

**Cancer Council Western Australia**  
[www.cancerwa.asn.au](http://www.cancerwa.asn.au)

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



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