

Living Well After Cancer

A guide for cancer survivors, their families and friends

Practical and support information

Cancer Council Helpline
131120
www.cancervic.org.au

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Note to reader

Always consult your doctor before beginning any health treatment. 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.

Interpreting service: Deaf or hearing or speech impaired

If you use text-based communication, call Cancer Council Helpline (13 11 20) through the National Relay Service (NRS) 13 3677. If you can hear and still use your voice, but have a speech impairment, call Cancer Council Helpline through NRS 1300 555 727.

Generous Victorians who fundraise to fight cancer make many Cancer Council services, including the publication of this booklet, possible. For information on how you can help, visit www.cancervic.org.au or call 1300 65 65 85.



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Introduction

This booklet is for people who have finished active treatment for cancer, such as chemotherapy or radiotherapy. It is about the emotional, physical, practical and social challenges that you may face now that treatment is over. These challenges will vary depending on the type of cancer you were diagnosed with and the treatment you received.

Many people diagnosed with cancer now live a long time after treatment. The end of treatment may be a time when you realise the impact cancer had on you, your family and friends.

You may like to pass this booklet to your family and friends for their information. It might help them to understand that although your treatment is over, you could still face some difficult times.

We hope this booklet will give you the information you need to live well after cancer. For details on support services see page 73.

How this booklet was developed

The information in this booklet was developed with help from people who have survived cancer and health professionals, and findings from research studies about cancer survivorship.

If you are still having treatment or your doctor has told you that the cancer has advanced, this booklet may not be helpful for you. Call Cancer Council Helpline **13 11 20** for other information.

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Who is a cancer survivor?

The term 'cancer survivor' means different things to different people. For some, it means anyone who has been diagnosed with cancer. Others use it to refer to people who are alive many years after their cancer treatment. You may feel that survivorship is a phase that you move in and out of at different times.

The idea of being a survivor brings many wide-ranging reactions. For many people it is a strong and positive label. However, some people don't like it because they feel it implies that they will struggle to cope with the cancer. You may find it difficult to relate to the title of survivor because you believe your treatment was relatively straightforward compared to other patients.

You may refer to yourself as living with cancer or someone who has had cancer. No matter how you feel about the word 'survivor', we hope the information in this booklet will be helpful.

The transition from patient to survivor is different for everyone. Some people consider themselves a survivor from the time they are free from signs of cancer (in remission), however for others this may occur when active treatment stops. Either way, you may wonder: what now?

In this booklet we use the term 'survivor' to mean anyone who has finished their active cancer treatment. There are more than 700,000 survivors in Australia and the number is growing due to earlier detection and better treatment.



Cancer is often described as a journey that starts at diagnosis. During treatment, some people feel that their life is on hold. After treatment ends, it may be hard to know how to resume normal activities. This can be described as being in limbo.

Survivors may expect life to return to what it was like before the cancer diagnosis. For many people, though, it isn't that simple. The reality is often more emotionally and physically complex. Some cancer survivors find they can't or don't want to go back to how life was before their treatment.

Finding a 'new normal'

Many survivors say that cancer changes them. After treatment, they may feel different, even though they look the same. With time, survivors often find a new way of living. Many call this a 'new normal'. It may take months or years to find a 'new normal'.

Misconceptions about treatment ending

- I should be celebrating.
- I should feel well.
- I should be the person I was before cancer.
- I should not need support.
- I should feel grateful.¹ (See page 79 for reference.)

Survival keeps on going; every day brings a new challenge.
 I think it's been both a curse and a blessing.

I was looking forward to the treatment ending, so why do I have mixed feelings now?

It's common for people to feel both excited and anxious when treatment ends. Many say they need time to stop and reflect on what has happened before they can think about the future. This process may mean they re-evaluate and change their values, goals, priorities and outlook on life.

- Many survivors feel a sense of loss for "the person I once was", "the way things used to be", and "the things I used to do".
- Some feel they should be happy and full of wisdom because they survived, but instead feel guilty that this isn't the case.
- Some people feel as though they have fought a battle and need time to rest. Others want to return immediately to their previous life.

How you feel and cope will depend on the type of cancer and treatment you had, and what you're like as a person. Any long-term side effects from your treatment will also play a big part. Many cancer survivors have ongoing health concerns because of the cancer or due to treatment. These may include fatigue, difficulty sleeping, pain and depression. The after-effects of treatment can make everyday life difficult.

♦ You never get back to the normal you knew before you had cancer. It's a series of evolution – evolving as a different person. ♥ Julie

My family and friends think my cancer experience is over. Why do I feel like it isn't?

Your family and friends care for you and it's natural for them to want the distress of cancer to be behind you. They may not fully understand what you've been through, and might not realise that the cancer experience doesn't necessarily stop when treatment ends.

It may be helpful to allow yourself time to adjust to these changes, and to explain to your friends and family that you need their support during this period. See page 28 for more information.

Can cancer be a positive experience?

Many people find there are positive aspects to having cancer. Some even refer to the disease as a life-changing experience. Cancer may cause you to re-examine your life choices, and may motivate you to travel, take up new activities or make lifestyle changes (e.g. starting exercise or quitting smoking). This shift is often gradual, as even positive change can take getting used to.

After treatment, some people want to help improve the cancer experience for others through advocacy or volunteer work. If this interests you, call Cancer Council Helpline 13 11 20 or contact Cancer Voices at www.cancervoicesaustralia.org.au.

What if I don't want to make changes after cancer?

Some people are happy with the way things were before the cancer diagnosis. This is okay; you don't have to feel pressured to make life changes if you don't want to.

tips

- Assess your life. You may want to ask yourself: Am I doing what fulfils me? Am I doing what I've always wanted to do? What is important to me?
- Focus on each day and expect both good and bad days.
- Do things at your own pace. Avoid pressure to make decisions or start new activities straight away. Plan rest time between activities.
- If you feel apprehensive about going out for the first time, ask someone you love and trust to come along.
- Be prepared for mixed reactions from family and friends. If people don't know how to react, try not to get upset. Some people avoid contact because cancer brings up difficult emotions. They are dealing with it in their own way.
- Share your feelings and worries with family and friends.

- Talk to your doctor if you are concerned about sadness or low moods.
- Practise some form of relaxation, such as meditation, visualisation, yoga or deep breathing.
- Keep a journal. Many people find it helps to write down how they're feeling.
- Join a support group. Speaking with other cancer survivors may help you cope and make you feel more optimistic about the future. For more information see page 73.
- Attend a survivorship program, if there is one in your area. Call **13 11 20** to ask what is available.
- Read other survivors' stories. Learning how other people have made meaning of a cancer diagnosis may help.
- Take part in a survivors' event. To find out more about Cancer Council's Relay For Life, call the Helpline.

Key points

- Cancer is often described as a journey that starts at diagnosis.
- For many people who have had cancer, life doesn't return to the way it was before diagnosis.
- After treatment ends, you may find that people expect you to feel well and not need support. This is not the case for everyone. It's natural to have mixed feelings.
- Many people find they need to reflect on what happened. This process may mean they re-evaluate their values, goals and priorities in life.
 With time they find a new way of living. This is often called a 'new normal'.
- Cancer survivors often say they found positive aspects in their cancer experience.

Understanding your feelings

It's natural to have many different – and sometimes conflicting – feelings after treatment ends. Although everyone is unique, many survivors have similar feelings.

Not everyone will have difficulties after their treatment finishes but, for many people, their concerns and fears are ongoing. You may need a lot of support – maybe even more than you did when you were diagnosed and during your treatment.

Common feelings

Relief – You might be relieved that the treatment has finished and seems to have been successful. You may feel happy to focus on your regular activities.

Isolation – One of the most common feelings people have is a sense of being on their own or loneliness. Many people feel isolated, abandoned or less secure when regular appointments with the health care team reduce or stop. This can be described as losing a security blanket or safety net. Changes to your relationships and feeling that other people can't relate to your experiences may also make you feel lonely.

▲ After treatment I felt very scared and very nervous about what things held for me. You're seeing somebody every day, day after day, and then suddenly it's goodbye, we'll see you in three months. So you're left on your own to cope with things. ♥● *Rosemary* **Fear of recurrence** – The most common fear is wondering if the cancer will return. It is often difficult to separate normal aches, pain and sickness from what may have previously been symptoms of cancer or side effects of treatment. This fear may never go away completely, but most survivors learn to manage it. For more information see page 14.

Uncertainty – Many survivors find planning for the future difficult because they feel uncertain about their health. They may feel stuck because they want to do things but are too scared.

Frustration – Some people feel frustrated because they think their family and friends have unreasonable expectations. You may still feel sick and need extra support.

Anxiety about follow-ups – The uncertainty about the types of tests you will need, which health professionals you will see, and how often you will need check-ups can make you feel anxious.

Worry – You may have questions about how long side effects will last, how they can be managed, and if they will affect your work, social life, relationships and hobbies. Many survivors are also concerned about worrying their family or being a burden to them.

Lack of confidence – You may feel differently about your body and health. Many people say they feel vulnerable and less confident. They also don't trust their body because they feel it has let them down. You may wonder how you will cope with the changes to your body image and sexuality – see page 39. **Anger** – When you were diagnosed you may have focused on getting through the treatment, and now that it's over you can let go of your emotions. You may feel relieved that the active treatment is over but angry that the cancer experience isn't.

Accepting your feelings

Most people find they need time to reflect on what has happened and consider their future. They are often too busy or unwell during treatment to do this.

Acknowledging how you're feeling may help you work through your emotions. Most cancer survivors find that they do feel better with time. However, you may be surprised to find that months or even years after treatment, you have periods of feeling down. This is common for many people who have recovered from cancer. See page 50 for more information.

Many friends and colleagues may advise you to 'think positively'. This can be difficult when you are dealing with what has happened and how your life has changed. There is no scientific evidence to suggest that thinking positively has any impact on if, and for how long, you survive cancer. However, many survivors say that feeling hopeful helped them to cope through their illness.

Key points

- It's normal to have many different feelings after treatment ends.
- Some of your feelings may be similar to how you felt when you were first diagnosed with cancer.
- Common feelings include relief, isolation, fear of the cancer coming back, uncertainty about the future, frustration with family and friends, anxiety about check-ups, worry about side effects, lack of confidence and anger.
- Acknowledging and talking about how you're feeling may help you work through your feelings.
- It's common to have periods of sadness for months or years after treatment.

Fear of the cancer coming back

Feeling anxious and frightened about the cancer coming back (recurrence) is the most common fear for cancer survivors, especially in the first year after treatment.

For some people, this fear may affect their ability to enjoy life and make plans for the future. Living with this fear has been described as a shadow on your life.

Some survivors say that with time their fears lessen. However, many people still find that they worry at certain times, such as:

- special occasions (e.g. birthdays or holidays)
- anniversaries (e.g. the date you were diagnosed, had surgery or finished treatment)
- before follow-up appointments
- hearing of others diagnosed with cancer
- experiencing symptoms similar to those when you were first diagnosed
- the death of a friend or family member from cancer or another type of illness
- passing by the hospital where you had treatment or visiting someone in the same hospital
- hearing media reports about cancer, new treatments and celebrities with cancer
- seeing related fundraising campaigns or advertisements (e.g. a graphic cigarette warning or melanoma warning).

• The fear is always there. It never goes away completely. • *Maria*

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 try to manage this in a healthy way. For example,

doing some meditation or light exercise might help.

- Join a support group to discuss your concerns with other cancer survivors.
- Speak to a counsellor if the fear of recurrence is overwhelming or if it is affecting your relationships. The counsellor may be able to help you balance your thinking or have a more positive frame of mind.

Will the cancer come back?

You may wonder how likely it is that the cancer will come back or how long people with your type of cancer live. You need to discuss your case with your doctor, who can give you an idea of what may happen to you or tell you the most recent survival statistics (see the next page). This is a general guide and there is always some uncertainty, which can be frustrating.

The risk of recurrence is different for each person. It depends on many factors including the type of cancer, stage at diagnosis, treatment and time since treatment. Generally, the more time that goes by, the less likely it is that the cancer will come back.

How does cancer come back?

- Local recurrence appears at or near its original site (this may be known as a relapse)
- Secondary cancer spreads (metastasises) to other parts of the body.

Survival statistics

Many doctors are wary of using the term 'cure' as undetected cancer cells can sometimes remain in the body after treatment, causing the cancer to return. Instead they may use the term 'five-year survival rate'. This is because research studies often follow people for five years, and this data is often used to predict a patient's risk of relapse.

Five-year survival rate means the percentage of people alive five years after diagnosis. For example, about 94 out of every 100 people (94%) diagnosed with thyroid cancer will be alive five years after they are diagnosed. Many of these people live much longer than five years after diagnosis.

How accurate are the statistics?

Five-year cancer survival rates are only a guide. They include everyone with a particular type of cancer, at all stages and grades of the disease. However, people diagnosed with early stage disease (small cancer that has not spread) may have a better outlook than people diagnosed with late stage disease (larger cancer that may have spread). Statistics take many years to calculate and are usually slightly out of date. For example, if you were diagnosed with cancer in 2011, the doctor may use survival rates from 2007. With cancer treatments improving all the time, your outcome (prognosis) may be better than it would have been in 2007.



Most cancers are more likely to come back in the first few years after treatment ends, but it is also possible for some to recur many years later.

Fear of getting a different cancer

Some survivors worry about developing a different cancer. Most people who get cancer only get one type. It is uncommon to develop another type of cancer. Your risk may be higher if:

- you were born with genes that increase your tendency to develop cancer this affects fewer than five out of every 100 people (<5%)
- you have previously been exposed to smoke or other cancer causing agents
- you have not used sun protection or have been exposed to the sun regularly
- your cancer treatment has increased your risk. For example, some forms of radiotherapy can increase the risk of getting a different cancer later in life, particularly if you were treated as a child.

If you are concerned about getting a different type of cancer, talk to your doctor about your risk.

Checking for signs of a new cancer

If you notice anything unusual or have any concerns, see your doctor as soon as possible.

Signs to look out for include:

- a lump anywhere in your body that doesn't go away
- a mole or skin spot that changes shape, size or colour
- a cough or hoarseness that won't go away
- changes in bowel habits (e.g. diarrhoea or constipation for more than six weeks)
- abnormal bleeding
- unexplained weight loss
- unexplained fatigue.

To help detect cancer early, you can participate in national screening programs for breast, cervical and bowel cancer. For more information visit www.cancerscreening.gov.au.

Key points

- Many cancer survivors worry that the cancer will come back.
- This concern may be worse at certain times such as special occasions, followup appointments, and hearing about other people diagnosed with cancer.
- Many find the fear of recurrence lessens with time.
- Risk of recurrence depends on the type of cancer, stage at diagnosis, treatment and time since treatment.
- Doctors use five-year survival statistics. This refers to the number of people who are alive five years after diagnosis.
- Most people who get cancer only get one type.
 It is uncommon to develop another, different cancer.

- If you notice new or concerning symptoms, schedule an appointment with your doctor.
- To help detect cancer early, you can participate in national screening programs for some types of cancer.



After your treatment has finished, you may need regular check-ups. These will allow your doctor to monitor your health and well-being. Follow-up care depends on the type of cancer and treatment you had, plus any side effects you are experiencing. It is usually different for each person.

Your treatment summary

It's a good idea to ask your oncologist for a written summary of your cancer type, treatment and follow-up care.

Share this summary with your GP or any new health care providers you see. It will provide medical guidance for your care when you've finished active treatment.

This plan should include the following information:

- type of cancer
- date of diagnosis
- diagnostic tests performed and results
- pathology results: stage, grade, hormonal status (usually for people with

breast cancer), tumour marker information

- treatment details (e.g. type of surgeries, sites and amounts of radiation therapy, names and doses of chemotherapy and all other drugs, results of scans and x-rays)
- list of symptoms to watch for and possible long-term side effects of treatment
- contact information for health professionals involved in your treatment and follow-up care.

Common questions What do check-ups involve?

During check-ups your doctor will:

- see how you're recovering
- ask how you're feeling and coping with life after cancer
- monitor and treat any ongoing side effects
- look for any signs that the cancer may be coming back
- investigate any new symptoms
- ask if you have any concerns
- discuss your general health and suggest things you can do to keep yourself healthy, such as eating a healthy diet and exercising.

Blood tests and scans may be taken, depending on the cancer type and treatment. For example, women treated for breast cancer need mammograms and men treated for prostate cancer need PSA tests.

Being honest with your doctors will help them manage any symptoms that are bothering you. For instance, you should let them know if you feel very low in mood or energy.

How often do I need check-ups?

The frequency of check-ups varies depending on the type of cancer you have. You may want to ask your doctor about the national guidelines for follow-up care available for some cancers (e.g. breast and bowel cancer).

Some people have check-ups every 3–6 months for the first few years after treatment, then less frequently thereafter. Talk to your doctors about what to expect or call Cancer Council Helpline 13 11 20.

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If you are worried or notice any new symptoms between appointments, contact your doctor. Don't wait until your next scheduled appointment.

Who do I see for follow-up care?

You may have follow-up appointments with the same doctor who provided your cancer treatment. In addition, you may see your general practitioner (GP), who can help coordinate your care and monitor your overall health. This may include monitoring your blood pressure, cholesterol levels and weight.

Some people only need to see their GP for follow-up care. Depending on where you live, this may be the most practical approach. The GP will liaise with your specialists so that if problems occur, you can be referred again.

You may need help from other health professionals such as a physiotherapist, exercise physiologist, dietitian or specialist nurse.

How can I prepare for check-ups?

Before you see the doctor, it may help to write down any questions you have – see the list of suggested questions on page 24. If your doctor uses medical terms you don't understand, it's okay to ask for a simpler explanation.

If you have several questions or concerns, ask for a longer appointment. Taking notes during the session can also help. Many people like to have a family member or friend go with them, to take part in the discussion, take notes or simply listen.

Tell your doctor or nurse if you have:

- trouble doing everyday activities
- new symptoms
- new aches or pains that seem unrelated to an injury, or familiar ones that have become worse
- changes in weight
- changes in appetite
- feelings of anxiety or depression
- other health problems, such as heart disease, diabetes or arthritis
- medicines you are taking and other complementary treatments you are using.

You can also talk to your health care team about other issues. For example, you may want to talk about changes to your sexuality, how cancer has affected your relationships, or practical issues such as returning to work.

You should tell other health professionals you see about your cancer diagnosis and its treatment, as this may affect their decisions about the treatment they provide you.

● My doctors know I've had pancreatic cancer. When I had some aches and pains in my abdomen, they wanted to make sure the cancer hadn't spread, so they ordered a colonscopy and gastroscopy. ● Leslye

Questions to ask your doctor

You may want to ask your doctor a few questions from this list:

- Why do I need check-ups?
- What happens during check-ups?
- How often do I need check-ups?
- What symptoms should I look out for?
- What tests will I have if there are signs the cancer may have come back?
- How long will it be before I feel better?
- What should I do if I have new symptoms between appointments?
- Is there anything I can do to improve my health?
- Where can I get further information about my follow-up care?

Managing anxiety before check-ups

Many cancer survivors say they feel anxious before routine check-ups. Sleeping problems, poor appetite, mood swings and feeling more aches and pains are common in the lead-up to the appointment.

You may feel anxious before check-ups because:

- you fear that you'll be told the cancer has come back
- going back to hospital brings back bad memories
- it makes you feel vulnerable and fearful just when you were feeling more in control
- other people (friends or family) make comments that upset you.

Finding ways to cope with your worries before check-ups may help. Once you have had a few and all is okay, you may feel less concerned.



- Take a close friend or relative with you to your check-ups. Sharing your fears may help you cope better, and people close to you may want to help.
- Make the day something to look forward to. Plan to do something special after your appointment – go out for a meal or buy yourself a treat.
- Try to see your check-ups as a preventive measure. Regular check-ups may increase the chance of any problems being picked up early when they may be easier to treat.
- If you find it overwhelming to go to the treatment centre, ask if it is possible to visit the doctor elsewhere.

- Do deep breathing or relaxation exercises to manage your anxiety when waiting for your appointment.
- Book the first appointment of the day or plan another activity beforehand so you are busy and don't have time to dwell on the appointment.
- Stay informed about any new treatments for the type of cancer you had. This may help you cope better.

You do get nervous and you tell yourself it's only a check-up – but it becomes this mountain. I have my scans on the Monday and see the doctor on the Wednesday, because I can't handle having to wait for the results any longer.
 Georgina



Key points

- Many cancer survivors say they feel anxious before their routine check-ups.
- Follow-up care is usually different for each person. It depends on the type of cancer and treatment you had, plus any long-term side effects you are experiencing.
- You may have a blood test and scans as part of the check-up.
- Asking your doctor what to expect may help you feel less anxious.
- Follow-up care may be provided by the doctor who initially treated you. Your GP can also help to coordinate your care and monitor your general health. You may also want to see a physiotherapist, dietitian or specialist nurse.

Communicating with family and friends

After treatment is over, your family and friends may also need time to adjust. Research shows that carers often experience high levels of distress, even when treatment has finished.

Your cancer diagnosis may make people around you question their own priorities and goals. Like you, they may be concerned about the cancer coming back. Let your family and friends know that you understand it is hard for them as well. Tell them how much you appreciate all they have already done to help you and let them know if you still need their support.

How family and friends may feel after treatment ends

People close to you can have a range of reactions when your cancer treatment ends.

They may feel:

- relieved that you're okay
- happy to focus on others and themselves
- exhausted
- confused, especially if your relationship has changed
- pleased they can catch up with family and friends without cancer dominating the conversation
- worried about what the future holds.

•• While I was filled with confidence, my parents were filled with dread when I came out of it. **••** *Mark*

When others don't understand

When treatment finishes, your family and friends may expect you to act the same as before the cancer. If you have changed, people close to you may be disappointed, worried or frustrated.

Friends and family may say things like "but you look fine", "your treatment has finished now" and "the cancer has gone, hasn't it?". They may have difficulty accepting that some symptoms, such as tiredness, persist for long periods of time, and you may need allowances to be made. You may feel you're expected to be grateful you're still alive, no matter the side effects.

It's natural for family and friends to want the distress and disruption of cancer to be behind you. They care for you and want you to be well. However, if you find their reactions difficult to handle, you might need to talk to them about how you're feeling. You may need to tell them that your recovery is ongoing, and you need time to think about what you've been through. You might not be able to just 'get on with it' as quickly as they might want you to.

Will my family inherit my cancer?

If you've had cancer, it doesn't automatically mean that your children will get it too.

If you are concerned the cancer is inherited, talk to your

doctor about any risk factors and whether your family needs regular screening. Your doctor may refer you to a family cancer clinic or to a genetic counselling service. Some friends backed off and I was disappointed. It's not necessarily that they don't care, it's just that possibly they just don't know what to do or to say. Some Rosemary

Coping with children's needs

If you have children or grandchildren, they may have seen less of you during treatment. It's common for young people to worry that the person with cancer will die.

Like many adults, children may find it difficult to understand why life can't go back to the way it was before the cancer. Children's reactions and needs will vary depending on their age. Try to be as open and honest as possible. This will make them feel safe.

- Acknowledge the temporary or permanent changes that your family has made to deal with the cancer. This is particularly important for teenagers.
- Be open about how you feel emotionally and physically, so the children understand if you're not bouncing back.
- Talk about your fears, such as if you're feeling anxious before a follow-up visit.

This may encourage children to talk about their fears when you go for a check-up.

- Spend time together doing something they enjoy.
- Explain any changes made to your family's lifestyle, and let them know if they are permanent.
- Download a copy of Talking to Kids About Cancer from www.cancercouncil.com.au.

tips



Key points

- Family and friends need time to adjust after treatment.
- They may also have many mixed emotions: relief, exhaustion, confusion and worry. Outwardly, they may have a range of different reactions to you.
- Some survivors find their family doesn't understand that they still need time to adjust to emotional and physical changes at the end of treatment.
- If you or your family is worried about inheriting the cancer, talk to your GP or oncologist. You may be referred to a family cancer clinic or genetic counselling service.
- Children may find it especially hard to understand how you have changed. Talking to them in an age-appropriate way and being as honest as possible may help.

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Treatment side effects

It can take time to get over the side effects of treatment. Side effects vary depending on the type of cancer you had, its stage and the treatment you were given. The changes can be both physical and emotional.

Some problems resolve quickly; others can take weeks, months or even years to improve. Your body will cope with the treatment and recovery in its own way. It is best not to compare yourself to others.

Common side effects include:

- feeling very tired (fatigue)
- pain
- loss of self-esteem and confidence
- changes in sexuality
- menopausal symptoms for women
- fertility problems
- swelling in the limbs (lymphoedema)
- cognitive changes (sometimes called chemo brain)
- changes in bladder and bowel functioning
- problems with eating or drinking
- weight loss or gain
- mouth and teeth problems
- bone loss (osteoporosis)
- hair loss or other physical changes
- sleeping difficulties.

Research has found that 20 out of every 100 cancer survivors (20%) have ongoing side effects 1–5 years after diagnosis.

For some people there may be permanent or late side effects. Late effects are problems that develop a long time after treatment finishes. If you are concerned about a new side effect, talk to your doctor.

It can be difficult to deal with any change in how your body looks, feels or functions. Other people may not understand how much these changes affect your day-to-day living, especially if it has been a few months or years since your treatment has finished. This can be frustrating and make it harder to cope with the side effects.

This chapter outlines many side effects common to cancer survivors and offers suggestions on how to cope with them. For further information and support call Cancer Council Helpline 13 11 20.

Fatigue

Fatigue, or feeling exhausted and lacking energy for day-to-day activities, 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.

Now that treatment is over, you may think you should be full of energy, but this often isn't the case. Many survivors say that fatigue has a big impact on their quality of life in the first year after treatment.

Most people get their energy back 6–12 months after treatment. However, some people lack energy for years after treatment and their energy levels may never fully recover.

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Many survivors worry fatigue is a sign that the cancer has come back or that it never really went away. This is usually not true.

Symptoms of fatigue

People living with cancer have described fatigue as overwhelming, unbelievable, debilitating and frustrating. Symptoms include:

- a lack of energy you may want to stay in bed all day
- difficulty sleeping (insomnia)
- finding it hard to get up in the morning
- feeling anxious or depressed, particularly if fatigue persists
- muscle pain you may find it hard to walk or climb stairs
- feeling breathless after light activity, such as having a shower or making the bed
- difficulty concentrating, even watching TV or talking to someone
- finding it hard to think clearly or make decisions easily
- little or no interest in sex (low libido).

You may worry that your friends or family won't believe you or think that you are complaining too much if you keep saying how tired you feel. They may not appreciate the long-term effects of fatigue. It's common for relationships to change if people feel misunderstood. Talking to family and friends about how you feel may help them to understand.

Fatigue and its symptoms may also sometimes be signs of depression (see page 50). If you have a persistent low mood, talk to your doctor. Treating depression may help you feel less tired and give you more energy.

Managing fatigue

Many cancer survivors don't tell their doctor about fatigue because they think that nothing can be done about it. However, there may be things that your treatment team can suggest that might help. For example, if your fatigue is caused by low red blood cells or the side effects of drugs, your doctor may be able to treat the cause.

- Set small, manageable goals.
 Focus on doing a little bit each day rather than a lot in one go.
- Ask for help. Get a friend to help with school pick-ups, shopping or running errands.
- Plan your day so you can do the activities that are most important to you at the time of day when you have the most energy.
- Take rest breaks between activities.
- Do things slowly so that you don't use too much energy as you go. Leave plenty of time to get to appointments.
- Try activities to help you relax, reduce stress and take

your mind off how tired you feel. For example, you might walk on the beach, sit in a peaceful setting, do some gardening, have a long bath or listen to some music.

- Say no to things that you don't feel like doing. It's okay not to please others all the time.
- Have realistic expectations. As soon as treatment finishes, don't expect to be able to instantly do all the things you used to do before the cancer. Your body is still recovering and it will take time for your energy levels to return.
- Do some regular light exercise, which can boost energy levels and make you feel less tired. A short walk

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For some people, fatigue is linked to low moods or depression, which can be treated separately.

The tips below may help you. These suggestions might not work for everyone, but you may find that small changes make you feel better. Talk to your health professionals for more suggestions.

may help to restore your energy without exhausting you. Talk to your health care team about suitable activities.

- Smoking reduces your energy. If you smoke, talk to your doctor about quitting or call the Quitline on **13 7848**.
- Save your energy. Sit down to talk on the phone or do chores, such as cutting up vegetables, ironing or loading the washing machine. Sit down to put wet clothes on hangers and use a trolley to transport them to the clothesline. Leave chairs around the house so that you can sit when you feel tired.
- If you have children, play with them sitting or lying down.

Board games, puzzles and drawing are good activities.

- Eat nutritious meals and snacks throughout the day.
- Go to the shops during quieter times or do your shopping online.
- Call 13 11 20 to get in touch with a Cancer Connect volunteer who has had the same type of cancer and can share their story.
- Consider joining a support group. Cancer Council Helpline can talk to you about support groups that may suit you. Talking about your feelings may ease the burden of fatigue, and you can hear how other people in similar situations have managed.

tips

●● I conserve energy at the supermarket by putting small articles into two baskets that I place inside the shopping trolley. When I get to the checkout, I put the basket onto the counter instead of having to stretch and dig in the trolley for small articles. ●● Ann

Pain

Some people experience pain after cancer treatment. Pain can prevent you from doing the things you want to do, which has a big impact on your life. Controlling the pain may allow you to return to many of the activities you enjoy.

Chemotherapy and surgery can injure nerves and cause pain and numbness in certain areas of your body. Your skin may be very sensitive in the area you received radiotherapy; this can last for a few months. Scars from surgery can also hurt for a long time.

Whatever type of pain you have, there are usually many ways to manage it. If your pain lasts for a long time or is constant, avoid waiting until it is out of control before doing something about it. Taking medication regularly is the best way to prevent pain from starting or getting worse. Some people call this 'staying on top of the pain'. It may mean you can use lower doses of pain relief than if you wait until the pain gets worse.

Common pain-killing medications

Pain-killing drugs, called analgesics, are available to treat different types and levels of pain.

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- Mild pain paracetamol or non-steroidal anti-inflammatory drugs
- Moderate pain mild opioids such as codeine
- Strong pain opioids such as morphine.

Your doctor may also prescribe other drugs. For example, medications normally used to treat depression or epilepsy have been found to be helpful for some types of pain. Although you may not have depression or epilepsy, taking these drugs may make it possible to control the pain with a lower dose of opioids.

Will I become addicted to pain-killers?

People taking opioids at the levels necessary to relieve pain are not at risk of addiction, unless they have had addiction problems in the past. However, it is common to experience symptoms of withdrawal when you stop taking a drug. For this reason, your doctor will gradually reduce your dosage. If you are concerned about drug dependence, talk to your doctor.

Will the pain-killers make me drowsy?

This is unlikely if you take the medication as your doctor prescribes. You may feel drowsy at first, but this usually wears off within a couple of days. If it doesn't, talk to your doctor. Your dosage may need to be adjusted.

Let your doctors know how pain is affecting your day-to-day life, as this helps them plan the best treatment for you. Your pharmacist may also be able to suggest ways to relieve the pain.

Other methods of pain relief

For some people, pain can be relieved without taking tablets. Some people have surgery or have an anaesthetic injected into their body (nerve block). Doctors usually use these methods if nothing else is effective.

Seeing a physiotherapist or occupational therapist may help you address physical or practical problems that are making you uncomfortable.

Some people use complementary therapies. These therapies may enhance your general well-being and help you cope better with pain. They may also increase your sense of control over the pain, improve your mood, and decrease your stress and anxiety.

- Relaxation techniques, such as deep breathing, meditation or listening to your favourite music may help you sleep at night, give you more energy, reduce your anxiety and make other pain-relief methods work better. Mindfulness and meditation use breathing techniques to quieten the mind. This may help you to focus on the present.
- A relaxing massage may relieve muscle spasms and contractions.
- Applying hot or cold packs to areas may provide good relief.
- Distraction involves focusing your attention on something other than the pain. For example, you can listen to music or do something creative, such as paint a picture.

• Other therapies, such as acupuncture, may stimulate the brain, relieve your pain and help you relax.

Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate depending on your situation. For example, your doctor may advise against a strong, deep tissue massage if you had surgery or bone problems during treatment. Always let the complementary therapist know that you have had cancer.

If you would like more information and support to cope with your pain, contact the Helpline.

Changed body image

Treatment for cancer can change the way your body looks and how it works. This may affect how you feel about your body (your self-esteem).

Your self-esteem may be affected by:

- speech difficulties
- eating and drinking problems
- breathing changes
- weight loss or gain
- changes to your appearance (e.g. mastectomy or oral surgery)
- hair loss or hair growing back differently
- bladder and bowel changes (e.g. colostomy or ileostomy)
- intimacy and sex life (see page 41)
- infertility (see page 46).

It will take time to adjust physically and emotionally to these changes. Many cancer survivors say they feel angry and upset by the changes the cancer and its treatment have caused.

It is natural to worry about how your family and friends will react, and whether your partner or a potential partner finds you physically attractive.

It may help to let others know how you are feeling. They probably want to support you and reassure you that they still love you and see you in the same way as they did before the diagnosis. Hearing what they have to say may boost your confidence.

If you don't feel comfortable talking to friends or family about how you feel, consider speaking to your health care team or a professional counsellor. You may also find it valuable to talk to someone who has had a similar experience. Call Cancer Council Helpline 13 11 20 for information on support services.

Look Good...Feel Better program

This free program teaches techniques to help restore appearance and self-esteem.

It is for people having cancer treatment, but may also be available to people who have recently completed treatment.

For more information and to learn if you are eligible for the program, call **1800 650 960** or visit **www.lgfb.org.au**.

Sexuality and intimacy

Cancer and its treatment may affect your sexuality and intimacy in physical and emotional ways. Some people don't feel any differently sexually after treatment, but if you do, it can be hard to deal with. These changes may be temporary or ongoing.

Anyone who has had cancer treatment may have sexual concerns, but those most likely to experience long-term problems include:

- women treated for breast or gynaecological cancers
- women who experience early menopause see page 44
- men treated for testicular or prostate cancer
- people treated for rectal or lower bowel cancer
- people who have a stoma because of their treatment.

Cancer Council has more information on how cancer treatments can affect sexuality and intimacy. Call the Helpline on **13 11 20**.

Types of problems you may have

Cancer and its treatment may change your appearance and your sexual response. Hormone levels or the nerves supplying the genital area may have been affected, causing physical problems such as vaginal dryness or erectile dysfunction. This can affect your desire for sex.

You may feel less sexual because you look different or feel less attractive. Some people feel embarrassed and upset by changes to their body and don't want their partner to see them naked. Some people say they were not prepared for the sexual changes caused by treatment. Others say that they avoid all forms of intimacy including hugs, kisses and sharing feelings, in fear that it may lead to sex when they don't want it. Some people worry that they will never be able to have an intimate relationship again.

If the cancer treatment has affected your ability to have children, this may also change the way you feel about having sex.

- Plan sexual activity for the time of day when your pain is lowest. To be most effective, pain medication should be taken shortly before sex.
- Show affection by touching, hugging, massaging, talking and holding hands.
- Talk to your partner if you have little or no interest in sex (low libido). They may be able to help you get in the mood. They may also need to accept that you may not be able to get in the mood for some time.
- Try different ways of getting aroused: shower together, have a weekend away, wear something sexy – whatever

makes you feel relaxed and good about yourself.

- If you have vaginal dryness or tightness, try a waterbased lubricant, vaginal moisturiser or cream during sex. Some women who have had radiotherapy or surgery may be advised to use a dilator to keep their vagina open and supple.
- Change position during sex to work out which position is the most comfortable for you.
- Ask your doctor if any medications can help with sexual problems, such as difficulties getting or maintaining an erection.

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You may not even be aware that you aren't taking an interest in sex or being as intimate as you were before. If you have a partner, this can be confusing for them and it may make them feel uncertain about how to react.

Talking to your partner about how you're feeling can help. Let them know why you don't want sex but reassure them that you love them. Most partners will be happy to do things at your pace.

- Spend more time on foreplay: watch a romantic movie, look at erotic magazines or DVDs, create a sexy atmosphere with dim lighting, music or candles.
- Physical activity can stimulate sexual desire by increasing energy and lifting your mood.
- Dancing is not only great exercise, but it can also arouse your sexual desire as you get physically close to your partner.
- Be intimate at the time of day best for you (e.g. in the morning when you feel refreshed) and have shorter lovemaking sessions.

- If you feel comfortable, stimulate yourself. This may give you the reassurance that you can still enjoy sex. Or you may want to stimulate your partner and help them reach orgasm, even if you don't want this yourself.
- Health professionals with specialised training can help you cope with specific sexual problems. It can be helpful to get advice and support, rather than 'put up with it'. Talk to your doctor – either with your partner or separately – and ask for a referral.

tips

Menopause

Menopause means a woman's ovaries no longer produce eggs and her periods stop. The average age for a woman to experience natural menopause is 52.

Menopause after treatment for cancer may be temporary or permanent. Whether your periods stop temporarily or permanently, you may experience menopausal symptoms. Cancer treatments that can cause menopause include certain chemotherapy drugs, radiotherapy to the pelvic area, hormone treatment and surgery to remove the ovaries (oophorectomy).

Men who are taking hormone treatment or have had their testicles removed may experience menopausal symptoms similar to women. It may help to read this section.

For women who want children, menopause can be devastating. Even if your family is complete or you didn't want children, you may have mixed emotions and worry about the impact on your relationship. Some women find menopause difficult because they feel it has taken away a part of their identity as a woman. See page 46 for more information about fertility problems.

Symptoms

While natural menopause can be a difficult time for a woman, it may be more difficult if menopause happens suddenly because of cancer treatment. Symptoms may be severe because the body hasn't had time to get used to the gradual decrease in hormone levels. You may experience hot flushes, mood swings, trouble sleeping, tiredness and vaginal dryness. Many of these symptoms will eventually pass, though it can take months or a few years.

You are also at risk of developing weak and brittle bones (osteoporosis). Ask your doctor how to manage this condition.

- Hormone replacement therapy (HRT) can help reduce symptoms.
 However, this may not be recommended because studies have shown that using HRT with oestrogen and progestogen for longer than five years can increase the risk of some diseases, such as breast cancer.
- Talk to your doctor about non-hormone medications that might help with symptoms such as hot flushes.
- Use oestrogen, contained in creams or pessaries, to relieve vaginal dryness.

Moisturisers without oestrogen can also be used.

- Eat a healthy diet with lots of fresh fruits and vegetables, and wholegrains. Ask your doctor if you want advice about diet modifications or herbal remedies.
- Extra lubrication may make intercourse more comfortable. Choose a water or silicone-based gel without perfumes or colouring to reduce irritation (e.g. Sylk[®] or Pjur[®]).
- Take more time before and during penetration to help the vagina relax and become more lubricated.

tips

Fertility problems

Some cancer treatments can cause temporary or permanent infertility (inability to conceive a child).

Although chemotherapy and radiotherapy reduce fertility, it may still be possible for women to become pregnant after treatment, or for men who have had treatment to father a child.

Your doctor may suggest you wait a certain period of time before trying to conceive. For example, some people wait for a year or two to give their body time to recover, and allow eggs and sperm to become healthy again. Some form of contraception must be used during this time.

If you are told you'll be permanently infertile, you may feel a great sense of loss and grief. You might be devastated that you won't have your own children or additional children, and you may worry about the impact of infertility on your relationship. Even if your family is complete, you may be distressed.

Infertility may make you feel that you have lost control of what you wanted in your life. You may feel very angry, sad or anxious that the cancer and its treatment caused these changes to your body. Talking to a counsellor about how you are feeling might help.

tip

If you have trouble conceiving after cancer treatment, ask your doctor for a referral to a fertility specialist.

Lymphoedema

Lymphoedema is a swelling of part of the body, usually a limb such as the arm. It may occur after lymph nodes are removed during surgery, or if they are damaged by other treatment. When lymph nodes do not drain lymph fluid properly, it causes fluid build-up and swelling.

Signs of lymphoedema include redness; swelling; skin warmth; a feeling of pain, heaviness or fullness in the arm; and tingling in the fingers.

Symptoms are better managed if treated early. For example, if you have swelling, it may be reduced by wearing a professionally fitted elastic sleeve. You can also have massage treatment from a trained lymphoedema drainage therapist, physiotherapist, nurse or occupational therapist. A directory of lymphoedema practitioners is available at www.nlpr.asn.au.

Infection can make the symptoms worse. To prevent infection in the affected arm:

- keep the skin moisturised
- avoid sunburn
- avoid cuts, burns and insect bites
- avoid using blood pressure cuffs and having injections.

Lymphoedema can take months or years to develop – some people who are at risk never develop it.

Some hospitals have specialist physiotherapists who can help reduce your risk of developing lymphoedema. You can do simple exercises such as shoulder rolls, elbow bends and hand clenching.

For more information see the Lymphoedema Association of Australia website, www.lymphoedema.org.au. You can also contact Cancer Australia for a copy of the booklet *Lymphoedema – What You Need to Know*. Call 1800 624 973 or download it from http://canceraustralia.nbocc.org.au.

● I had some lymphoedema in my right arm. This causes me little trouble unless it is a particularly hot day or if I have exercised too much. I have regular massages to keep the fluid moving. ● Amanda

Cognitive problems

After treatment many people say they have difficulty concentrating, focusing and remembering things. This usually happens after chemotherapy, so cancer survivors call it chemo brain. However, other treatments (e.g. hormone therapy and radiotherapy) and side effects such as fatigue or depression can also affect how well you function.

Researchers are looking into what causes the memory and concentration problems that some patients have after treatment. Chemo brain usually improves, but it may take a year or more.

tips

- Use your mobile phone, a calendar or daily planner to keep track of tasks, appointments, social commitments, birthdays etc.
- Plan your activities so you do things that require more concentration when you are more alert, e.g. mornings.
- Set aside time each day to read and respond to emails.
- If you are working and have your own office, close the door when you don't want to be interrupted.
- Put personal items (e.g. wallet, keys) in a dedicated place at home and at work so you don't misplace them.
- Let phone calls go through to your answering machine or voicemail. You can listen

to them and think about how you will respond when you feel ready.

- Make notes of things you have to remember, e.g. a shopping list or where you parked the car.
- Do tasks one at a time rather than multi-tasking.
- Get plenty of sleep and exercise. Deep sleep is important for memory and concentration, and getting some physical activity every day will help you sleep better.

I've returned to work in my full-time role. I'm probably at 90% of what I used to be. I'm aware that I can't overdo it. I need to get a lot of rest and take it easy in the evening so I can be productive the next day.

Feeling down or depressed

Feeling low or depressed after treatment finishes is common. Some people may feel fine at first and then start to feel sad or down a few weeks, months or even years later.

Feeling down

Knowing why you feel low can help you to work your way through your feelings. Some people feel sad or depressed because of the changes that cancer has caused. Others become very down because they are frightened about the future. They may wonder if the cancer will come back, if they will be able to work again and how their family will cope if they can't earn enough money.

Support from family and friends or health professionals may help you cope better during these periods.

Depression is more than feeling down for a few days. It may mean you feel in a low mood most of the time, or your sadness lasts two weeks or more.

Signs of depression

If you have one or more of these symptoms for a few weeks or more, you should see your GP:

- feeling very sad and low most of the time
- loss of interest in and pleasure in normal activities
- having negative thoughts about yourself a lot of the time
- eating more or less than usual

- weight gain or loss
- feeling very tired most of the time
- having trouble concentrating
- loss of interest in sex (low libido)
- changes in your sleep habits, e.g. not being able to fall asleep, waking in the early hours of the morning or sleeping much more than usual
- feeling restless, agitated, worthless, guilty, anxious or upset
- having very little or reduced motivation
- being extremely irritable or angry
- thinking that you are a burden to others or feeling guilty
- a desire to self-harm
- a desire to kill yourself.

These are not only the symptoms of depression; some can be caused by other medical conditions. Talk to your doctor about how you are feeling.

Getting help with depression

Depression won't go away by itself – it needs specific treatment. There are many effective treatments for depression, and they don't necessarily include medication. Treatment for depression may include therapy provided by a GP, trained psychologist, psychiatrist or counsellor. Tackling depression early may mean that you can deal with problems quickly and avoid symptoms becoming worse.

In addition to getting professional help to treat depression, the tips on the following pages may help you.

tips

- Take care of yourself. Eat a well-balanced diet with lots of fresh fruit and vegetables and drink plenty of water.
- Set small and achievable goals. Remember to not expect too much from yourself.
- Get regular exercise. Studies have shown that being active helps lift a person's mood and improves fatigue.
- Share your feelings with someone close to you. Just having them know exactly how you feel may help you feel less alone.
- Go out and do something you enjoy. A change of scenery can often make you feel better. Spend time outside in the fresh air. Schedule a pleasant event or daily activity.
- Review your priorities.
- Try not to judge yourself too harshly. Self-criticism can lead to more feelings of hopelessness.

- List activities you used to enjoy and plan to do one of these activities each day.
- Write down how you're feeling or express yourself in painting, drawing, music or singing.
- Get up at the same time each morning, regardless of how you feel.
- Try a complementary therapy, such as massage, yoga, hypnosis, acupuncture and reflexology.

Herbal products to treat depression

Some people who have recovered from cancer are interested in using herbal products to treat depression. Though these products are labelled as natural, it doesn't always mean that they are safe. Some can have serious side effects and may interact with other drugs that you are taking.

Two herbal products that are commonly used to treat depression are St John's wort and Ginkgo biloba. Some research suggests that these herbs may help lift mood for some people, however other research has not found this to be the case. Both have side effects and should not be taken along with any other anti-depressant drugs. St John's wort also interacts with many other standard medications.

Check with your doctor before using any herbal products. You can also call Cancer Council Helpline 13 11 20 for more information about complementary therapies.

Other problems

You may have other problems after treatment, such as:

- changes in the way your bladder and bowel work
- problems with eating, drinking and your weight
- mouth and teeth problems
- tingling hands and feet.

If you would like more information on managing these problems or any other problems, contact the Helpline.



Key points

- After treatment, side effects can take weeks, months, or even years to resolve.
- Fatigue is the most common side effect of treatment.
- Controlling any pain may allow you to return to many of the activities you enjoy.
- Taking medications regularly is the best way to prevent pain from starting or getting worse.
- Changes to your body after treatment can change how you feel about your body (self-esteem).
- The effects of treatment on sexuality may be temporary or ongoing.
- Some people are infertile after treatment. Infertility can be difficult for people who want to have children or who would like the choice to have children in the future.

- Lymphoedema can occur if the lymph nodes are damaged or removed. It is managed by preventing or controlling the swelling, and taking care to avoid infections.
- After treatment, many people say they have difficulty concentrating. This is often referred to as chemo brain.
- Feeling low or depressed after treatment finishes is common. Talk to a counsellor, psychologist or psychiatrist if you are feeling down.

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Staying healthy after treatment

Many cancer survivors adopt a healthier lifestyle after their cancer experience.

Studies on people who have survived cancer are limited compared with studies about preventing cancer. The evidence varies for different cancers, but research does suggest that a healthy lifestyle can stop or slow the development of many cancers (in combination with conventional treatment). It also shows that some people who have had cancer may be at an increased risk of other health problems, such as heart disease, lung problems or diabetes.

While more research needs to be done, the lifestyle changes recommended for cancer prevention may also help reduce the chance of the cancer coming back or a new cancer developing. They can also prevent other health problems.

Maintain a healthy body weight

A healthy body weight is important for reducing the risk of cancer recurrence and improving survival. The health risk associated with your body weight can be estimated using different techniques including the Body Mass Index and waist circumference (see next page). Visit www.health.gov.au for more information on the Body Mass Index.



If you have lost a lot of weight during treatment, you may have to regain some weight to return to a healthy weight.

Waist circumference and health risk

Having fat around the abdomen or a potbelly, regardless of your body size, means you are more likely to develop certain obesity-related health conditions. Fat predominantly deposited around the hips and buttocks doesn't appear to have the same risk. Men, in particular, often put on weight around their waist.

MenWomen• 94 cm or more –
increased risk• 80 cm or more –
increased risk• 102 cm or more –
substantially increased risk.• 88 cm or more –
substantially increased risk.

Waist circumference can be used to indicate health risk.

Dietitians can help

Dietitians can help you with any nutrition concerns. They are available in all public hospitals and some private hospitals. Community health centres often have a dietitian. Ask at your local centre.

The Dietitians Association of Australia can direct you to an accredited practising dietitian in your area or to one who has experience in particular problems. Go to www.daa.asn.au or call 1800 812 942. Dietitians in private practice are also listed in the *Yellow Pages*.

tips

- Make fruit and vegetables, wholegrain breads, cereals, pasta and rice and other lowfat foods the basis of your diet.
- Choose lean cuts of meat and trim as much fat as possible before cooking.
- Remove the skin from chicken.
- Limit your intake of red meat and processed meat, such as sausages.
- Cook food in ways that use less fat – grill, steam, poach or bake.
- Use a non-stick frypan or a spray of oil when pan-frying.
- Try low-fat varieties of milk, yoghurt and cheese.
- Don't use butter or margarine, or use only a scrape.

- Limit the number of high-fat takeaways. For instance, avoid Asian foods with a lot of coconut milk.
- Avoid high-fat snacks such as crisps and biscuits.
- Reduce portion sizes.
- Eat slowly and listen to your body – only eat when you're hungry and stop eating when you're full.

• Before he goes to work, my husband makes me a salad for lunch. Then I know that there is something healthy to eat, even if I'm too tired to prepare it. • Denise

Eat more vegetables and fruit

Vegetables and fruit contain vitamins, minerals and phytochemicals, which are natural substances such as antioxidants that may destroy cancer-causing agents (carcinogens). Vegetables and fruit are also high in fibre and low in fat, which helps to control your weight.

Aim to eat a variety of different coloured vegetables and fruits to ensure you get enough of the substances in plant foods that may protect against certain types of cancer. The Australian Dietary Guidelines recommend two serves of fruit and 5–6 serves of vegetables a day.



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How to eat more vegetables and fruit everyday

- Enjoy fruit as a snack or for dessert.
- Add fresh or canned fruit as a topping on breakfast cereal.
- Fill half your dinner plate with vegetables.
- Include at least three different coloured vegetables with your main meal.
- Keep it interesting cook vegetables in different ways, e.g. oven roasted, grilled, barbecued, stir fried.
- Include salad with lunch.

- Eat raw or cooked vegetables as a snack.
- Keep fresh fruit on the table.
- Shop for fresh vegetables and fruit regularly to ensure you have a fresh supply available.
- Use frozen, dried or canned vegetables and fruit if fresh varieties are not available.
- Adapt your recipes to include more vegetables, e.g. add carrot, celery and peas to bolognaise sauce.

Handle and prepare food safely

Food safety is particularly important for many people who have survived cancer.

Some cancer treatments, such as chemotherapy, may weaken the immune system. People who have a weakened immune system are at increased risk of food-borne illness (food poisoning). You may need to take extra precautions with food preparation and storage.

tips

- Wash your hands with warm water and soap before preparing and cooking food.
- Keep kitchen counters, chopping boards and utensils clean.
- Avoid cross-contamination by using separate chopping boards and knives for preparing raw meat, fish or chicken.
- Thaw frozen foods in the refrigerator or microwave. Do not thaw frozen food on the kitchen bench.
- Keep hot food steaming hot and cold food cold.

- Read expiry dates on food products and check for signs of food spoilage. If in doubt, throw it out.
- Keep cooked food on a higher shelf in the fridge above raw food to lower the chance of uncooked meat juices falling into cooked food.
- Avoid pre-prepared or precooked cold food that will not be reheated, e.g. deli salads, pâté, quiches and cold meats like ham and salami.

Dietary supplements

People who have survived cancer often consider taking dietary supplements such as vitamins and herbal tablets to optimise their health.

Some believe that high-dose vitamin supplements strengthen the body's immune system. However, there is little scientific evidence to support these claims, and some studies have suggested that vitamin supplements may be harmful at high dosages. The general rule is that dietary supplements should never replace whole foods like fruit and vegetables, which are the best source of vitamins and minerals. Discuss plans to take vitamin supplements with your doctor or dietitian.

Frequently asked questions about food Should I stop eating meat?

There is no conclusive evidence that vegetarians or those who become vegetarians do better after cancer treatment. However, eating too much red meat, especially processed meats such as sausages, bacon and frankfurts, is associated with a slightly increased risk of bowel cancer.

It is important to eat a diet that is high in plant foods, such as fruits, vegetables and cereal foods, but there is no need to give up meat.

Should I only eat organic foods?

The term 'organic' is used to describe foods grown without pesticides or herbicides. Organic fruit and vegetables tend to be higher in vitamin C compared with conventionally grown varieties.

However, all types of fruits and vegetables are good for your health, whether organic or conventionally grown. There is no current evidence that organic fruit and vegetables are more effective in reducing cancer risk than conventionally grown fruit and vegetables. It is a good idea to thoroughly wash fruits and vegetables to remove any traces of pesticides.

Which is best - raw or cooked vegetables?

Try to eat both raw (e.g. salad) and cooked vegetables. Boiling vegetables for a long time can reduce the amount of vitamins. Steaming and microwaving vegetables are good cooking methods to maintain their nutritional goodness.

Should I juice vegetables and fruit?

It is best to mostly eat whole vegetables and fruit rather than as juices because they contain fibre, which is protective against bowel cancer. Juices are much higher in kilojoules (calories) than fresh vegetables and fruit, which is an issue if you're watching your weight.

I saw a news story about a certain type of food that is said to prevent/cause cancer. Should I eat a lot of it/avoid it?

News stories about certain foods or diets can be confusing. They sometimes present evidence relating to studies done in laboratories, rather than on humans.

Certain types of fruit and vegetables are sometimes called 'superfoods'. Although all fruit and vegetables are healthy and should be eaten regularly, there is no single superfood. This word may be used as a marketing term rather than as scientific fact. It's wise to consider whether an advertiser is promoting the superfood label.

There is also no single food that has been shown to cause cancer. Evidence supports eating plenty of fruit and vegetables and moderate serves of red meat and energy-dense foods. Talk to your health care team or call the Helpline for more information. **6** Being diagnosed with stomach cancer gave me the incentive to give up smoking...I feel so much fitter. **9** *Tim*

Quit smoking

If you are a smoker, Cancer Council strongly recommends that you quit. There is no safe level of tobacco use. Tobacco smoke contains more than 7000 chemicals, including 69 known cancer-causing agents (carcinogens). Research shows that by continuing to smoke, you are more likely to develop another type of cancer.

Many smokers find quitting difficult. Don't be discouraged if it takes several attempts before you are able to quit successfully.

- Ask your doctor for advice. Subsidised prescription medications are available on the Pharmaceutical Benefits Scheme (PBS).
- Call Quitline on **13 QUIT** (**13 7848**) to talk confidentially to a quitting advisor and request a free Quit Pack.
- Make a decision not to "just have one".
- Make your home and car smoke-free zones.

- Think of previous attempts to quit as practice, and learn what worked and what didn't.
- Keep a list of all the reasons you want to quit.
- Think of yourself as an ex-smoker.
- Avoid tempting situations.
- Get support online visit www.quitcoach.org.au or www.icanquit.com.au.

tips

Be physically active

Physical activity helps to protect against some types of cancer coming back. There are many other benefits to being active besides this possible protection. Exercise can also boost energy levels, decrease fatigue, increase strength, relieve stress, reduce heart disease and lower anxiety and depression.

If you are unsure about whether you are well enough to exercise or if it will interfere with your recovery, talk to your doctor first.

Start physical activity slowly and increase gradually. Every person is different and the amount and type of activities will vary. Doctors usually recommend about 20–30 minutes a day of moderate physical activity.

tips

- Walking is great exercise.
 Walk with a friend or join a walking group, walk to the corner shop instead of driving, or try walking in the water instead of swimming.
- Do some gardening.
- Do some simple stretching exercises while watching television.
- Take the stairs instead of the lift or escalators.

- Do vigorous housework such as vacuuming or mowing the lawn.
- Get off the bus or train one stop earlier or park further away from your destination and walk the rest of the way.
- Take your children or grandchildren to the park or kick a ball around the backyard.
- Take a dance class.

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Protect yourself in the sun

Skin cancer is the most common cancer diagnosed in Australia. More than 1200 Australians die from skin cancer every year, yet it is almost totally preventable. Protect your skin from the sun and avoid other sources of UV radiation (such as solariums).

- Wear clothing that covers as much of your skin as possible, including the back of your neck. Shirts with sleeves and a collar, trousers, and long skirts or long shorts that cover a large part of your legs are ideal. The best protection comes from closely woven fabric, as UV radiation can go through thin material.
- Protect your face, neck and ears with a hat. Broad brim, bucket style and legionnaire style hats provide good protection.
 Baseball caps aren't recommended. Adult hats should have at least an 8–10 cm brim.
- Wear SPF30+ broad-spectrum water-resistant sunscreen when you go into the sunlight for periods longer than 15 minutes and reapply every two hours.
- Protect your eyes with sunglasses that meet the Australian Standard AS 1067 (check the tag). Wrap-around styles are best.
- Never allow your skin to burn. Avoid being in the sun when UV radiation is high, between 10am and 3pm.
- Check the daily SunSmart UV Alert reported in weather forecasts across Australia. See www.cancer.org.au/sunsmart.

Limit or avoid alcohol

Alcohol is a risk factor for some cancers, particularly cancer of the mouth, throat, oesophagus, bowel, liver and breast. Limiting alcohol may also decrease the risk of cancer recurrence.

Cancer Council recommends that, to reduce the risk of cancer, you should limit or avoid alcohol.

For more information on standard drinks and alcohol, visit www.alcohol.gov.au.

A guide to standard drinks

For men and women who choose to drink alcohol, the recommended amount is an average of no more than two standard drinks a day. One standard drink contains 10 grams of alcohol. However, different drinks have different alcohol volumes, so it is best to drink in moderation and know what you are consuming.

- 100 mL (small glass) of red wine = 1 standard drink
- 100 mL (small glass) of white wine = 0.9 standard drinks
- 30 mL (one nip or shot) of spirits = 1 standard drink
- 60 mL (two nips or shots) of port = 0.8 standard drinks
- 285 mL (one middy, half pint or pot) of normal strength beer
 = 1.1 standard drinks
- 375 mL of mid-strength beer = 1 standard drink
- 425 mL (one schooner) of low-alcohol (light) beer = 0.9 standard drinks.

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A balanced approach

The risks and benefits of drinking alcohol vary for different diseases. A small amount of alcohol taken regularly may provide some protection against heart disease, but usually only for middle-aged people. This possible benefit needs to be balanced against the increased risk of liver cirrhosis, stroke, high blood pressure and cancer.

There are many other healthy habits that can reduce both the risk of cancer recurrence and heart disease, such as healthy eating, regular physical activity and not smoking.

- Use water to quench thirst.
- Start with a non-alcoholic drink.
- Sip alcoholic drinks slowly.
- Switch to light beer. Alternate alcoholic drinks with water or soft drinks.
- Order half nips of spirits.
- Don't fill wine glasses to the top.
- Have a spritzer or shandy (wine or beer mixed with non-alcoholic soda or mineral water).

- Wait until your glass is empty before topping it up to help keep count of your drinks.
- Have a few alcohol-free days during the week, especially if you are a regular drinker.
- Eat while you drink to slow your drinking pace and to fill you up.
- Avoid salty snacks, which make you thirsty so you drink more.
- Offer to be the designated driver so that you don't drink or limit your alcohol intake.

tips



Key points

- Many survivors say they want to live a healthier lifestyle after cancer treatment.
- A healthy body weight is important for reducing the risk of recurrence and improving survival.
- Eating a variety of fruit, vegetables, wholegrain breads and cereals, pasta, rice and other low-fat foods helps to maintain a healthy body weight.
- If your immune system is weak after treatment, take extra precautions to handle and prepare food safely.
- There is little scientific evidence to suggest that taking high-dose vitamin supplements is beneficial. Talk to your doctor before taking a supplement.
- There is no safe level of tobacco use. Your doctor

can give you advice about quitting smoking.

- Sun protection will reduce your risk of skin cancer.
- Exercise is important for weight maintenance and also helps boost energy levels, decreases fatigue and relieves stress. Doing regular exercise may reduce the chance of cancer coming back.
- Limiting alcohol may help decrease the risk of cancer recurrence and will improve your general health and well-being.

Legal, financial and workplace concerns

After any serious illness, people may have concerns about financial issues, insurance policies, superannuation and work. Cancer Council Helpline 13 11 20 can provide contact details for local support services to help you cope with these problems.

Financial assistance

Cancer treatment can be expensive. Stopping work, paying for treatment, buying medications and travelling to treatment may leave some people with financial problems.

If you're struggling with debts, ask your lender if there is a financial hardship provision. Centrelink may be able to provide benefits – call 13 27 17. You can also see a financial adviser – visit www.financialcounsellingaustralia.org.au.

Insurance and superannuation

Applying for new insurance (life, income cover or travel) may be more difficult because you have had cancer. You will need to provide your medical history for many insurance policies. However, you shouldn't have problems claiming on policies you had before diagnosis.

If your mortgage is associated with some kind of insurance, you may need to let your lender know that you had cancer.

It may be difficult to get travel insurance that covers medical problems related to the cancer, but you should be able to get a policy to cover basics such as lost baggage, theft and cancelled flights. You may also be able to claim on an insurance policy provided by your superannuation fund. For more information, talk to the fund manager or contact National Legal Aid on 1300 888 529 or www.nla.aust.net.au.

Working after treatment ends

Work is an important part of life for many people. Besides income, it can provide satisfaction and a chance to socialise. If you took time off work for treatment, you may choose to return to work or get a new job when you have recovered. Some people need to do this because of income and family needs.

Do I have a right to return to my job?

Australian laws require an employer to take reasonable steps to accommodate the effects of an employee's illness, e.g. providing a supported chair or moving your workstation to the ground floor.

If you are unable to carry out your previous role, your employer doesn't have to offer you a different job, but they can't terminate your employment for at least 12 months.

Must I disclose that I had cancer when applying for a new position?

While some people want to mention their cancer experience when they apply for a job, you don't have to tell a potential employer unless it is relevant to the position. If you'd prefer not to, and are asked about a gap in your resume, you might want to say that you had a health issue and it's now resolved.
A prospective employer can ask you about your ability to perform tasks that are an essential part of the job, e.g. lifting heavy boxes. If something is a problem for you because of the cancer or treatment, it's best to mention it at the interview.

What if I can no longer work?

If treatment has made it impossible to return to your previous work, then rehabilitation and retraining programs can prepare you for another job. Your employer may have a rehabilitation scheme.

Where can I get more information?

Cancer Council has more detailed information about employment and cancer. Visit www.cancercouncil.com.au to download a free copy of *Cancer, Work and You*.

Discrimination at work

Misconceptions about cancer may mean some people are treated differently at work after a cancer diagnosis. Employers and colleagues may doubt your ability to work, or think you need more time off.

Anyone who has had cancer is protected by the Disability Discrimination Act, which prevents employers from discriminating against people with disabilities in the workplace.

If you need advice, speak to a social worker, a solicitor, your state or territory antidiscrimination body, Fair Work Australia, the Australian Human Rights Commission, a union official or a local community health centre.



Key points

- If you have financial problems, you may be able to get assistance through payments or subsidies. Talk to a social worker or financial counsellor if you are struggling with debts.
- You shouldn't have problems claiming on an insurance policy you had before you were diagnosed with cancer.
 If you aren't satisfied with an insurer, you can complain or appeal.
- Cancer survivors can get travel insurance, but the terms and conditions will vary depending on your condition and the insurer.
- You don't have to disclose a cancer diagnosis when applying for a new job.
- When returning to work, your employer must make reasonable adjustments to help you do your job.

 You should not be treated negatively in the workplace on the basis of your diagnosis.
 The Disability Discrimination Act protects anyone who has had cancer.



Many people find they need support after treatment finishes. The availability of services may vary depending on where you live. Some services are free, but others may have a cost.

Community education programs

Some areas offer free community education programs for cancer patients and survivors. These may be held at treatment facilities or community centres.

Programs present information about cancer and its treatment and practical information about life after treatment. They may be open to carers, family, friends and work colleagues. You may find it helpful to share tips and ideas with other participants.

Call Cancer Council Helpline 13 11 20 to ask if there are any cancer survivor programs in your area.

Talk to someone who's been there

Getting in touch with other people who have been through a similar experience can be very beneficial. There are many ways to contact others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future. Ask your nurse or social worker to tell you about support groups in your area. You can also call Cancer Council Helpline 13 11 20 to find out how you can connect with others.

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**

Telephone support groups – for certain situations or types of cancer, which trained counsellors 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*

Cancer Council library

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

Your local library may have some relevant and useful resources. Cancer Council also has a range of books, CDs, DVDs and medical journals that may be helpful for you and your family. Call the Helpline to find out how to access the library service.

* This service is not available in Victoria and Queensland.



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

Australian

Cancer Council Australia	www.cancer.org.au
Cancer Australia	www.canceraustralia.gov.au
Cancer Connections	www.cancerconnections.com.au
Cancer Voices Australia	www.cancervoicesaustralia.org.au
Carers Australia	www.carersaustralia.com.au
Australian Cancer Survivorship Centre	www.petermac.org/cancersurvivorship
NSW Cancer Survivors Centre	www.cancersurvivors.unsw.edu.au
beyondblue	www.beyondblue.org.au

International

American Cancer Society	
Cancer Survivors Network	http://csn.cancer.org
Lance Armstrong Foundation	www.livestrong.com
National Cancer Institute	www.cancer.gov/
	cancertopics/life-after-treatment
Cancer Survivorship Research	
National Cancer Institute	http://survivorship.cancer.gov
National Coalition for	
Cancer Survivorship	www.canceradvocacy.org
Memorial Sloan Kettering Cancer (Center www.mskcc.org
Macmillan Cancer Support	www.macmillan.org.uk

Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about living well after treatment. If your doctor gives you answers that you don't understand, it is okay to ask for clarification.

- Am I at risk of getting a different type of cancer or another serious health problem, due to the cancer or its treatment?
- Are my children at risk of inheriting my type of cancer?
- How can I stop worrying about the cancer coming back?
- What problems should I watch out for?
- Am I likely to have long-term problems with pain? How can I control pain?
- What can I do to stop feeling so tired all the time? What can I do to help me sleep better?
- Where can I get help for dealing with my feelings? Can you refer me to a professional counsellor or psychologist?
- Should I follow a special diet now that treatment has finished? Who can give me advice about eating a healthy diet?
- Is there a particular exercise program you would recommend?
- What sexual changes are likely to be short term and what changes are likely to be long term?
- Who can I talk to about financial problems?
- Is it possible to talk to someone who has survived the same type of cancer?
- Are there any complementary therapies that might help me?
- Where can my family get help and advice?



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

acupuncture

A traditional form of Chinese medicine in which fine, sterile needles are inserted into points in the body to reduce symptoms of ill health.

active treatment

Treatment given to cure the cancer, such as chemotherapy or radiotherapy. This does not include long-term treatment such as hormone medication, which may be taken for several years to maintain remission.

advanced cancer

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

analgesic

A drug or natural remedy used to relieve pain.

anti-depressant

Medication to help relieve the symptoms of depression.

cancer survivor

A person who has finished their active cancer treatment and is free from any signs of cancer.

check-up

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

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

complementary therapies

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

depression

Very low mood and lack of motivation lasting for most days and more than two weeks.

diagnosis

The identification and naming of a disease.

fatigue

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

fertility

The ability to conceive a child. **five-year survival rate**

The percentage of people alive five years after diagnosis.

follow-up

Medical appointments to follow your progress after your treatment. See check-up.

hormone therapy

A treatment that blocks the body's natural hormones, which help the cancer to grow.

late effects

Side effects of cancer treatment that occur several months or years after treatment.

lymphoedema

Swelling caused by a build-up

of lymph fluid when lymph nodes do not drain properly.

menopause

When a woman stops having periods (menstruating). metastasis (plural: metastases)

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

morphine

A strong opiod commonly given to people with cancer.

opioids

The strongest pain relievers available. Include morphine, fentanyl, codeine, oxycodone, hydromorphone and methadone.

osteoporosis

Thinning of the bones that can lead to bone pain and fractures.

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.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Internal radiotherapy is called brachytherapy.

recurrent cancer

Cancer that comes back after an initial remission.

remission

When the symptoms and signs of the cancer reduce or disappear. A partial remission is when there has been a significant reduction in symptoms but some cancer is still present. A complete remission is when there is no evidence of active disease.

secondary cancer

See metastasis.

statistics

Collecting and analysing data to make comparisons and see patterns in research results. Reference from page 5: Stanton, AL., Ganz, PA., Rowland, JH., Meyerowitz, BE., Krupnick, JL., Sears, SR. (2005). Promoting adjustment after treatment for cancer. Cancer. 104 (11 Suppl), 2608–13.

🔒 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 Helpline 13 11 20

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

For the cost of a local call (except from mobiles), you, your family, or friends can talk about your concerns and needs confidentially with experienced cancer nurses. Helpline nurses can send you information and put you in touch with support services in your area.

If you need information in a language other than English, you can call the Multilingual Cancer Information Line (see the back cover).

Helpline is open Monday to Friday, 9am to 5pm. If calling outside business hours, you can leave a message and your call will be returned the next business day.

Cancer Council Publications

If you found this booklet helpful, you might want to request another free resource from the Cancer Council. Call the Helpline if you would like a copy of any of the following resources:

- Life with cancer
- Sexuality and cancer
 Nutrition and exercise
- Loss and grief: A guide for cancer survivors and people with cancer
- Coping with cancer fatigue



Cancer information in your language

Do you speak a language other than English? Do you have guestions about cancer?

For the cost of a local call (except from mobiles), you can confidentially talk to a nurse from Cancer Council Helpline with the help of an interpreter.

Simply follow these steps:

- 1. Call 13 14 50, Monday to Friday, 9am to 5pm.
- 2. Say the language you need.
- **3.** Wait on the line for an interpreter (may take up to 3 minutes).
- **4.** Ask the interpreter to contact Cancer Council Victoria Helpline **13 11 20**.
- 5. You will be connected to the interpreter and a cancer nurse.

For further information and details please visit our website: **www.cancervic.org.au**