Cancer Council

Emotions and Cancer

A guide for people with cancer, their families and friends

Coping with cancer

For information & support, call

13 11 20

Emotions and Cancer

A guide for people with cancer, their families and friends

First published July 2002. This edition January 2016.
© Cancer Council Australia 2016. ISBN 978 1 925136 74 6

Emotions and Cancer is reviewed approximately every three years. Check the publication date above to ensure this copy is up to date.

Editor: Jenny Mothoneos. Designer: Paula Marchant. Printer: SOS Print + Media Group.

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: Prof Jane Turner, Psychiatrist, Faculty of Medicine and Biomedical Sciences, The University of Queensland, QLD; Andreea Ardeleanu, Social Worker, Cancer Counselling Service, Phillip Community Health Centre, ACT; Dr Lisa Beatty, Research Fellow, School of Psychology, Flinders University, SA; Joshua Chalmers, Consumer; Valmai Goodwin, Psychologist, Cancer Council Queensland, QLD; Karen Hall, Clinical Nurse, Cancer Services Division, Flinders Medical Centre, and Nurse Health Counsellor, Cancer Council SA, SA; and Judith McGrath, 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.

This booklet is funded through the generosity of the people of Australia.

Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.

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Introduction

This booklet has been prepared to help you understand more about the emotional impact of cancer. For many people, a cancer diagnosis is a life-changing event.

We hope this booklet will help you understand the common reactions people have when they are diagnosed with cancer. It offers a range of suggestions for adjusting to the diagnosis, as well as information about support services.

As a cancer diagnosis affects not only you, but also your family and friends, this booklet provides practical tips on how to talk to others about your diagnosis and how they can help.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

This information was developed with help from health professionals and people affected by cancer. It is based on clinical practice guidelines for the psychosocial care of people diagnosed with cancer.[1,2]

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.

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13 11 20

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Dealing with the diagnosis

When you are diagnosed with cancer it is often difficult to take in the news immediately – you might hear the words, but not be able to absorb them or believe them. There are many reasons for this reaction. Cancer is a serious disease and, at first, most people feel overwhelmed and confused about treatment options and possible side effects. You may wonder if you will be the same person as before, if you will be able to do the things you usually enjoy, if your work life will be impacted, and if your relationships will change.

These thoughts and feelings are a natural reaction to a serious health situation. However, you can explore ways to manage these feelings before they overwhelm you.

Common reactions

For many people, the first few weeks after they are diagnosed with cancer are very stressful. There is no right way to feel – experiencing a range of emotions is normal and everyone will cope differently.

These feelings may be constant, or they may come and go. You may find that some pass with time, while others last longer. At times, it may feel like you're on an emotional rollercoaster.

There are many ways to cope with how you're feeling. Everyone is different, and you need to deal with the diagnosis in your own way. Talking to family and friends is often helpful, and some people find joining a support group makes them feel reassured and less alone (see page 38).

Feelings you may experience

shock and disbelief	It may take time to accept that you have cancer, especially if you don't feel sick. However, some people may never accept the diagnosis.
fear	It's frightening to hear you have cancer. Most people cope better when they learn more about the diagnosis and treatment options.
distress	The cancer diagnosis may cause you, your carers and family members to experience high levels of emotional distress.
sadness	Feeling sad after a cancer diagnosis is common. If you feel continually sad or down for two or more weeks and are not enjoying or interested in your usual activities, or are unmotivated, talk to your doctor – you may be experiencing depression.
anxiety	It's natural to worry about the prognosis and treatment, and the impact the diagnosis will have on your family, work and other responsibilities, but looking too far ahead may be unhelpful.
anger	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. Perhaps you are angry that you did everything right, and you still got cancer.
guilt and blame	It is common to ask 'why me?' and to look for a cause of cancer. While you may blame yourself, no-one deserves to get cancer.

loneliness	You might feel lonely and isolated if your family and friends have trouble understanding or dealing with your diagnosis, or if you are too sick to work or socialise with others and enjoy your usual activities.
loss of control	Being told you have cancer can be overwhelming and make you feel as though you are losing control of your life.

Finding hope

In Australia, the rates of cancer survival have increased significantly over time[3], but it can be hard to feel hopeful when you have just been diagnosed with cancer. Worrying about the future is natural. Treatments are improving constantly, and if the cancer can't be controlled, symptoms can be relieved to make life more comfortable.

Often the first thing people ask when 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.

If you've been told your cancer is advanced, you may find it harder to feel hopeful. In some cases, advanced cancer can be controlled for many years, allowing you to do the things you enjoy for as long as possible. For more information call Cancer Council 13 11 20 for a copy of *Living with Advanced Cancer*.

Physical effects and emotions

The physical impact of cancer and cancer treatments may affect your quality of life and emotions in different ways. People who experience physical symptoms, such as fatigue, pain and nausea, can also experience emotional distress. How long these effects last varies from person to person, but they can increase the risk of developing anxiety and depression (see page 40).

Fatigue

Feeling exhausted and lacking energy for day-to-day activities is the most common side effect of cancer treatment. This is known as fatigue. It differs from normal tiredness as it often doesn't go away with rest or sleep. For example, when chemotherapy affects red blood cells (anaemia). It can also be caused by the effort of coping with the physical and emotional effects of diagnosis and treatment.

Ways to manage fatigue

- Plan to do things at the time of day when you feel less tired. Keep a journal to track your 'good times'.
- Limit daytime naps to 30 minutes so they don't make it hard to sleep at night.
- Try to spend time outside in the fresh air each day.
- Pace yourself by doing one thing a day rather than overdoing it just because you feel a bit better.
- Do some exercise every day. Research shows it can help reduce tiredness and preserve muscle strength.

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.

Cancer Council's *Overcoming Cancer Pain* booklet covers the different medicines used to manage pain. Call 13 11 20 for a copy or download it from your local Cancer Council website.

Changes in appetite

Your appetite might change if you feel unwell, anxious or depressed or because of the physical effects of cancer treatment. Some people lose their appetite, while others eat more. A change in appetite can make you feel distressed.

Ways to manage appetite

- Try to eat a well-balanced diet to help your body cope better with the effects of treatments, give you more energy and maintain your wellbeing.
- Eat smaller portions more often during the day and choose full-fat foods whenever possible.
- Talk to a dietitian for suggestions on managing your appetite.
- Contact Cancer Council **13 11 20** for information and ideas on improving your nutrition and to request a copy of *Nutrition and Cancer*.

Changing body image

Cancer treatments, such as surgery, chemotherapy and radiotherapy, can cause changes to your body. Whether these changes are temporary or permanent, they can change the way you feel about yourself (your self-esteem) and make you feel self-conscious. You may feel less confident about who you are and what you can do. This is a common reaction whether or not your body has changed physically.

Ways to improve self-esteem

- 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.
- Participate in the Look Good Feel Better program. This free two-hour workshop teaches women, men and adolescents how to use skin care, hats and wigs to reduce appearance-related side effects during and after treatment. Call **1800 650 960** or go to **lgfb.org.au** for more information and to register for a workshop.
- Have your wig fitting before starting treatment so you match it to the colour and texture of your real hair.
- Care for dry skin with a mild soap and moisturiser, and avoid exfoliating ingredients.
- Participate in activities you enjoy, such as sport, painting, music and craft, which may increase your self-confidence.
- For practical suggestions about hair loss and other physical changes, call Cancer Council Information and Support **13 11 20**.

Loss of interest in sex

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.

Cancer treatments may affect your sexual organs or your ability to become aroused. You may also feel tired and unwell, or you may be too worried about the cancer to think about sex. Low libido can also occur when cancer treatments disturb your normal hormone balance or if you are feeling depressed. Often low sex-drive starts to improve after treatment is finished, but for some people it's ongoing.

Ways to maintain intimacy

- While sexual intercourse may not always be possible during and immediately after treatment, holding, cuddling, kissing and caressing are other ways to show love and affection or express sexual feelings.
- If sex is painful, or you have concerns about the safety of sexual activity, check with your doctor.
- Use counselling, either individually or together, to discuss how cancer affects your sense of self and the relationship with your partner.
- Cancer Council offers a private and personalised online program that addresses sexual concerns for adults. Find out more at **rekindleonline.org.au**.
- Read more about managing interest in sex in *Sexuality, Intimacy and Cancer*. Call **13 11 20** to request a copy.
- Talk to your treatment provider about any concerns you have about low sex drive.

Fertility

Some cancer treatments affect the reproductive organs, which may lead to temporary or permanent infertility. This means it may no longer be possible to conceive a child.

Many people experience a sense of loss when they learn that their reproductive organs will be removed or will no longer function. You may feel devastated if you are unable to have children, and may worry about the impact of this on your relationship or future relationships. Even if your family is complete or you were not planning to have children, you may feel some distress.

Ways to preserve fertility

- Talk to a fertility specialist before starting treatment to discuss options for preserving fertility before and during cancer treatment, and to find out what your options may be after treatment ends.
- Common options for women include in vitro fertilisation (IVF), ovarian tissue freezing and hormone treatments known as ovarian suppression.
- Common options for men include sperm banking and shielding the testicle during radiotherapy.
- If you have a partner, let them know how you're feeling. Speaking to a counsellor, gynaecological oncology nurse or prostate care nurse may also help.
- You can find more information in Cancer Council's booklet *Fertility and Cancer*. Call **13 11 20** for a free copy, or download it from your local Cancer Council website.

Sleeping problems

Sleep is important to help your body cope with cancer treatment, including physical and emotional aspects. Sleep can be affected by worry, pain (for example, after surgery), hormonal changes such as hot flushes in women who become menopausal, and nausea. As many people are not as physically active during their treatment, their body is not as tired and they find it harder to sleep. Feeling sad or depressed can also make it difficult to sleep well at night.

Ways to improve sleep

- Go to bed and get up at the same time every day, even on weekends.
- Put screens (mobile phone, tablet, computer or TV) away an hour before bedtime and do something relaxing – have a bath, read, listen to music or drink a glass of warm milk.
- Avoid coffee, tea and other caffeine products, such as chocolate and cola drinks, after early afternoon.
- Try to not sleep during the day. If you feel you can't stay awake, limit naps to 30 minutes.
- Get some physical exercise every day, but avoid any exercise two hours before going to bed.
- Use relaxation techniques, such as the Cancer Council relaxation CD, to prepare you for bedtime.
- Keep your bedroom dark, cool and quiet.
- If you can't sleep, get up and sit quietly on the couch until you feel sleepy again. Avoid turning on bright lights, reading or watching TV as these activities tend to wake you up more.

Your coping toolbox

Most of us have various ways of coping with difficult situations, which we have learned over time.

These could include:

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

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 after a cancer diagnosis that you need more than your usual ways of coping. There is no best or right way of coping, but having a few different strategies may help you feel a greater sense of control and confidence.

Some coping strategies reduce stress and anxiety temporarily, but don't reduce it in the long run and can cause other problems. Denial, drugs and alcohol are some examples of less effective coping strategies.

Building coping skills

A coping toolbox is a set of strategies or 'tools' you can use to help you cope. Each person's toolbox will look different, but this chapter includes a variety of techniques that may help. It's useful to consider several strategies or tools for coping with a cancer diagnosis and treatment.

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 information relevant to your situation or a way of dealing with the information 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 appointments and side effects, 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 you need to know – 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 – Ask people you trust to help gather and make sense of new information.

Find out about suitable clinical trials – Research shows that people who take part in clinical trials often have better outcomes than people treated outside of a clinical trial. They help test new or modified treatments to see if they are effective. You can find trials online at australiancancertrials.gov.au.

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 of poor quality. See page 44 for a list of reliable websites.

Ask questions – If you are unsure or confused about certain information, it can help to talk to your doctor. Write down your questions beforehand so you remember what to ask when you see your health care team. You can also call Cancer Council 13 11 20 Information and Support service with your questions.

Take a close family member or friend to consultations – They can take notes to help you remember the details. If you are comfortable with it, they can also ask questions.

Update your affairs – Many people with cancer review their insurance policies and update their will. This doesn't mean you have given up or that your prognosis is poor. Everyone needs to do these things at some point.

Find support – Some people join a support group as it gives them the opportunity to talk to other people in a similar situation. See page 38 for more details. If you think a support group is not for you, there are other ways to connect with people.

> "My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain." *Sam*

Looking after yourself

Cancer can cause physical and emotional strain. Some days you may feel better than others. Looking after 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. Call Cancer Council 13 11 20 to ask for a copy of *Nutrition and Cancer*.

Be active – Physical activity can 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 daily walk can help. Cancer Council's booklet on *Exercise for People Living with Cancer* has useful suggestions.

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.

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 – Keeping in touch with the world through work, hobbies, or time spent with family and friends may help you see a life outside of cancer and provide a break from your worries.

Tap into spiritual beliefs – Some people find meaning and comfort from their faith and spiritual practices. Others may experience spirituality more generally. A cancer diagnosis may challenge the beliefs of some people, and it may help to talk to a spiritual leader or pastoral care worker about your feelings.

Recognise signs of stress and anxiety – In times of stress, 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 natural responses help people deal with a crisis. For most people, these feelings settle, but for others they are ongoing. For ways to reduce stress and lower anxiety levels, see pages 18–19.

Does thinking positively help?

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

While it can help to be hopeful, this doesn't mean denying the reality that cancer is serious or frightening. Trying to put on a brave face all the time 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 how you feel to those around you may also help you get the support you need.

Using complementary therapies

Complementary therapies are widely used by people with cancer in Australia. They are generally used alongside conventional cancer treatments such as surgery, chemotherapy and radiotherapy. They may offer physical, emotional and spiritual support, reduce side effects from medical treatment, and improve quality of life.

Complementary therapies are different to alternative therapies. Alternative therapies are used in place of conventional cancer treatments, but many alternative therapies have not been shown to be effective treatments for cancer.

Many complementary therapies focus on a mind–body connection. These techniques are based on the belief that thoughts and feeling can affect 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. Below are examples of some types of mind–body complementary therapies.

Relaxation and meditation – Both of these therapies can help reduce stress, anxiety and fatigue, and improve quality of life.

- Relaxation usually includes slow breathing and muscle-loosening exercises to physically and mentally calm the body.
- Meditation involves focusing on a single thing, such as breathing.
- Mindfulness meditation helps you to take things one day at a time. It allows you to focus more easily on the present, rather than worrying about the past or fearing the future.

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

Art therapy – This technique uses visual art (drawing, painting, collage, sculpture or digital work) to express feelings. It can be done individually or in groups – some hospitals run programs. You do not need artistic talent to participate or benefit – the emphasis is on the process of producing artwork, not the end result. An art therapist helps you explore the images you have created to encourage understanding of your emotions and concerns.

> "The most significant change that occurred for me from art therapy was finding a way to express difficult feelings. Art therapy helped me find a way to share my experience. It was very positive." *Ray*

Let your doctor know about any complementary or alternative therapies you are using or thinking about trying. Some may not be appropriate and may be harmful if you are having some types of medical treatment. Some alternative therapies may even cause harm.

Contact Cancer Council 13 11 20 to ask for a free copy of the booklet *Understanding Complementary Therapies* or for a copy of our meditation and relaxation CDs. These are also available to stream from cancercouncil.com.au.

Dealing with unhelpful thoughts

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

Identify where the thoughts come from – Ask yourself if your thoughts are the result of an underlying belief, such as 'The world should be a fair and just place', 'If I can't do everything I used to do, I am useless' or 'I am a burden to my loved ones'. Or perhaps you have a tendency to attribute personal meaning to everything that is happening, even to events that are beyond your control. For example, if you arrive at the treatment centre and can't find a carpark you think, 'Nothing ever goes right for me. I don't know why I'm bothering with the treatment, I know it won't work'.

Imagine what you would say to others – Think of someone you love and imagine what you might say to them if they felt the same way.

Check 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?

Write down your thoughts – This helps slow down your thinking and makes it easier to focus. It may also help you determine if a thought is based on facts, realistic or helpful.

Acknowledge life events – 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.

Practise letting your thoughts come and go – Thoughts are fleeting. Some we notice and many we don't. Practise letting your thoughts come and go without getting caught up in them. The Cancer Council *Mindful Meditation* CD may help you practise this, contact Cancer Council 13 11 20 for a free copy.

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

Seek help – There are a range of professionals who help people manage how they're feeling. See next page for a list. Check if one of these is available at your treatment centre, or ask your GP for a referral. Medicare provides rebates for mental health services provided by a psychologist – talk to your GP about this.

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

Mental health nurse – A registered nurse who has completed further study in mental health nursing. Role includes assessing people, giving medicines and assisting in behaviour modification programs.

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 qualification standard they have to meet. Counsellors listen to what's going on and offer strategies for dealing with issues.

Social worker – A social worker must complete a four-year undergraduate or two-year masters degree. They provide emotional support, offer practical and financial assistance and help people find support services.

Psychologist – A registered psychologist 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 often develop expertise in particular approaches.

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 medicines to help manage a range of emotional conditions. You need a referral from your GP to see a psychiatrist.

Tool to help measure distress

Distress is an unpleasant emotional state that may affect how you feel, think and act. It can include feelings of unease, sadness, worry, anger, helplessness and guilt. While everyone with cancer experiences distress at some point, it can be difficult to know if how you are feeling is a typical reaction or something more serious.

The National Comprehensive Cancer Network has developed a tool called the Distress Thermometer that you can use to measure how you are feeling. It asks you to rate the level of distress you have been experiencing in the past week, including today. The scale ranges from 'no distress' (0) to 'extreme distress' (10). If you have a distress level of 4 or more on the thermometer you may benefit from professional support.

The thermometer also includes a list of specific problems people diagnosed with cancer may experience and asks you to check or mark any that have been a problem for you in the past week, including today.

Use the Distress Thermometer on the next page to rate how you're feeling and answer the simple questions. It should take only a minute to complete.

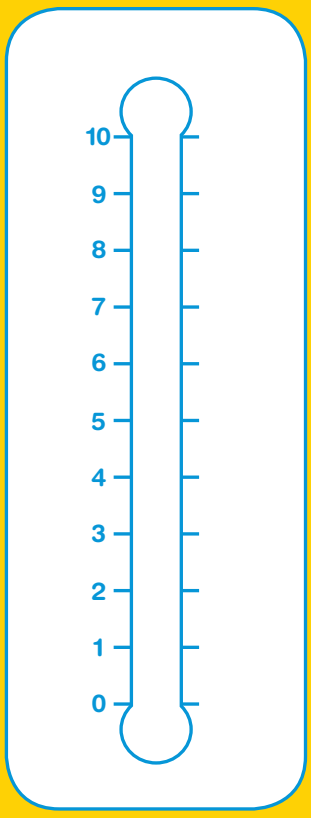
Talk to your health professional about the Distress Thermometer. Your responses to the problem list help health professionals to identify issues that are of concern to you and offer suitable support services. You may want to show the completed thermometer and questions to your doctor.

Distress thermometer for patients

Instructions

First, please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress



No distress

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Second, please indicate if any of the following has been a problem for you in the past week, including today. Be sure to check YES or NO for each.

YES	NO	Practical problems
❑	❑	Child care
❑	❑	Housing
❑	❑	Insurance/financial
❑	❑	Transportation
❑	❑	Work/school
❑	❑	Treatment decisions
		Family problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues
		Emotional problems
❑	❑	Depression
❑	❑	Fears
❑	❑	Nervousness
❑	❑	Sadness
❑	❑	Worry
❑	❑	Loss of interest in usual activities
❑	❑	**Spiritual/religious concerns**

YES	NO	Physical problems
❑	❑	Appearance
❑	❑	Bathing/dressing
❑	❑	Breathing
❑	❑	Changes in urination
❑	❑	Constipation
❑	❑	Diarrhoea
❑	❑	Eating
❑	❑	Fatigue
❑	❑	Feeling swollen
❑	❑	Fevers
❑	❑	Getting around
❑	❑	Indigestion
❑	❑	Memory/ concentration
❑	❑	Mouth sores
❑	❑	Nausea
❑	❑	Nose dry/congested
❑	❑	Pain
❑	❑	Sexual
❑	❑	Skin dry/itchy
❑	❑	Sleep
❑	❑	Substance abuse
❑	❑	Tingling in hands/feet

Other problems: _____

_____

Making decisions

After a cancer diagnosis, you will probably need to make several decisions. These could include the choice of treatment, how to involve or care for your family and friends, whether or when to return 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 take time to gather information and think about the possible consequences.

Get expert advice – Ask your health care professionals to explain your treatment options and the benefits and side effects of each. Social workers can give you details about financial assistance and support services.

Write it down – Organising your thoughts on paper can be easier than trying to do it in your head. Write down the aims of the treatments available to you, and the pros and cons of each option. Identify the purpose of the treatment – to cure the cancer, control it or to be as comfortable as possible. Think about what treatments will help to achieve the aim you want. 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 the importance of a point, look at the short-term and long-term effects on you and others.

Talk it over – Discuss the options with those close to you, like your partner or a close friend. As most decisions will affect others in your life, it's also important to consider their opinions.

Use a decision aid – Decision aids are available for some particular issues, for example, whether to have breast reconstruction. A decision aid is designed to help you make choices about different treatment options by focusing on what matters most in your own case. You could ask your doctor or cancer care coordinator if a decision aid is available for your situation.

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. Asking yourself, 'Did I make the right decision?' is rarely useful. Also, decisions are not always final – it may be possible to change your mind even after you have already started down a particular treatment path.

Get a second opinion

Asking another specialist what they think can be a valuable part of your decision-making process.

It can confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. 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.

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.

Telling others

You will need to decide who 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 find out that you have cancer either through changes in your appearance or by hearing it from others.

Telling people can also help prevent misunderstandings, puts you in control of what information is given out, and allows those who care about you to offer support.

Telling different people repeatedly about a cancer diagnosis can be emotionally draining. You may want to ask a few people to spread the news among family and friends. To avoid repeating the same details to everyone in their social network, some people use social media.

How to 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 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.
- For help finding the right words, call Cancer Council 13 11 20 to talk through what you might say.
- Ask family or friends to tell others for you if you don't feel up to it.

Other people's reactions

The reactions from your family and friends will vary. These will depend on many factors, including their previous experience of cancer. People may not be aware that treatments are improving all the time and that prognosis is improving.

People often don't know what to say. They may appear too positive or make light of your situation, or they may avoid or withdraw from you. Friends stay away for different reasons. Sometimes it may be because they are not able to cope with what you're going through.

After the initial shock of the diagnosis, family and friends are often supportive.

How to handle other people's reactions

- Make time to talk. Don't wait for the 'right' time – it may never come.
- Your family and friends will find it easier to be told what you need rather than having to guess. Make some specific suggestions. For example, you may like someone to drive you to appointments or keep you company at the doctors. Don't fall into the trap of thinking, 'If they really cared, they would know what I need'. They're not mind-readers. Be honest about what you are thinking and feeling, 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. Put aside your own thoughts and judgements and try to understand where they are coming from.
- Talk openly about what is happening and what you need. If you think not knowing what to say is keeping a friend from visiting, call them to ease the way. You may find that talking openly about your illness and treatment helps everyone.
- Give your family and friends time to adjust to the diagnosis. They may need as much information, support and advice as you do. They might be fearful of losing you, frustrated at their inability to do anything about the disease, or worried about how the illness will change their lives.
- The reactions of others may make you feel hurt, angry or frustrated. Try not to take their reactions as a sign that they don't care. Some people may need more time to take in the diagnosis before they are ready to face it.

Telling children

When you are diagnosed with cancer, one of your concerns might be how to tell your children, grandchildren or other young people in your life. Talking to young kids or teenagers about cancer can feel difficult and overwhelming.

Parents and other adults can feel overcome by their own anxiety and fears, and their first impulse may be to protect children from feeling these same strong emotions. Some parents avoid telling their children they have cancer. Others wait until treatment starts and side effects, such as hair loss or nausea, are noticeable.

Most children sense that something is wrong even if they don't know what it is. When they are not told what is going on, children may imagine the worst. They may also find out from someone else, and this may leave them feeling angry and confused.

Children usually cope better with a parent's cancer diagnosis if they are told in a way that is suitable to their age and development. With planning, practice and support from family or health professionals, most parents and other adults are able to talk to kids about cancer. See the table on the next page for ways to tell children and how to help them cope.

"Sooner or later they were going to find out. Why not tell them straightaway? I tell them frankly what is happening. I think they find it much easier to cope because they are ready for things." *Susie, mother of three children aged 12, 13 and 16*

How to tell children

- Practise what you will say and how you will say it before talking to kids.
- Start with questions to check what the children know about cancer. This gives you the opportunity to clear up any misunderstandings.
- Use language that children will understand. Younger children need simpler explanations while teenagers and young adults might ask for more details.
- Answer their questions simply and honestly.
- Try not to overload kids with too much information.
- Explain that the cancer is not their fault, and is not contagious.
- Leave kids with feelings of hope that even though you or they may be upset now, there will be better times.
- Tell other people close to your children (grandparents, friends and schoolteachers) about the diagnosis and what you plan to tell your children. If you all say similar things, your kids will hear a consistent message about cancer.
- Ask a trusted family member or friend to talk to your children about cancer, if you feel unable to discuss it yourself.
- Discuss the importance of letting the school know. It may be better to ask older primary school and high school children how they would like you to tell the school, and if they'd like to tell their friends.
- Call Cancer Council **13 11 20** for a free copy of *Talking to Kids About Cancer,* or download a digital version from your local Cancer Council website. This will give you more tips on talking to children throughout all stages of cancer, from breaking the news about a cancer diagnosis to coping with life after treatment.

How to help children adjust

- Trying to always be upbeat in front of your children can be exhausting, so tell children if you're tired or not feeling well. They may be relieved to know your mood is not because of something they've done.
- Listen and give children a chance to discuss how they're feeling.
- Ask their schoolteacher or school counsellor to look for changes in behaviour or marks. Ask if the school has a copy of Cancer Council's *Cancer in the School Community* as this may help them support your child.
- Continue the children's usual routine as much as possible. They feel safer with a regular routine. Talk about their activities, and let them know that it's still okay to have fun.
- Explain any changes that need to be made to the family's lifestyle, and negotiate where possible.
- 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.
- Tell them they will be looked after throughout your cancer treatment, even if you can't always do it yourself.
- Expect that children will react in different ways. They may feel angry, sad or guilty. Reactions may be physical, such as bedwetting or a change in sleeping patterns.
- Suggest that teenagers talk to a trusted adult or a counsellor about how they're feeling as they may find it hard to share this with you.
- Talk to your GP or a counsellor if the behaviour of your child or teenager changes significantly.

Ways to share how you're feeling

Your own physical health and emotions could fluctuate during and after your treatment. Sometimes 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 to others about how you're coping, you can share the experience in the following ways:

- keep a journal or blog – some people keep two journals, one private and one to share with others
- make music, draw, paint or create craft
- show others your Distress Thermometer ratings (see pages 23–25).

It's okay to say no

Sometimes you will switch between wanting to talk about what's going on and wanting to avoid difficult thoughts and feelings. It is okay to say no – whether it is about discussing your personal concerns or in response to an offer of help.

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. They can handle enquiries, monitor calls, or keep visits to more suitable times.

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 dealing with treatment and side effects, your support network can make an enormous difference. You don't have to deal with cancer alone. Family and friends usually appreciate being allowed to provide support – it helps them feel useful.

Offers of help

Friends and family can help in different ways. Some people will be comfortable talking about the cancer and comforting you if you are upset. Other people may prefer to support you in practical ways, such as helping with meals, transport or work around the home. You may want to use an app to set up a roster so people can choose activities that match their abilities and interests.

Different ways people can help

- **Providing practical support –** preparing meals, doing household chores, going grocery shopping, driving you to appointments, sharing an after-school roster, helping you exercise
- **Keeping others informed –** screening calls and emails, acting as a gatekeeper or support coordinator
- **Offering companionship –** listening without trying to solve your problems
- **Keeping you involved –** getting you out and about, and talking about other things aside from cancer

Getting support when you need it

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 on the next page for details of services that offer practical and financial assistance.

Other sources of support could include non-profit organisations, faith-based groups and, if you have children, formal or informal school-based assistance, such as the school counsellor.

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

People are often willing to help if they know you need it. If you feel comfortable, you may consider reaching out to friends or acquaintances. You may want to ask one of them to coordinate offers of help.

"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*

If you want to talk about the diagnosis or how you're coping with treatment and side effects, you may want to consider connecting with a support group. See page 38 for further details.

Practical and financial help

After a cancer diagnosis, many people worry about how they will manage the financial impact. Depending on your individual circumstances, you may need to deal with reduced income and extra costs. There are many services that can help deal with practical or financial problems caused by the cancer.

- 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 or child-care assistance may be available to you.

Ask the hospital social worker which services are available in your area and if you are eligible to receive them. Cancer Council offers free legal and financial services in all states and territories for people who can't afford to pay. For copies of *Cancer and Your Finances* and *Cancer, Work & You*, call 13 11 20 or download a digital version from your local website.

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.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support group, you may find that you are more comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups –** often held in community centres or hospitals
- **telephone support groups –** facilitated by trained counsellors
- **peer support programs –** match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums –** such as **cancerconnections.com.au**

Talk to your nurse, social worker or Cancer Council **13 11 20** about what is available in your area.

Life after treatment

For most people, the impact of cancer doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

You may feel pressure to return to your 'normal life', and frustrated that others don't really understand just how different things are for you. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace. This is often referred to as the 'new normal'.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of life after treatment ends. You can also request a copy of the booklet *Living Well After Cancer,* or download a digital version from your local Cancer Council website.

Worrying about cancer coming back

Feeling anxious and frightened about the cancer coming back (recurrence) is a common concern people have, especially in the first year after treatment finishes. For some people, this worry may affect their ability to enjoy life and make plans for the future.

Some people say that with time their fears lessen, but the worry often returns at certain times, such as before follow-up appointments, special occasions (e.g. birthdays or holidays) or anniversaries of the date they were diagnosed, had surgery or finished treatment.

Ways to manage the fear of recurrence

- Talk to a medical professional about your risk of recurrence.
- Focus on what you can control, e.g. being involved in your follow-up appointments and making changes to your lifestyle.
- Recognise the signs of stress, such as a racing heartbeat or sleeplessness, and manage these in a healthy way. For example, you could try meditation or light exercise.
- Join a support group to discuss your concerns with other people who have had cancer.
- Speak to a counsellor if the fear of recurrence is overwhelming. The counsellor may be able to help you balance your thinking or have a more positive frame of mind.

Dealing with feelings of sadness or worry

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 diagnosed with cancer.

Talk to your GP, as counselling or medicines – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist or social worker. Ask your doctor if you are eligible. Your local Cancer Council may also offer access to a counselling program.

The organisation beyondblue has information about coping with depression and anxiety.

Go to **beyondblue.org.au** or call **1300 22 4636** 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 programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit carersaustralia.com.au for more information and resources.

You can also call Cancer Council Information and Support 13 11 20 to find out more about carers' services and to get a free copy of the *Caring for Someone with Cancer* booklet, or download it from your local Cancer Council website.

Ways carers can help

There are many ways to show your concern or offer support to someone who has been diagnosed with cancer.

Offer to go with them to appointments

You can take part in the discussion, take notes or simply listen.

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.

Don't be afraid to say nothing

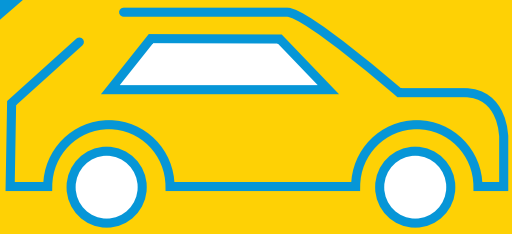
The silence might feel awkward, but simply being close to the person or holding their hand also shows you care and provides comfort.

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 and independence. They may appreciate the chance to be useful and connected to activities they enjoy, such as reading to the kids, even if they can't do as much physically.

Provide practical help

Take the kids to school, cook a meal, help with the house or garden, or offer to drive them to appointments. You don't have to do everything yourself – accept offers of help from family and friends.



Focus on other things

Make time to watch your favourite sport or TV show together or play a card game.

Look after yourself

Give yourself time to rest, as well as time away from the person with cancer. They probably would also appreciate some time alone. 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.

Listen to their concerns

Try to understand their feelings and perspective about treatment, side effects, finances and the future.

Talk honestly about your feelings

Try not to change the subject if it gets uncomfortable. Instead, share how you feel.

Keep them involved

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.

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.

Useful websites

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

Australian

Cancer Council Australia ..... **cancer.org.au**
Cancer Australia ..... **canceraustralia.gov.au**
Cancer Connections ..... **cancerconnections.com.au**
beyondblue ..... **beyondblue.org.au**
Australian New Zealand Clinical Trials Registry ..... **anzctr.org.au**
Canteen ..... **canteen.org.au**
Carers Australia ..... **carersaustralia.com.au**
Department of Health ..... **health.gov.au**
Department of Human Services ..... **humanservices.gov.au**
healthdirect Australia ..... **healthdirect.gov.au**
Lifeline ..... **lifeline.org.au**
National Indigenous Cancer Network ..... **nican.org.au**
Relationships Australia ..... **relationships.org.au**

International

American Cancer Society ..... **cancer.org**
Macmillan Cancer Support (UK) ..... **macmillan.org.uk**
National Cancer Institute (US) ..... **cancer.gov**
Ottawa Hospital Research Institute
Patient Decision Aids ..... **decisionaid.ohri.ca**

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?
- Can I get a second opinion?
- Are there any clinical trials I can join?
- Am I able to access treatment in other states or overseas?
- 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

active surveillance
When a person does not need immediate treatment, but instead has their health monitored regularly with the option of future treatment if necessary. Sometimes called watchful waiting.

advanced cancer
Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

alternative therapies
Therapies that are used in place of conventional treatment, often in the hope that they will provide a cure.

anxiety
Strong feelings of fear, dread, worry or uneasiness. Physical symptoms can include racing heart, shallow/fast breathing, shaking, nausea and agitation.

benign
Not cancerous or malignant.

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

cancer
Uncontrolled growth of cells that may result in abnormal blood cells or grow into a lump called a tumour. These cells may spread throughout the lymphatic system or bloodstream to form secondary or metastatic tumours.

check-up
A medical appointment involving tests and scans 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. May be given alone or in combination with other treatments.

complementary therapies
Treatments used in conjunction with conventional treatment, which improve general health, wellbeing and quality of life, and help people cope with side effects of conventional cancer treatment.

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

diagnosis
The identification and naming of a person's 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 (GP)
A doctor in general practice.

infertility
The ability to conceive a child.

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

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

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

primary cancer
The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

prognosis
The predicted outcome of a person's disease.

radiotherapy
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 called radiation therapy.

side effect
Unintended effect of a drug or treatment.

symptoms
Changes in the body that a patient feels or sees, which are caused by an illness or treatment, e.g. pain, tiredness, rash or a stomach-ache.

tumour
A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

Can't find a word here?

For more cancer-related words, visit:
- *cancercouncil.com.au/words*
- *cancervic.org.au/glossary*
- *cancersa.org.au/glossary.*

References

1. National Breast Cancer Centre and National Cancer Control Initiative, *Clinical practice guidelines for the psychosocial care of adults with cancer,* National Breast Cancer Centre, Camperdown, NSW, 2003.
2. Cancer Australia, *Clinical guidance for responding to suffering in adults with cancer,* Cancer Australia, Sydney, 2014.
3. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia: an overview 2014*, AIHW, Canberra, 2014.

How you can help

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

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and 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 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

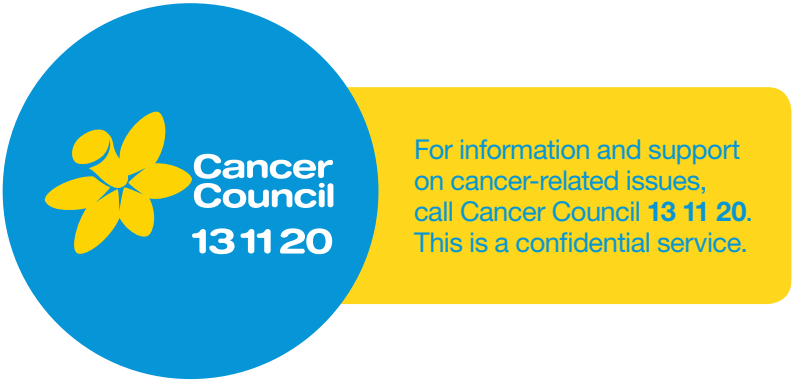
Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).

Interpreter

If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

NATIONAL RELAY SERVICE

If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

This booklet is funded through the generosity of the people of Australia.
To support Cancer Council, call your local Cancer Council or visit your local website.

JAN 2016 CAN754