



Living Well After Cancer

A guide for cancer survivors,
their families and friends

Practical and
support
information

For information & support, call

13 11 20



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Thank you to the health professionals and consumers who worked on previous editions of this title.

Note to reader

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

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

Cancer Council

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



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Cancer Council 13 11 20

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

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

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

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

Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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



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

Introduction

This booklet is for people who have finished cancer treatment, such as surgery, chemotherapy or radiotherapy. Many people now live for a long time after cancer treatment. After a cancer diagnosis, people are often kept very busy and preoccupied with medical appointments and the demands of treatment. The end of treatment may be a time when you realise the impact cancer had on you, your family and friends.

We hope this booklet assists you with the emotional, physical, practical, spiritual and social challenges you may face now that treatment has finished. These challenges will vary depending on the type of cancer and treatment you had, and your personal situation. For details on support services see page 78.

You might like to pass this booklet to your family and friends. It may help them to understand that you may still face some difficult times even though your treatment is over.

How this booklet was developed

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

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



**Cancer
Council**
13 11 20

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Who is a cancer survivor?

‘Cancer survivor’ means different things to different people. For some, a cancer survivor is anyone who has been diagnosed with cancer. Others use the term to refer to people who are alive many years after their cancer treatment.

The transition from patient to survivor is different for everyone. Some see themselves as a survivor from when they become free from signs of cancer. Others see themselves as a survivor when active treatment stops. Either way, you may wonder: what now?

For many people, ‘survivor’ is a strong and positive term. However, others feel it implies that they will struggle to cope with cancer in the future. Some people do not like being labelled at all and may prefer to put their cancer experience in the past. You may find it difficult to relate to the title of survivor because you believe your treatment was relatively simple. Instead, you may refer to yourself as someone who has had cancer or is living with cancer.

In this booklet we use the term ‘survivor’ to mean anyone who has finished their active cancer treatment. No matter how you feel about the word ‘survivor’, or the words you choose to use, we hope this booklet will be helpful.



Improved methods of cancer detection and treatment have led to an increase in the numbers of people surviving and living with cancer for longer periods of time. There are approximately 920,000 people who have been diagnosed with cancer at some stage in their life currently living in Australia.



Finding a ‘new normal’

Cancer is often described as a journey that starts during the process of diagnosis. During treatment, some people feel that their life is on hold, or in limbo.

When treatment ends, you may want life to return to normal as soon as possible, but you may not know how. Or you may want or need to make changes to your life. Over time, survivors often find a new way of living. This process is often called finding a ‘new normal’ and may take months or years.

Adjusting to the ‘new normal’

People often feel both excited and anxious when treatment ends. You may need time to stop and reflect on what has happened before you can think about the future.

- You may feel a sense of loss or abandonment as your engagement with the treatment team and support from family and friends becomes less intense.
- On the outside, you may look normal and healthy. But on the inside you may still be recovering physically and emotionally.
- Your family and friends may not fully understand what you’ve been through, or realise that the cancer experience doesn’t necessarily stop when treatment ends.

It may help to allow yourself time to adjust to these changes, and to ask your friends and family for their support and patience during this period.

A life-changing experience

Most people refer to cancer as a life-changing experience, with many finding there are positive aspects to having had cancer. Some people discover an inner strength they didn't know they had. Others may develop new friendships during their treatment or discover new sources of support.

Cancer may cause you to re-examine your priorities in life. You may find you now place more value on your relationships with family or friends, or you may want to make changes to some relationships. Some people are motivated to travel or start new activities. You may want to make changes to your lifestyle, such as reducing stress, starting exercise or quitting smoking. See *Taking control of your health* on page 58 for more information. This shift is often gradual; even positive change can take time.

After treatment, some people want to help improve the cancer experience for others through advocacy, support groups, fundraising or volunteer work. If this interests you, call Cancer Council **13 11 20** when you are ready to find out what options are available in your area. There is no hurry. Focus first on your recovery. It is important to look after yourself if you want to help others.

““ 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

Misconceptions about treatment ending

I should be over it

After finishing treatment, people may expect life to return to the way it was before the cancer diagnosis. For many people, the reality is 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. Many feel as though they have fought a battle and need time to recover.

I should feel well

Many cancer survivors have ongoing health concerns because of the cancer or treatment side-effects. These may include fatigue, sleep disturbance, physical disability, poor body image or self-esteem, pain, anxiety, or depression. The after-effects of treatment may make everyday life difficult.

I should feel grateful

Survivors can sometimes feel

pressured to feel grateful.

However, the impact of cancer and its treatment on your life and future may leave you feeling upset, angry and resentful.

I should not need any more support

Some survivors are surprised to feel that they need more support than ever now.

I should be celebrating

Some survivors feel they should be happy and full of wisdom because they survived, and may feel guilty or confused if they don't.

I should be the person I was before cancer

Many survivors say that cancer changes them. You may need time to adjust to changes in your body or physical appearance. You may feel different after treatment, even though you look the same. Many survivors feel a sense of loss for the person they once were or thought they'd be.

“After my treatment, a psychologist explained that it’s common to feel like you’ve had the rug pulled out from underneath you after a major trauma. It’s also common to question your view of the world and your beliefs. Knowing that, and how normal it is, helped tremendously.” David

tips

Adjusting to the ‘new normal’

- Assess your life. Ask yourself: What fulfils me? What is important to me? What gives my life meaning?
- Focus on each day and expect both good and bad days.
- Do things at your own pace. Rest between activities.
- Share your feelings and worries with family and friends, a psychologist or counsellor.
- Seeing a life coach may help you to develop goals and strategies to get your life back on track.
- Keep a journal. Many people find it helps to write down how they’re feeling.
- Talk to your doctor if you are feeling sad or have low moods.
- Learn some form of relaxation or meditation, such as mindfulness, visualisation, yoga or deep breathing.
- If you are worried about going out for the first time, ask someone to accompany you.
- Read about other survivors’ stories. Learning about other people’s experiences may help.
- Join a support group or attend a survivorship program. Connecting with other cancer survivors may help you cope and feel more positive about the future. For more information see page 78.



Key points

- Cancer is often described as a journey that starts at diagnosis.
- For many people who have finished cancer treatment, life has changed and is not quite the same as it was before diagnosis.
- After treatment ends, you may find that people expect you to feel well, get on with your life and not need support. For many, this may not be the case.
- Many survivors find they need ongoing support after their treatment finishes.
- Having mixed feelings after treatment ends is common.
- Many survivors don't feel the way they expect to after their treatment ends.
- You may find you need time to recover, physically and emotionally, after your treatment ends.
- Many people find they need time to reflect on their cancer journey. This may mean re-evaluating their values, goals and priorities in life. With time they find a new way of living – a 'new normal'.
- Some cancer survivors say there were positive aspects to their cancer experience.



Understanding your feelings

While the majority of people adapt well to life after treatment, many people experience ongoing fears or concerns. You may find you need a lot of support – maybe even more than you did when you were diagnosed or during treatment.

Common feelings

Relief – You might be relieved that the treatment has finished and seems to have been successful. You may welcome the chance to focus on other things, such as your usual activities.

Isolation – Many people feel abandoned or less secure when regular appointments with their health care team reduce or stop. This can feel like losing a safety net. You may also feel alone or lonely if your relationships have changed or people don't understand what you've been through.

Fear of recurrence – Fear that the cancer will return is common among cancer survivors. For many, this fear never fully goes away, but most survivors learn to manage it. You may have difficulty distinguishing normal aches, pain or sickness from cancer symptoms. For more information see page 17.

Uncertainty – Many survivors feel stuck and are reluctant to plan for the future because they feel uncertain about their health.

Frustration – Some people feel frustrated because they think their family and friends expect too much from them. You may still feel unwell and need extra support.

Anxiety about follow-ups – Many people feel anxious in the lead up to follow-up appointments and may feel these appointments ‘bring it all back’. Waiting for test results can also be a very anxious time.

Worry – You may be concerned about side effects: how long they will last and if they will affect your life. Many survivors are worried about financial pressures or being a burden to their family.

Worry about returning to work – Many survivors worry about coping with work and colleagues asking them about their diagnosis and treatment. For more information see page 75.

Lack of confidence – You may feel differently about your body and health. You may not trust your body and feel it has let you down. Many people feel vulnerable and self-conscious about their body image and sexuality (see page 49).

Feeling down/depressed – You may feel sad or down about your cancer experience and its impact on your life (see page 12).

Survivor guilt – Some people feel guilty or question why they have survived their cancer when others have not.

Anger – You may feel angry about your cancer experience and how it has affected your life.

Delayed emotions – You may find your emotions catch up with you now that treatment is over. Many people find this confusing, as they do not expect negative emotions once their treatment ends.

“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

Accepting your feelings

Acknowledging how you are feeling may help you to work through your emotions. Most cancer survivors find that they do feel better over time. However, cancer survivors often experience worry, fear of recurrence, or periods of feeling down for months or even years after treatment.

Friends and family may advise you to ‘think positively’. It is almost impossible to be positive all the time; everyone has good and bad days, before and after a cancer diagnosis. There is no scientific evidence to suggest that positive thinking has any impact on surviving cancer. However, many survivors say that feeling hopeful helped them to cope with their illness and make positive changes, such as increased exercise.

Feeling down or depressed

Feeling low or depressed after treatment ends 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. Support from family and friends or health professionals may help you cope better during these periods.

Feeling down

Some people feel sad or depressed because of the changes that cancer has caused, or 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 whether their family will cope if they can't earn enough money. Sometimes you may feel down for no particular reason.

Depression

Depression is more than feeling down for a few days. If you have one or more of the following symptoms for a few weeks or more, you should see your GP:

- feeling very sad and low most of the time
- loss of interest or pleasure in activities you normally enjoy
- having negative thoughts about yourself a lot of the time
- eating more or less than usual
- weight gain or loss
- feeling very tired or a lack of energy most of the time
- having trouble concentrating
- loss of interest in sex (low libido)
- sleep changes or problems, 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 little or reduced motivation
- being extremely irritable or angry
- thinking that you are a burden to others
- thinking about hurting or killing yourself.

Some of these symptoms can also be caused by other medical conditions. Talk to your doctor about how you are feeling.

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

Getting help with depression

Depression generally won’t go away by itself – specific treatment is needed. Treating depression early may mean that you can deal with the problem quickly and avoid symptoms becoming worse.

There are many effective treatments for depression, which don’t necessarily include medication. Treatment for depression may include therapy provided by a GP, psychologist, psychiatrist or counsellor. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

beyondblue has information about coping with depression and anxiety. Go to www.beyondblue.org.au or call **1300 224 636**.

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

“No matter how good your support people are, sometimes you need someone who’s professionally trained.” Jenny

Managing your mood

- 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 and review your priorities. Don't expect too much from yourself.
- Try to do some physical activity every day – this will help you sleep better and improve your mood.
- Share your feelings with someone close to you. Having someone know exactly how you feel can help you feel less alone.
- Spend time outside in the fresh air. A change of scenery might make you feel better.
- Try not to judge yourself too harshly. Self-criticism can lead to increased 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, music or singing.
- Get up at the same time each morning, regardless of how you feel. Make an effort to have a shower and get dressed.
- Allow yourself a 'low mood day' every now and again. You don't have to be 'up' everyday.
- Consider complementary therapies, such as massage, yoga, meditation, acupuncture or reflexology.
- Keep a record of positives about each day.



Key points

- It's normal to have many different feelings after treatment ends.
- Some of your feelings may be similar to those you experienced 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, concern about returning to work, lack of confidence, and anger.
- Acknowledging and talking about how you're feeling may help you manage your emotions.
- It's common to have some worries or periods of sadness for months or years after treatment.
- Feeling low or depressed after treatment finishes is common. Talk to your GP, a counsellor, psychologist or psychiatrist if you are feeling down.
- Visit www.beyondblue.org.au for resources to help with managing depression/anxiety.



Fear of the cancer coming back

Feeling anxious or frightened about the cancer coming back (recurrence) is one of the most common challenges and greatest concerns for cancer survivors. Most cancer survivors are likely to experience this fear to some degree.

This fear may affect your physical wellbeing, as well as your ability to enjoy life and make plans for the future. Some survivors describe it as a dark cloud or a shadow over their life.

Many people find that their worry is worse 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
- 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 or melanoma warning).

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

Managing the fear of recurrence

- A number of psychological interventions specifically address the fear of cancer recurrence and have been shown to be effective. Ask your GP for more information or call Cancer Council 13 11 20.
- Learn to recognise and manage the signs of stress and anxiety, such as a racing heartbeat or sleeplessness.
- Mindfulness, meditation and yoga have been found to help in managing this fear.
- Talk to your specialist about your risk of recurrence and educate yourself about your type of cancer.
- Focus on what you can control, e.g. being actively involved in your follow-up appointments and making changes to your lifestyle.
- Social support is important and has been found to play a protective role in the fear of recurrence.
- Joining a support group may help. See page 78 for more information.
- Not all symptoms are a sign of cancer, they may indicate other health problems e.g. diabetes, arthritis, high blood pressure etc.
- See your doctor if you notice any new symptoms, or symptoms that have returned. Don't wait for your next check-up.

Will the cancer come back?

You may wonder how likely it is that the cancer will come back or how long people with the same type of cancer survive. The risk of cancer coming back (recurrence) is different for each person and depends on many factors including cancer type and stage, genetics, type of treatment and time since treatment. Talk to your doctor about your risk of recurrence. Generally, the likelihood of cancer recurring decreases over time.

For information on how to take control of your health and reduce your risk of cancer recurrence, see page 58.

Survival statistics

Many doctors are wary of using the term ‘cure’ because undetected cancer cells can remain in the body after treatment, causing the cancer to return. Instead they may use the term ‘five-year survival rate’. Australia has among the best survival rates for cancer in the world.

The five-year survival rate is determined by the percentage of people alive five years after diagnosis.

Cancer is most likely to recur in the first five years after treatment ends. Risk of recurrence depends on the type and stage of cancer, type of treatment and time since treatment.



These statistics are usually adjusted to account for other causes of death in the general population (called ‘relative survival rates’), and thus refer to the percentage of people who would have survived if cancer was the only cause of death. For example, it is estimated that 10 out of every 100 people diagnosed with breast cancer will die from the disease within five years. Another way of saying this is that the relative survival from breast cancer is 90%. 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) are likely to have a much better outlook than people diagnosed with late stage/advanced 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 2014, the doctor may use survival rates for people diagnosed in 2007 (followed for five years until 2012). With cancer treatments improving all the time, your outcome (prognosis) is likely to be better than it would have been in 2007.

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

Asking your doctor how your risk has changed at your check-ups can be a good way of learning what the latest statistics are, or how much your risk has reduced since your treatment finished.

Fear of getting a different cancer

Some survivors worry about developing a different type of cancer. While this is not common, approximately 10% of cancer survivors will develop a second primary (new) cancer.

See *Managing the fear of recurrence* on page 18 for useful tips that may also assist with the fear of developing a different cancer.

The following factors may increase your risk of developing another type of cancer:

- being born with an inherited gene that increases your tendency to develop cancer (accounts for 5–10% of all cancers)
- exposure to cigarette smoke or other cancer-causing agents
- skin damage caused from overexposure to the sun's UV rays
- ageing
- undergoing some forms of cancer treatment, particularly as a child.

Talk to your doctor if you are concerned about your risk factors.

“ It helps to focus on what is happening now, what is actually known – not all the possibilities. One step at a time. ” Jane

Checking for signs of a new cancer

It's important to know what is 'normal' for you. If you notice any unusual changes in your body or have any concerns, see your doctor as soon as possible. Don't wait until your next scheduled check-up.

The main signs and symptoms to look out for include:

- a lump, sore or ulcer that doesn't heal
- a mole that bleeds or has changed shape, size or colour
- a cough or hoarseness that doesn't go away, or a cough that produces blood
- a change in bowel habits (e.g. diarrhoea or constipation for more than six weeks)
- urinary problems or changes
- unusual changes in your testicles (for men) or breasts (for women)
- persistent abdominal pain or bloating
- abnormal bleeding
- unexplained weight loss
- unexplained fatigue.

To help detect cancer early, national screening programs are available for breast (women aged 50–69), cervical (women aged 18–70) and bowel (men and women aged over 50) cancers.

For more information, talk to your doctor, call Cancer Council **13 11 20** or visit www.cancerscreening.gov.au.

““ Having cancer has meant I've learn a lot more about my body and about life than a lot of people ever learn. ●● Petronella



Key points

- Many cancer survivors worry that the cancer will come back.
- This concern may be worse at certain times such as special occasions, follow-up appointments, and hearing about other people diagnosed with cancer.
- Many find the fear of recurrence lessens with time. However, this is not always the case.
- To help detect cancer early, people of certain ages can take part in free national screening programs for the early detection of bowel, breast and cervical cancers.
- You can reduce your cancer risk through healthy lifestyle choices such as quitting smoking, eating healthily, limiting or avoiding alcohol, staying SunSmart every day and taking time to be active.
- The risk of recurrence depends on cancer type and stage, type of treatment and time since treatment.
- Doctors use five-year survival statistics to refer to the number of people who are alive five years after diagnosis.
- Most people who get cancer only get one type. However, approximately 10% of cancer survivors will develop another type of cancer.
- If you notice new or concerning symptoms, make an appointment with your doctor.



Follow-up care

After your treatment has finished, you will be advised about regular check-ups. These will allow your doctor to monitor your health and wellbeing. Follow-up care differs depending on the type of cancer and treatment and the side effects experienced.

Many treatment centres now work with people as they approach the end of their treatment to develop survivorship care plans. These care plans are designed to set out a clear schedule for follow-up care and ensure that any medical and psychosocial problems which may develop after treatment are identified and managed. For more information or to develop your own survivorship care plan, visit www.livestrongcareplan.org or www.journeyforward.org.

Your treatment summary

Ask your surgeon or oncologist for a written summary of your cancer type, treatment and plans for follow-up care. A copy should be given to your GP and other health care providers.

This summary should include the following information:

- cancer type
- date of diagnosis
- diagnostic tests results and pathology results, including cancer stage and grade, and tumour marker information
- full treatment details
- symptoms to watch for and possible long-term side effects
- contact details for the health professionals involved in your treatment and follow-up care.

Common questions

What do post treatment check-ups involve?

During check-ups your doctor may:

- assess your recovery
- 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
- perform a physical examination
- ask if you have any concerns or questions
- discuss your general health and give healthy lifestyle advice refer you to other health professionals and services, as necessary (such as a dietitian, psychologist, physiotherapist).

Blood tests and scans may be required, e.g. mammograms for women treated for breast cancer and Prostate-Specific Antigen (PSA) tests for men treated for prostate cancer. Not everyone will require or benefit from ongoing tests.

It is important to be honest with your doctors so that they can help you manage any problems you may be having. For example, tell them if you feel low in mood or energy.

If you see a news story about cancer and you want to know if this research or information could be relevant to you, note down some of the details and ask your doctor about it at your next check-up.



How often do I need check-ups?

The frequency of check-ups depends on the type of cancer and treatment you had, and your general health. Some people have check-ups every 3–6 months for the first few years after treatment, then less often after that. Talk to your doctors about what to expect and ask if Australian guidelines exist for your follow-up care.

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

Who do I see for follow-up care?

You may have follow-up appointments with your specialist, GP or a combination of both. Often, your GP will provide your primary follow-up care, and liaise with specialists if needed. You will still need to see your GP to monitor your overall health e.g. checking your blood pressure, cholesterol levels and weight.

You may also need to see other allied health professionals such as a psychologist/counsellor, oncology social worker, occupational therapist, physiotherapist, exercise physiologist, dietitian, speech pathologist or specialist nurse.

How can I prepare for check-ups?

It may help to write down any questions you have and take this list with you to your appointment (see the list of suggested questions on page 82). If your doctor uses medical terms you don't understand, ask for them to explain in plain English. If you have several questions or concerns, ask for a longer appointment when

booking. Taking notes or making an audio recording during the consultation can also help you to remember what was discussed.

Many people like to have a family member or friend go with them for emotional support or to take part in the discussion. You may wish to ask them to take notes or simply wait in the waiting room.

Tell your doctor or nurse if you have:

- difficulty doing everyday activities
- any new symptoms
- new aches or pains that seem unrelated to an injury, or usual ones that have become worse
- changes in weight or appetite
- feelings of anxiety or depression
- other health problems, such as heart disease, diabetes or arthritis
- new medications you are taking or other complementary or alternative 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 sex life, how cancer has affected your relationships, or practical issues such as returning to work or financial difficulties.

You may want to ask about a referral to see an allied health professional, such as a dietitian, psychologist, physiotherapist or exercise physiologist. You should tell each health professional you see about your cancer diagnosis and treatment, as this may affect the treatment they give you.

Managing anxiety before check-ups

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

You may feel anxious before check-ups because:

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

You may find check-ups easier once you have had a few and things are going okay.

In the meantime, finding ways to cope with your anxiety before check-ups may help. You may find some of the coping strategies on the opposite page helpful in easing your anxiety.

““ 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. ●● Georgia

Coping with check-ups

- Take a close friend or relative with you to your check-ups.
- Share your fears with people close to you.
- Plan to do something special after your follow-up appointment.
- Try to see your check-ups as a way of taking care of and protecting yourself. If problems are picked up early they may be easier to treat.
- Learn mindfulness and meditation skills, or practise deep breathing.
- 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 feel more optimistic.
- Ask if it is possible to see the doctor elsewhere if you are not comfortable going to the hospital or treatment centre.
- Try to book tests close to your next doctor's appointment.



Key points

- Many cancer survivors say they feel anxious before their routine check-ups.
- Follow-up care is usually different for each person and depends on the type of cancer and treatment you had, and any long-term side effects you are having.
- You may have a physical examination, blood test and scans as part of the check-up. Although not everybody needs these.
- Having a clear follow-up plan and asking your doctor what to expect at your follow up appointments may help you feel less anxious.
- Ask your surgeon or oncologist for a copy of your treatment summary. This will provide medical guidance for your GP and other health care providers.
- Follow-up care may be provided by your GP, the doctor who first treated your cancer or both. Your GP can also help to coordinate your care and check your general health. You may also want to see other health professionals such as a physiotherapist, psychologist, dietitian or specialist cancer nurse.
- It's a good idea to work with your treatment team to develop a survivor care plan.



Family and friends

After treatment is over, your family and friends may also need time to adjust. Research shows that carers can also go through 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. You may want to tell them how much you appreciate all they have already done to help you, and let them know if you still need their support.

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 again
- exhausted
- confused, especially if your relationship has changed
- pleased that cancer no longer dominates conversations
- worried about what the future holds.

Encourage your family and friends to seek support. They can call Cancer Council **13 11 20** or Carers Australia on **1800 242 636** for support or information.

“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 you did before the cancer. If you have changed, people close to you may be confused, 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, can persist for long periods of time, and you may need continued support.

It's natural for family and friends to want the distress and disruption of cancer to be behind you. They care about 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, that you need time to adjust and think about what you've been through. It may be useful to ask friends and family to read this booklet.

Will my family inherit my cancer?

If you've had cancer, it doesn't necessarily 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.

Coping with children's needs

Like many adults, children may struggle with the way family life changes after a cancer diagnosis. They may worry about the future or find it difficult to understand why life can't go back to the way it was before the cancer.

Talking to children about cancer can be difficult. However, conversations that are handled sensitively and honestly can be reassuring for young people. Children's reactions and needs will vary depending on their age.

tips

Communicating with children

- Try to be as open and honest as possible.
- Acknowledge the impact of cancer on your family. This is particularly important for teenagers.
- Depending on the age and understanding of the children, talk to them about your fears, e.g. anxiety before a follow-up visit. This may encourage children to also talk about their fears.
- Spend time together doing something they enjoy.
- Be open about how you feel emotionally and physically, so the children understand if you're not bouncing back.
- Explain any changes made to your family's lifestyle, and let them know if they are going to be permanent.
- Call Cancer Council 13 11 20 for a free copy of Talking to Kids About Cancer.



Key points

- Your family and friends may have many mixed emotions of their own: 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 they may be experiencing at the end of treatment.
- Encourage your family and friends to seek support. Cancer Council has a range of support services for family and friends. Call 13 11 20.
- If you or your family are worried about inheriting the cancer, talk to your GP or oncologist. You may be referred to a family cancer clinic or genetic counselling service.
- Family and friends also need time to adjust after your treatment.
- Children may find it especially hard to understand how you have changed. Talking to them at their level and being as open and honest as possible may help.



Treatment side effects

It can take time to recover from the side effects of treatment. Side effects can be both physical and emotional and vary depending on the cancer type and stage, and the treatment you had.

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

Common side effects include:

- feeling very tired (fatigue)
- pain
- loss of self-esteem and confidence
- changes in sexuality and sexual function
- menopausal symptoms for women
- fertility problems
- persistent swelling (lymphoedema)
- forgetfulness or memory problems (chemo brain)
- changes in bladder or bowel functioning
- problems with eating or drinking
- weight loss or gain
- mouth or teeth problems
- bone density loss (osteoporosis)
- hair loss or changes
- sleeping difficulties
- numbness or tingling in feet or hands (peripheral neuropathy)
- muscle aches and pains

Some people experience late side effects. These are problems that develop months or years after treatment finishes. They may result from scarring to parts of the body or damage to internal organs. If you are concerned about a new side effect, talk to your doctor.

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 **13 11 20**.

Fatigue

Fatigue, or feeling exhausted and lacking energy for daily activities, is a common physical side effect of cancer treatment.

Now that treatment is over, you may think you should be full of energy, but often this isn't the case. If you were unable to be active during treatment, you may have experienced a loss of muscle and fitness. This could contribute to your fatigue. Many people say that fatigue has a big impact on their quality of life in the first year after treatment.

Most people find that their energy returns 6–12 months after finishing treatment. However, some people lack energy for years after treatment and their energy levels may never fully recover.



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 have described fatigue after cancer treatment as overwhelming, debilitating and frustrating. Symptoms include:

- 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
- reduced mobility and loss of muscle strength (weakness)
- breathlessness after light activity, such as making the bed
- difficulty concentrating
- finding it hard to think clearly or make decisions
- having little or no interest in sex (low libido).

Managing fatigue

Many cancer survivors don't tell their doctor about fatigue because they think that nothing can be done about it. However, your treatment team may be able to help. For example, your fatigue may be caused by low red blood cells (anaemia), an underactive thyroid gland, depression or the side effects of drugs, which your doctor may be able to address.

The tips on the following page may help you. Not all suggestions will work for everyone, but you may find that small changes make you feel better. Talk to your health care team for more suggestions.

●● A lot of rest, and doing Pilates and other exercise has helped my ongoing well-being. ●● Donna

tips

How to manage fatigue

- Set small, manageable goals – Focus on doing a little bit each day rather than a lot all at once.
- Ask for help – Get a friend to help with school pick-ups, shopping or mowing the lawn.
- Plan your day – Make a task list and do the activities that are most important to you when you have the most energy.
- Take it slow – Work at your own pace and take regular breaks.
- Relax – Try calming activities like walking on the beach, sitting in a peaceful setting, spending time in the garden, having a long bath or listening to music.
- Leave plenty of time to get to appointments.
- Be realistic – Don't expect to be able to instantly do everything you used to do. Your body is still recovering and it will take time for your energy levels to return.
- If you have children, sit down to play. Try activities like reading, board games, puzzles and drawing.
- Say no to things that you don't feel like doing.
- Regular light exercise can boost energy levels and reduce fatigue. Try short walks, pilates or tai chi. A physiotherapist or exercise physiologist can develop a suitable rehabilitation program. Talk to your GP before starting a new exercise program.
- Smoking reduces your energy. If you smoke, talk to your doctor about quitting, call the Quitline on 13 QUIT (13 78 48) or visit www.quitnow.gov.au.
- Take it easy – Sit down to talk on the phone or do light chores. Do your shopping online. Talk to an occupational therapist for more tips on reducing fatigue in specific daily activities.

“I had no idea that I would still be feeling tired months after finishing treatment. I didn’t know how to make it better and I was scared that’s how it would be; that I wouldn’t go back to normal, that I would never go back to having energy again.” George

Sleep disturbance

Difficulty sleeping is common among people who have had cancer. Sleep can be affected by symptoms related to the cancer treatment as well as environmental, physical and psychological factors. People who have pre-existing sleep problems can have additional sleep difficulties after their cancer diagnosis.

tips

Managing sleep disturbance

- Only go to bed when tired.
- Get up at the same time each morning, including weekends.
- Do not take daytime naps.
- Reduce/eliminate the use of alcohol, caffeine, nicotine or certain food (e.g. spicy food).
- Exercise regularly.
- Avoid looking at the clock throughout the night.
- Ensure the room is dark, quiet and a comfortable temperature.
- Set up a pre-sleep routine to help you to relax.
- If medication interferes with your sleep, discuss alternatives with your doctor.
- Call Cancer Council 13 11 20 for a free relaxation CD.

Pain

Pain can have a big impact on your life and prevent you from doing the things you want to do.

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

Controlling the pain may allow you to return to many of the activities you enjoy. Discuss your pain with your doctor so that the cause of the pain can be worked out and the best treatment plan developed. How you manage your pain depends on the type of pain you have. If your pain lasts for a long time or is constant, do something about it before it gets out of control.

Taking medication regularly is often 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.

tip

Let your doctors know how pain is affecting your day-to-day life, as this helps them plan the best treatment for you. A referral to a pain specialist or physiotherapist may help, or your pharmacist might be able to suggest ways to manage the pain.

Common pain-killing medications

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

- **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 help for some types of pain. 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 as prescribed by their doctor are generally not at risk of addiction, unless they have had addiction problems in the past. However, you may experience withdrawal symptoms when you stop taking a drug. For this reason, your doctor will reduce your dosage gradually. Talk to your doctor if you are concerned about drug dependence.

Will the pain-killers make me drowsy?

You may feel drowsy when you first start taking the medication, but this usually wears off within a couple of days. If the drowsiness continues, talk to your doctor. They may be able to adjust your dosage or change your medication.

Other methods of pain relief

For some people, pain can be relieved without taking tablets. Some people have surgery or an anaesthetic injected into their body (nerve block).

A physiotherapist or occupational therapist can suggest exercises or postural changes to address physical or practical problems that are causing your pain.

The following therapies may also help to 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 music may improve the effectiveness of other pain-relief methods, help you sleep and focus your attention on something other than the pain. Mindfulness and meditation use breathing techniques to quieten the mind and help you focus on the here and now.
- Massage may relieve muscle spasms and contractions. Call Cancer Council **13 11 20** for a free copy of *Massage and Cancer*.
- Applying hot or cold packs to areas of your body may provide relief.
- Acupuncture may help by stimulating the nerves to release the body's own natural chemicals, which help reduce pain or regulate the brain and other functions.

- Other therapies, such as hydrotherapy and Transcutaneous Electrical Nerve Stimulation (TENS) may also assist with pain relief. See a physiotherapist for more information.
- Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate. For example, your doctor may advise against a strong, deep tissue massage if you had surgery or bone problems during treatment. Always let your treating therapist know that you have had cancer. For more information call Cancer Council **13 11 20** for a free copy of *Overcoming Cancer Pain*.

Tingling or numbness in the hands or feet

Tingling or numbness in the hands or feet (peripheral neuropathy) is a common side effect for people who have had chemotherapy, and may last for some time after treatment finishes. Peripheral neuropathy can be annoying and frustrating, and may make it difficult for you to return to normal hobbies and activities. It may help to talk to your GP, or see an occupational therapist.

The lack of feeling in your hands and feet can cause safety problems. Protect yourself around the home by following these precautions:

- check your water temperature in your home to avoid burns
- use protective gloves while washing dishes
- wear cotton socks
- clear walkways and avoid the use of rugs
- install rubber mats in showers and baths to prevent slipping.

“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

Lymphoedema

Lymphoedema is swelling that occurs in soft tissue, usually a limb such as the arm or leg, after lymph nodes have been removed during surgery, or damaged by infection, injury, or other treatment such as radiotherapy. The likelihood of developing lymphoedema after treatment depends on the extent of the surgery, your cancer treatment and your body weight. Lymphoedema may be permanent, but it can usually be managed, especially if treated early. Signs of lymphoedema include persistent swelling, which may be associated with new feelings of heaviness, tightness, aches, or pins and needles.

Some hospitals have specialist lymphoedema physiotherapists or occupational therapists who can help to manage lymphoedema. They can provide advice on lymphatic drainage massage and exercises and can teach you simple exercises to reduce your risk.



For more information visit the Australasian Lymphology Association website, www.lymphoedema.org.au or call Cancer Australia on 1800 624 973 for a copy of *Lymphoedema – What You Need to Know*.

Managing your lymphoedema risk

- Avoid cuts, scratches, bites and injections in your affected limb.
- Use sunscreen to protect your skin from sunburn.
- Regularly moisturise your skin to prevent dryness and irritation, which can lead to infection.
- Avoid constrictions to your limb (e.g. don't apply blood pressure cuffs to the affected limb).
- Maintain a normal body weight.
- Take care cutting your toe nails or get a podiatrist to cut them.
- Engage in activities like swimming, bike-riding or using light weights to aid the flow of lymph fluid.
- Treat lymphoedema early so that you can deal with the problem quickly and avoid symptoms becoming worse.
- Lightly massage the affected area to help move fluid back towards the heart.
- Avoid exposure to heat.
- Wear a professionally-fitted compression sleeve or stocking when travelling, if advised by your physiotherapist or occupational therapist.
- Visit the Australasian Lymphology Association, www.lymphoedema.org.au, or ask your doctor to refer you to a lymphoedema therapist in your area.
- Raise your legs if watching TV and avoid sitting for long periods.
- Seek medical help urgently if you have lymphoedema and experience redness, swelling, throbbing or pain in your limb as these can be signs of infection which requires urgent treatment.
- Remember, lymphoedema can take months or years to develop and not everyone who is at risk will develop it.

Memory and cognitive problems

Many cancer survivors say they have difficulty concentrating, focusing and remembering things. This is often called ‘chemo brain’, as it is common after chemotherapy. However, some cancer survivors who did not have chemotherapy also report similar problems.

These memory and cognitive problems can also be caused by:

- fatigue
- emotional concerns, such as stress, anxiety or depression
- radiotherapy to the head, neck or whole body
- hormone therapy
- immunotherapy
- other medications
- infections
- vitamin or mineral deficiencies, such as iron, vitamin B or folic acid
- other health problems, including anaemia
- brain surgery
- tumours, cancer or metastases in the brain.

‘Chemo brain’ usually improves with time, sometimes taking a year or more. Researchers still aren’t sure exactly what causes the memory and concentration problems experienced by some cancer survivors, but there is ongoing research to try to find out.

Tell your doctor about any memory or cognitive problems you are having. Ask for a referral to a health care professional such as an occupational therapist who can advise you on strategies to overcome these difficulties and improve memory.

Managing memory problems

- Use your mobile phone, 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.
- Discuss these problems with your partner, family or workplace and ask for their support or assistance.
- Let phone calls go through to your answering machine or voicemail. You can listen to them when ready and prepare how you will respond.
- Do tasks one at a time rather than multi-tasking.
- If you are working and have your own office, close the door when you don't want to be interrupted.
- Make notes of things you have to remember, e.g. a shopping list or where you parked the car.
- Set aside time each day to read and respond to emails.
- Put personal items (e.g. wallet, keys) in a dedicated place at home and at work so you don't misplace them.
- Do some physical activity every day to help you sleep better. Deep sleep is important for memory and concentration.

Other physical problems

Cancer survivors can also experience a range of other physical problems after treatment.

Bowel or bladder changes

Changes to how your bowel or bladder works can be very distressing and difficult to adjust to. Some medications and cancer treatments can cause constipation, diarrhoea, or incontinence of the bowel or bladder. Some people have a stoma because of their treatment. These changes may be temporary or ongoing and may require specialised help or products.

For more information and support, call the National Continence Helpline on **1800 330 066** or visit www.continence.org.au or www.bladderbowel.gov.au.

Heart problems

Sometimes radiotherapy to the chest and heart area leads to an increased risk of heart problems after treatment. Risk factors for radiation-associated heart damage include:

- radiotherapy combined with chemotherapy
- younger age at treatment
- diabetes
- high blood pressure (hypertension)
- obesity
- smoking.

If you have received radiotherapy to the chest or whole body, or combined radiotherapy and chemotherapy, talk to your doctor about your heart health.

Mouth or teeth problems

You may have problems with your mouth or teeth, or find it difficult to swallow. These problems can affect your ability to eat, drink, manage your weight or talk. Depending on the type of cancer and treatment, these problems may be temporary or ongoing. It may help to see a dietitian or speech pathologist.

Balance or mobility problems

Surgery or cancer treatment may have affected your balance or ability to walk or move around. A physiotherapist or occupational therapist may be able to assist with these problems.

Hearing problems

Some chemotherapy drugs can affect your hearing. Some people lose the ability to hear high-pitched sounds or develop a constant ringing in their ears, known as tinnitus. Tell your GP if you notice any change in your hearing or if these symptoms don't go away.

If you would like more information about managing these or any other problems, call Cancer Council **13 11 20**.

Changed body image

Treatment for cancer can change how your body looks and works. How you feel about yourself (your self-esteem) may be affected by:

- changes to your appearance (e.g. from surgery)
- hair loss or hair growing back differently
- speech difficulties
- problems with eating or drinking

- breathing changes or shortness of breath
- weight loss or gain
- bladder or bowel changes (e.g. colostomy, ileostomy or nephrostomy)
- changes to your sex life and intimacy (see page 51)
- infertility (see page 56).

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

You may worry about how your family and friends will react, and whether your partner or a potential partner will still find you physically attractive. It may help to let others know how you are feeling. They probably want to provide support and reassurance that they still love you, and hearing what they have to say may boost your confidence.

If you don't feel comfortable talking to friends or family, consider speaking to your health care team or a counsellor. It may help to talk to someone who has had a similar experience. Call Cancer Council **13 11 20** for information on support services.



Look Good...Feel Better program

This is a free community service program dedicated to teaching people how to manage the appearance-related side effects caused by cancer treatment. Workshops are offered throughout Australia. For more information, 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. These changes may be temporary or ongoing and can be difficult to deal with.

Sexual difficulties can affect any cancer survivor, but those most likely to experience long-term sexual problems include:

- women treated for breast or gynaecological cancers
- women who experience early menopause (see page 54)
- men treated for testicular or prostate cancer
- people treated for cancer of the rectum or lower bowel
- people who have had head and neck surgery
- people who have a stoma because of their treatment.

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 this 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.

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, they may be confused or feel uncertain about how to react.

Talk openly with your partner about how you're feeling, what you want and any fears you have about sex. Ask your partner about how they are feeling. They may be worried about hurting you or appearing too eager. You may want to ask your partner to do things differently or talk about other ways of being intimate.

Common sexual problems after cancer treatment

General

- Loss of interest in sex
- Tiredness and fatigue
- Changed body image (due to scarring, loss of a body part or changes in weight)
- Infertility
- Pain
- Depression or anxiety
- Relationship changes or pressures

Men

- Erectile dysfunction
- Ejaculation problems

Women

- Difficulty reaching orgasm
- Vaginal dryness
- Reduced vaginal size
- Loss of sensation
- Pelvic pain
- Menopausal symptoms

Useful resources

- Sexuality, Intimacy and Cancer – for a free copy of this booklet call Cancer Council 13 11 20 or download it from your local Cancer Council website.
- Rekindle is a free and private online resource that addresses sexual concerns for all adults affected by cancer. Cancer survivors (whether in a relationship or single) and their partners can

use Rekindle. Rekindle can be personally tailored to meet your specific needs. Visit www.rekindleonline.org.au.

- Breast Cancer and Sexual Wellbeing – download a copy at www.bcna.org.au
- Intimacy and sexuality for women with gynaecological cancer – starting a conversation. To download a copy go to www.canceraustralia.gov.au

Managing sexual difficulties

- Seek professional advice and support. Talk to your doctor (with or without your partner). A referral to a sex therapist or physiotherapist may help.
- Show affection by touching, hugging, massaging, talking and holding hands.
- Spend more time on foreplay and try different ways of getting aroused: shower together, have a weekend away, watch a romantic or erotic movie, wear something sexy. Do whatever makes you feel relaxed and good about yourself.
- Try different positions during sex to work out which position is the most comfortable for you.
- Use a water or silicone-based lubricant during sex. Avoid products with perfumes or colouring to reduce irritation (e.g. Sylk® or Pjur®). Some women who have had radiotherapy or surgery may be advised to use a dilator to keep their vagina open and supple.
- Ask your doctor if medication can help with sexual problems, e.g. difficulty getting or maintaining an erection.
- Do some physical activity to boost your energy and mood.
- Dance with your partner. The physical closeness may help arouse sexual desire.
- Be intimate at a time best for you (e.g. when your pain is lowest or your energy levels are higher).
- Take some pain relief medication before having sex if you have ongoing issues with pain.
- Try shorter lovemaking sessions.
- If you feel comfortable, stimulate yourself. This may reassure you 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 any stimulation for yourself.

Menopause

Menopause means that a woman's ovaries no longer produce eggs and her periods stop. The average age for a woman to experience natural menopause in Australia is 51.

Some cancer treatments, including certain chemotherapy drugs, radiotherapy to the pelvic area, hormone treatment and surgery to remove the ovaries (oophorectomy), can cause symptoms of menopause. These symptoms can be temporary or permanent.

For women who want to have children, menopause can be devastating. Even if your family is complete or you didn't want children, you may have mixed emotions or worry about the impact of menopause on your relationship. See page 56 for more information about fertility. Some women find menopause difficult because they feel it has taken away a part of their identity as a woman.

Symptoms

When menopause occurs suddenly as a result of cancer treatment, symptoms may be more severe because the body hasn't had time to get used to the gradual decrease in hormone levels. Symptoms may include hot flushes, mood swings, trouble sleeping, tiredness and vaginal dryness. Many of these symptoms will eventually pass, although this may take months or a few years.



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

Some women who have already been through menopause find that these symptoms return during or after treatment.

Menopause also increases your risk of developing thinning of the bones (osteoporosis). Ask your doctor how to manage or prevent this.

tips

Managing menopause symptoms

- Hormone replacement therapy (HRT) can help reduce symptoms of menopause, but may not be recommended for some women who had hormone dependent cancers, such as breast or ovarian cancer. For more information and non-hormone alternatives, talk to your specialist.
- Ask your doctor for advice about diet modifications or herbal remedies
- Maintain a healthy weight and eat a healthy diet with lots of fresh fruits and vegetables, and whole grains.
- See page 53 for more tips about sexuality and intimacy.
- See your doctor about trying an oestrogen cream, which may relieve vaginal dryness.
- If vaginal dryness is a problem, take more time before and during sex to help the vagina relax and become more lubricated.

Fertility problems

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

Although chemotherapy and radiotherapy can reduce fertility, women may be able to become pregnant after treatment, and men may still be able to father a child.

Your doctor may suggest you wait a certain period of time before trying to conceive, in order to give your body time to recover, and allow eggs or sperm to become healthy again. Some form of contraception must be used during this time.

If you are told your infertility is permanent, you may feel a great sense of loss and grief, even if your family is complete. You may feel angry, sad or anxious that the cancer and its treatment caused these changes to your body or your plans for the future. Talking to a counsellor about how you are feeling might help.

Call Cancer Council **13 11 20** for more information or a free copy of *Fertility and Cancer*.

tip

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



Key points

- After treatment, side effects can take weeks, months, or even years to resolve.
- Side effects can be both physical and emotional and vary depending on the cancer type and stage, and the treatment you had.
- Fatigue is one of the most common physical side effects of treatment.
- Controlling any pain may allow you to return to many of the activities you enjoy.
- Pain medications should be taken regularly as advised by your doctor to best manage your pain by preventing it from starting or getting worse.
- Changes to your body after treatment can change how you feel about yourself (self-esteem).
- 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'.
- The effects of cancer treatment on sexuality may be temporary or ongoing.
- Some cancer treatments can cause symptoms of menopause. This can be temporary or permanent.
- Some people become infertile after treatment. Infertility can be distressing regardless of whether you want to have children in the future.



Taking control of your health

Cancer survivors may benefit from maintaining or adopting a healthier lifestyle after their cancer treatment.

Research suggests that a healthy lifestyle (in combination with conventional treatment) can stop or slow the development of many cancers. Research also shows that some people who have had cancer may be at an increased risk of other health problems, such as heart disease or diabetes.

While more research needs to be done in this area, the lifestyle changes recommended for cancer prevention may also help reduce the risk of the cancer coming back or a new cancer developing. Such lifestyle changes can also help prevent other health problems, such as heart problems and arthritis. Make sure you see your GP for regular lifestyle health checks. For more information, visit www.cutyourcancerrisk.org.au

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).



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

Waist circumference and health risk

Having fat around the abdomen or waist, regardless of your body size, means you are more likely to develop certain obesity-related health conditions. Fat that is mainly around the hips and buttocks doesn't appear to have the same risk. Men and post-menopausal women are more likely to gain fat around the waist.

Waist circumference can be used to indicate health risk. Place a measuring tape around your waist at the narrowest point between the lower rib and the top of the hips at the end of a normal breath.

Men	Women
• 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

Dietitians can help

Dietitians can help you with any nutrition concerns and are available in all public hospitals and some private hospitals and community health centres. Ask at your local centre or ask your GP for a referral.

To find an Accredited Practising Dietitian in your area or with experience in particular problems, call The Dietitians Association of Australia on **1800 812 942** or visit their website, www.daa.asn.au. Dietitians in private practice are also listed in the *Yellow Pages*. Ask about Medicare rebates.

tips

Strategies to improve your diet

- Make fruit and vegetables, wholegrain breads, cereals, pasta and rice, and other low-fat, low-sugar, high-fibre 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 to less than 500g a week and limit processed meats, such as ham, bacon and sausages.
- Grill, steam, poach and bake rather than fry.
- Use a non-stick frypan or a spray of oil when pan-frying.
- Try low fat, low-sugar milk, yoghurt and cheese.
- Use minimal butter or margarine, or go without.
- Limit take away foods that are high in fat and salt.
- Avoid snacks that are high in fat, sugar and salt such as chips, biscuits and chocolate.
- Avoid sugary drinks and sweetened beverages, such as milkshakes, and caffeine, sports and soft drinks.
- Reduce portion sizes.
- Eat slowly and only eat when you're hungry. Stop eating when you're full.
- Drink plenty of water.
- Adapt your recipes to include more vegetables, e.g. add grated carrot and zucchini, celery, capsicum and peas to pasta sauces.
- Fill half your dinner plate with vegetables.

“ 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 fruit and vegetables

Fruit and vegetables are low in fat and calories and help maintain a healthy body weight. They are high in nutrients such as fibre, vitamins and minerals.

The Australian Dietary Guidelines recommend two serves of fruit and 5–6 serves of vegetables each day (www.eatforhealth.gov.au). Aim to eat a variety of different coloured fruits and vegetables. Fruit and vegetables are best consumed fresh and whole (i.e. not in a juice or supplement form) and a combination of both cooked and raw vegetables is recommended.

One serve is equal to:



1 medium-sized piece of fruit



2 smaller fruits, e.g. plums, apricots or kiwi fruit



1 cup of fruit pieces



1 glass of fruit juice



1½ tablespoons of sultanas



½ cup of cooked vegetables



1 cup of salad vegetables

Frequently asked questions about food

Should I take dietary supplements?

People who have survived cancer often consider taking dietary supplements such as vitamins and herbal tablets to optimise their health. However, these products are not usually necessary for people who eat a healthy, well-balanced diet and there is no evidence that they improve survival after cancer.

Some people who have had treatment for cancer of the oesophagus, stomach, bowel, head or neck may have ongoing problems with food and eating, and may need to see a dietitian. However, in general dietary supplements should never replace whole foods like fruit and vegetables, which are the best source of vitamins and minerals.

When considering any dietary supplements or other complementary therapies, research the products and consider the following factors to make an informed choice:

- Talk to your doctor, pharmacist or dietitian before starting any dietary supplements or complementary therapies, to ensure the product is safe for you to use based on your medical history and current medications. Even products labelled as natural can have serious side effects and interact with your other medications.
- Check the product is listed or registered on the Australian Register of Therapeutic Goods (an AUST L or AUST R number is on the label), although this does not guarantee that the product is safe or effective.

- Consider the cost of the product, especially if its benefits are unclear or you are already experiencing financial difficulties.

Sometimes, cancer survivors can feel pressure from friends and family to use dietary supplements or other complementary therapies.

For more information about dietary supplements or other complementary therapies, call Cancer Council **13 11 20** to request a free copy of *Understanding Complementary Therapies* or visit www.iheard.com.au

Should I stop eating meat?

Eating a balanced diet that is high in plant foods, such as fruits, vegetables and wholegrain cereal foods is important, but there is no need to give up meat. Lean red meat is an important contributor to dietary iron, zinc, vitamin B12 and protein. Cancer Council recommends people eat moderate amounts of unprocessed lean red meat (65–100g of cooked red meat, 3–4 times a week).

There is no conclusive evidence that being (or becoming) a vegetarian has a positive impact on survival after cancer treatment.

However, eating too much red meat, especially processed meats such as sausages, bacon and frankfurts, is associated with an increased risk of bowel cancer and possibly prostate cancer.

Should I eat only organic foods?

The term 'organic' is used to describe foods grown without pesticides or herbicides. These foods are generally more expensive. There is no current evidence that organic fruit and vegetables are more effective in reducing cancer risk than conventionally grown fruit and vegetables. However, organic fruit and vegetables may be higher in vitamin C.

All types of fruits and vegetables are good for your health, whether organic or conventionally grown. It is important to thoroughly wash all fruits and vegetables to remove any dirt or traces of pesticides.

Which is better – raw or cooked vegetables?

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

Should I juice fruit and vegetables?

It is better to eat whole fruit and vegetables, rather than juices. Juices are much higher in kilojoules (calories) and do not contain the dietary fibre (which is protective against bowel cancer) of whole fruit and vegetables.

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’. However, this is more of a marketing term than a scientific fact. All fruit and vegetables are healthy and should be eaten regularly.

There is also no single food that has been shown to cause or prevent cancer. Evidence supports eating plenty of fruit and vegetables and moderate serves of red meat and energy-dense foods. For more information, talk to your health care team or call Cancer Council **13 11 20** or visit www.iheard.com.au.

Quit smoking

If you are a smoker, Cancer Council strongly recommends that you quit. There is no safe level of tobacco use and research shows that by continuing to smoke, you are more at risk of developing another type of cancer.

There are many benefits to quitting smoking. Research indicates that quitting after a cancer diagnosis can increase your expected survival time.

Many smokers find quitting difficult. Seek support and don't be discouraged if it takes several attempts before you are able to quit for good. See quitting tips on the following page.

 Being diagnosed with stomach cancer gave me the incentive to give up smoking...I feel so much fitter.  Tim

tips

Quitting smoking

- Ask your doctor for advice about subsidised medications to help you quit.
- Call Quitline on 13 QUIT (13 78 48) to talk to an advisor and request a free Quit Pack.
- Set a date to quit and tell your family and friends so that they can support you.
- Don't be tempted to "just have one".
- Make your home and car a smoke-free zone.
- Buy a reward with the money you would spend on cigarettes.
- Consider previous quit attempts as practice, and learn from what did and did not help.
- Keep a list of all the reasons you want to quit.
- Think of yourself as a non-smoker.
- Avoid tempting situations.
- Distract yourself if you feel tempted, e.g. going for a walk, having a drink of water etc
- Get support online – visit www.quitcoach.org.au or www.icanquit.com.au.

Be physically active

Being physically active and limiting sedentary behaviour every day is essential for health and wellbeing. Physical activity helps to reduce the risk of some types of cancer coming back and can boost energy levels, increase physical strength, relieve stress, reduce the risk of heart disease, improve sleep, and decrease fatigue, anxiety and depression.

Start physical activity slowly and build up gradually. Doing any physical activity is better than doing none. If you are unsure if you

are well enough to exercise or are concerned about disrupting your recovery, talk to your doctor about the amount and type of activity suitable for you or ask for a referral to an exercise physiologist. Many people lose physical strength during cancer treatment.

For more information, call Cancer Council **13 11 20** for a free copy of *Exercise for People Living with Cancer*.

tips

How to be more active

- Walking is great exercise. Walk with a friend or join a walking group, walk to the corner shop instead of driving.
- Do some simple stretches while watching television.
- Take the stairs instead of the lift or escalators.
- Do vigorous housework and activities around the home 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.
- Do some gardening.
- Take your children or grandchildren to the park or kick a ball around the backyard.
- Join a dance, tai chi or yoga class.
- If you are being physically active outdoors, remember to be SunSmart and use sun protection.

Protect your skin from the sun

Use a combination of protective measures to protect your skin from the sun when the UV index is 3 or above.

- SLIP on clothing that covers your shoulders, neck, arms, legs and body. Choose closely woven fabric.
- SLOP on SPF30 or higher broad-spectrum water-resistant sunscreen 20 minutes before going outdoors and reapply every two hours.
- SLAP on a broad-brimmed hat that shades your face, neck and ears. Adult hats should have at least an 8–10 cm brim.
- SLIDE on sunglasses. Choose close-fitting, wrap-around sunglasses that meet the Australian Standard AS 1067.
- SEEK shade. Make use of available shade such as trees or awnings or take your own shade such as umbrellas or beach tents.
- Avoid solariums and tanning beds, which give off UV radiation.

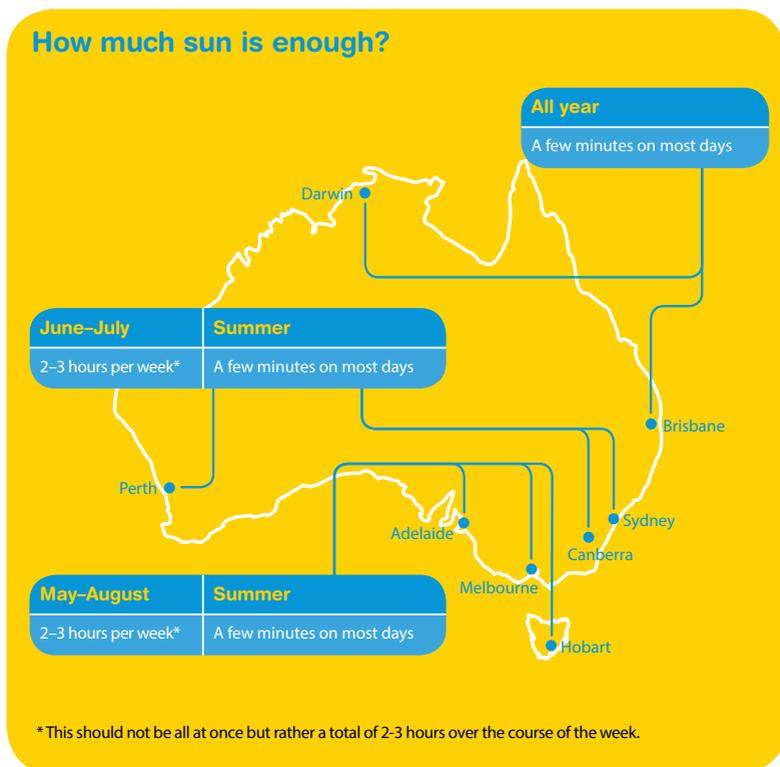
Some cancer treatments may make your skin more sensitive to the sun, causing it to burn or be damaged by the sun more quickly or easily than before. Ask your treatment team if this applies to you.



For more information, or to check the SunSmart UV Alert, visit www.sunsmart.com.au

How much sun is enough?

Some exposure to the sun is healthy. Vitamin D, which is essential to develop and maintain healthy bones and muscle function, is produced in the body when skin is exposed to UV radiation in sunlight. UV levels vary across Australia, according to the location, the season and the time of day. This means the amount of time you need to be in the sun to make enough vitamin D will vary.



Limit or avoid alcohol

Alcohol is a known risk factor for cancer. Cancer Council recommends that to reduce the risk of cancer, people limit their consumption of alcohol. Even low levels of alcohol consumption can increase cancer risk. Neither the World Health Organisation nor the National Heart Foundation of Australia recommend consuming red wine or any other alcoholic beverage to prevent cardiovascular disease.

A guide to standard drinks

For people who choose to drink alcohol, the National Health and Medical Research Council (NHMRC) recommends no more than two standard drinks a day. One standard drink contains 10 grams of alcohol. However, different drinks have different alcohol volumes.

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

Strategies for reducing your alcohol intake

- Use water to quench thirst.
- Alternate alcoholic drinks with non-alcoholic drinks, such as water.
- Sip alcoholic drinks slowly.
- Switch to light beer.
- Order half nips of spirits.
- Don't fill wine glasses to top.
- Have a spritzer or shandy (wine or beer mixed with soda or mineral water).
- Wait until your glass is empty before topping it up to 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 fill yourself up.
- Avoid salty snacks, which increase your thirst and make you drink more.
- Offer to be the designated driver so that you limit your alcohol intake or don't drink.



Key points

- Cancer survivors may benefit from maintaining or adopting a healthier lifestyle after their cancer treatment.
- Many survivors say they want to adopt a healthier lifestyle after cancer treatment.
- Physical activity and a healthy body weight are important for reducing the risk of cancer recurrence and improving survival.
- Physical activity is important to manage your weight and helps boost energy levels, decrease fatigue, relieve stress and improve overall wellbeing.
- Eating a variety of fruit, vegetables, wholegrain breads, cereals, pasta, rice and other foods low in saturated fat, salt and sugar helps to maintain a healthy body weight.
- If you have lost a lot of weight during treatment, you may need to regain some weight to return to a healthy weight.
- There is little scientific evidence to suggest that taking high-dose vitamin supplements is beneficial. Talk to your doctor before taking a supplement.
- Quitting smoking can have a significantly positive impact on your survival. Ask your doctor for help and support. There is no safe level of smoking.
- Sun protection will reduce your risk of skin cancer.
- Alcohol is a known risk factor for cancer. Limiting or avoiding alcohol will reduce the risk of cancer and improve your general health and wellbeing.



Legal, financial and workplace concerns

After any serious illness, people may have concerns about financial issues, insurance policies, superannuation and work.

Financial assistance

Cancer treatment can be expensive. Stopping work, buying medications, and paying for 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. Call Centrelink on **13 27 17** to find out if you are eligible for any benefits. It may also help to see a financial counsellor. Visit www.financialcounsellingaustralia.org.au or call Cancer Council **13 11 20** for a free copy of *When Cancer Changes your Financial Plans*.



Cancer Council's Pro Bono Program may be able to connect you with a lawyer, financial planner, accountant or HR/recruitment professional if you need help with:

- legal issues
- financial planning
- small business accounting
- workplace (HR or recruitment) advice

Advice is free for eligible clients. You will need to pass a means test in order to qualify for assistance. Some services may not be available in all states or areas. Call 13 11 20 for more information.

Insurance and superannuation

Applying for new insurance (life, income protection or travel) may be harder because you have had cancer. You are generally required to provide your medical history. However, you shouldn't have problems claiming on policies you had before the diagnosis.

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

Obtaining travel insurance that covers cancer-related medical problems may be difficult, 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.nationallegalaid.org.

“ I have a letter from my surgeon recommending I get travel insurance with full coverage. I ask for a new letter at every appointment. The letter states that I had surgery and radiotherapy over a year ago, and the likelihood of recurrence is minimal. I've been able to get full coverage with the letter. ” Richard

Working after treatment ends

Work is an important part of life for many people. Besides income, work can provide satisfaction, a sense of normality, a means of maintaining personal identity, self-esteem 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.

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 unless your cancer is work-related.

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

While some people may want to tell a potential employer that they have had cancer, you don't need to unless it is relevant to the position. If you are asked about a gap in your resume, you can say that you had a health issue and it's now resolved.

A prospective employer is permitted to ask you about your ability to perform tasks that are an essential part of the job, e.g. lifting heavy boxes. If some tasks are 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 or you could discuss this with your GP. You may be eligible for a payout through your income protection insurance. If you are unable to return to work contact Centrelink on **13 27 17** to see if you are eligible for the Disability Support Pension or other payments.

Discrimination at work

A lack of knowledge about cancer may mean some people are treated differently at work after a cancer diagnosis. Employers and colleagues may think you need more time off or wonder about your ability to work.

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

Call Cancer Council **13 11 20** for further information, or for a free copy of *Cancer Care and Your Rights* or *Cancer, Work & You*. For further advice, speak to a social worker, union official or solicitor, or contact your anti-discrimination body, Fair Work Australia, or the Human Rights Commission.



Cancer Council's online Workplace Fact Sheets assist employers and workplaces to provide a supportive and fair work environment for people affected by cancer. Fact sheets can be downloaded from your local Cancer Council website.



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 lodge a complaint 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 unless it is relevant to the position.
- When returning to work, your employer must make reasonable adjustments to help you do your job.
- You should not be treated differently in the workplace on the basis of your cancer diagnosis. The Disability Discrimination Act protects anyone who has had cancer.
- Cancer Council's Pro Bono Program may be able to help with legal, financial, small business, and workplace advice. Some services may not be available in all states or areas. Call 13 11 20 for more information.



Seeking support

Many people find they need support after treatment finishes. The availability of services may vary depending on where you live. Some, but not all, services are provided free of charge.

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, or as online webinars.

These programs present information about cancer and its treatment, as well as practical information about life after treatment. They are usually open to carers, family, friends and work colleagues. You may find it helpful to share tips and ideas with other participants.

Talk to someone who's been there

Getting in touch with other people who have had similar experiences to you can be helpful.

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

“I found joining a support group helped me dry up some of the tears.” Ashley

Types of support

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

- **Face-to-face support groups** often held in community centres or hospitals
- **Telephone support groups** facilitated by trained counsellors
- **Peer support programs** match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **Online forums** provide the opportunity to connect with other people anywhere and anytime, see www.cancerconnections.com.au

Talk to your health care team or call Cancer Council **13 11 20** to find out about support groups and programs in your local area.

“I found that my support group was a useful, safe place to express my emotions and experiences without having to censor myself to protect the feelings of other people.” Jann



Useful websites

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

Australian

Cancer Council Australia.....	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Australian Cancer Survivorship Centre.....	petermac.org/ cancersurvivorship
Breast Cancer Network of Australia	bcna.org.au
beyondblue	beyondblue.org.au
Cancer Connections	cancerconnections.com.au
Cancer Voices Australia	cancervoicesaustralia.org.au
Carers Australia	carersaustralia.com.au
iheard.....	iheard.com.au
NSW Cancer Survivors Centre	cancersurvivors.unsw.edu.au
Suicide Callback Service	suicidecallbackservice.org.au

International

American Cancer Society	
Cancer Survivors Network.....	csn.cancer.org
Children's oncology group.....	survivorshipguidelines.org
Journey Forward.....	journeyforward.org
Livestrong Foundation	livestrong.com
Macmillan Cancer Support	macmillan.org.uk
National Cancer Institute (USA).....	cancer.gov/ cancertopics/life-after-treatment
National Coalition for Cancer Survivorship.....	canceradvocacy.org
Office of Cancer Survivorship	cancercontrol.cancer.gov/ocs/



Other Resources

You might find the following free Cancer Council publications useful:

- *Nutrition and Cancer*
- *Massage and Cancer*
- *Understanding Complementary Therapies*
- *Cancer, Work & You*
- *Cancer Care and Your Rights*
- *Talking to Kids About Cancer*
- *Living with Advanced Cancer*
- *Understanding Clinical Trials and Research*
- *Overcoming Cancer Pain*
- *Sexuality, Intimacy and Cancer*
- *Fertility and Cancer*
- *Exercise for People Living with Cancer*
- *Workplace Fact Sheets*

Call **13 11 20** to order or download from your local Cancer Council website.



Question checklist

This checklist includes the kinds of questions you may want to ask your doctor about living well after cancer treatment.

- Is it possible to get a 'survivorship care plan'?
- Can I have a copy of my cancer treatment summary?
- 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 manage the fear of the cancer coming back?
- What can I do to reduce the chance of the cancer returning?
- How likely is it that my cancer will come back?
- What symptoms/problems should I watch out for?
- Am I at risk of developing late effects? What might these be? What can I do to prevent this?
- Am I likely to have long-term problems with pain? How can I control the 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?
- What exercises would you recommend?

- What sexual changes are likely to be short term and what changes are likely to be long term? Who can I speak to about this?
- Did the cancer and treatment affect my fertility?
- What advice do you have about returning to work?
- Are there any complementary therapies that might help me?
- Where can my family get help and advice?
- Why do I need check-ups?
- What will happen during my check-ups?
- How often do I need check-ups?
- What symptoms should I look out for?
- What happens if there are signs the cancer has come back?
- How long will it be before I feel better?
- Who should I contact if I develop new symptoms?
- Is there someone I can see about persisting side effects?
- Is there anything I can do to improve my health?
- Where can I get further information about my follow-up care?
- Are there any support services you can refer me to?



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.

advanced cancer

Cancer that has spread deeply into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured.

analgesic

A drug or natural remedy used to relieve pain.

anti-depressant

Medication to treat depression.

BMI (Body Mass Index)

This is a measure of a person's relative weight based on their weight and height.

cancer survivor

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

cardiotoxicity

Damage to the heart muscle.

chemo brain

Memory and cognitive problems sometimes experienced following chemotherapy, including difficulty concentrating and focusing.

chemotherapy

The use of 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, wellbeing and quality of life.

deconditioning

Loss of physical strength

depression

Persistent low mood and lack of motivation on most days and lasting more than two weeks.

diagnosis

The identification and naming of a disease.

erectile dysfunction

Difficulty getting or keeping an erection firm enough for intercourse.

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.

hormone replacement therapy (HRT)

The use of hormones to treat the symptoms of menopause.

hormone therapy

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

infertility

The inability to conceive a child.

late effects

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

lymphoedema

Swelling caused by a build-up of lymph fluid when lymph nodes do not drain properly.

lymph fluid

Fluid that circulates throughout the lymphatic system and transports proteins, fats, bacteria and other substances.

lymph nodes

Small, bean-shaped structures forming part of the lymphatic system. Also called lymph glands.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids, transports fats and produces immune cells.

libido

Sex drive or interest in sex.

menopause

When a woman stops having periods (menstruating).

metastasis (plural: metastases)

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

mindfulness

Learning to live more fully in the here-and-now by intentionally bringing your attention to the present moment.

morphine

A type of strong pain killer commonly given to people with cancer.

nerve block

An anaesthetic injected into the body.

oestrogen

A female sex hormone produced mainly by the ovaries.

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.

peripheral neuropathy

Pins and needles, numbness in hands and feet due to side effects of chemotherapy.

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.

progesterone

A female sex hormone produced mainly by the ovaries that prepares the lining of the uterus (endometrium) for pregnancy.

prognosis

The expected outcome of disease.

radiotherapy

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

recurrence

Cancer that comes back.

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.

side effect

Unintended effect of a drug or treatment.

stage

How far the cancer has spread.

statistics

Collecting and analysing information to make comparisons and see patterns in research results.

survivorship care plan

A schedule for follow-up care and the identification and management of medical and psychosocial problems that may arise after treatment.

Can't find what you're looking for?

For more information on cancer-related words, visit www.cancercouncil.com.au/words or www.cancervic.org.au/glossary or www.cancersa.org.au/glossary



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.

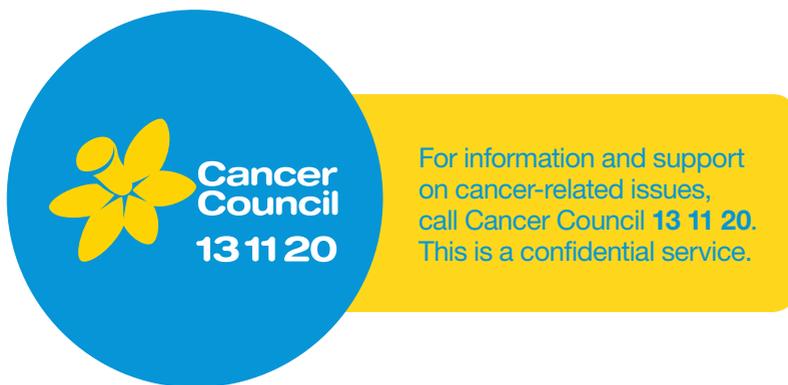
Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

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.



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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