



Living Well After Cancer

A guide for people with cancer,
their families and friends

Practical
and support
information

For information & support, call

13 11 20

Living Well After Cancer

A guide for people with cancer, their families and friends

First published February 2010. This edition April 2018.

© Cancer Council Australia 2018. ISBN 978 1 925651 17 1

Living Well After Cancer is reviewed approximately every three years. Check the publication date above to ensure this copy of the booklet is up to date.

Editor: Ruth Sheard. Designer: Eleonora Pelosi. Printer: SOS Print + Media Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Working Group initiative. We thank the reviewers of this booklet: Dr Haryana Dhillon, Senior Research Fellow, Centre for Medical Psychology & Evidence-based Decision-making, School of Psychology, University of Sydney, NSW; Polly Baldwin, 13 11 20 Consultant, Cancer Council SA; Jessica Barbon, Dietitian, Southern Adelaide Health Network, SA; Dr Anna Burger, Liaison Psychiatrist and Senior Staff Specialist, Psycho-oncology Clinic, Canberra Region Cancer Centre, ACT; Elizabeth Dillon, Social Worker, Peter MacCallum Cancer Centre, VIC; Prof Paul Glare, Chair in Pain Medicine and Director, Pain Management Research Institute, University of Sydney, NSW; Nicole Kinnane, Nurse Coordinator, Gynaecology Services, Peter MacCallum Cancer Centre, VIC; Amanda Piper, Manager, Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, VIC; Kyle Smith, Exercise Medicine Research Institute, Edith Cowan University, WA; Aaron Tan, Consumer; Dr Kate Webber, Medical Oncologist and Research Director, National Centre for Cancer Survivorship, NSW. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

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

Note to reader

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

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

Cancer Council

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



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

Introduction

This booklet is for people who have finished their initial cancer treatment or are on maintenance therapies to try to prevent the cancer coming back.

After a cancer diagnosis, people are often kept busy with medical appointments and the demands of treatment. Coming to the end of treatment may be a time when you notice the impact cancer had on you, your family and friends.

Many people live for a long time after cancer treatment. We hope this booklet helps you with the challenges you may face now that active treatment is finished. These challenges will vary depending on the type of cancer and treatment you had, and your personal situation.

You might like to share this booklet with your family and friends. It may help them to understand your experience and their own reactions at this time.

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.



Contents

Who is a cancer survivor?.....	4
Finding a “new normal”	5
Understanding your feelings	10
Common feelings	10
Accepting your feelings.....	12
Feeling down or depressed.....	12
Fear of the cancer coming back	17
Will the cancer come back?	19
Survival statistics.....	19
Fear of getting a different cancer	21
Checking for signs of a new cancer	22
Follow-up care	24
Survivorship care plans	24
Common questions about follow-up.....	26
Preparing for check-ups.....	28
Managing anxiety before check-ups	29
Impact on family and friends.....	32
When others don’t understand.....	33
Coping with children’s needs	34
Coping with side effects	36
Fatigue.....	37
Sleep disturbance	40
Pain	41
Lymphoedema.....	44

Memory and thinking changes	46
Tingling or numbness in hands or feet	48
Other physical problems	49
Changed body image	52
Sexuality and intimacy	53
Menopause.....	56
Fertility problems.....	58
Taking control of your health.....	60
Maintain a healthy body weight.....	60
Have a healthy, well-balanced diet.....	62
Be physically active.....	66
Quit smoking	68
Use sun protection	69
Limit or avoid alcohol	72
Legal, financial and workplace concerns	74
Financial assistance	74
Insurance.....	74
Working after treatment ends	75
Seeking support	79
Survivorship programs	79
Talk to someone who's been there.....	80
Cancer Council services	81
Question checklist.....	82
Useful websites	84
Glossary	85



Who is a cancer survivor?

“Cancer survivor” means different things to different people, and moving from patient to survivor is different for everyone. Some see themselves as a survivor as soon as they are diagnosed with cancer, others see themselves as a survivor when active treatment stops or when they become free from signs of cancer.

For many people, survivor is a strong and positive term. Others feel guilty for surviving or feel the term implies that they will struggle to cope with cancer in the future. Some people do not like being labelled at all and do not identify as a cancer survivor. Others prefer to look forward to a future that is not focused on their past cancer experience. You may find it difficult to relate to the term survivor. Instead, you may refer to yourself as someone who has had cancer or is living with cancer.

However you feel about the label, you may wonder: what now? Research has shown that getting information about what to expect after treatment can help you prepare for this change.

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



Improvements in diagnosing and treating cancer have led to an increase in the number of people surviving and living with cancer. There are about 1 million people living in Australia today who have been diagnosed with cancer at some stage in their life.



Finding a “new normal”

Having cancer is often described as an experience that starts at 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 commonly called finding a new normal and it may take months or years.

Adjusting to the new normal

- You may 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 you engage less 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.
- You may have thought you would just resume your life exactly where you left off before cancer. This can take longer than you expect.
- Your family and friends may not fully understand what you’ve been through, or realise that the cancer experience doesn’t stop when treatment ends.
- It may help to allow yourself time to adjust to your life after treatment. 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. Many people surprisingly find that there are positive aspects to having had cancer. Some people discover an inner strength they didn't know they had. Others develop new friendships during their treatment or discover new sources of support.

Cancer may prompt you to re-examine your priorities in life. This shift is often gradual; even positive change can take time.

- You may find you now place more value on your relationships with family or friends. You may choose to focus on the more meaningful relationships in your life.
- Some people are motivated to travel or start new activities.
- Other people reconsider their career goals and work values, and may decide to seek part-time work or a new role.
- You may want to make changes to your lifestyle, such as reducing stress, starting exercise or quitting smoking (see pages 60–73).

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

“ I've changed my career path and am studying community services in order to help people through changes in their life. The way you view life is different after cancer. ” *Pete*

Myths about the end of treatment

I should be back to normal – Some people expect life to return to the way it was before the cancer diagnosis. The reality is often more emotionally and physically complex. Some cancer survivors find they can't or don't want to go back to how life was before their treatment. Others need time to recover from the turmoil of cancer.

I should feel well – Many cancer survivors have ongoing health concerns because of the cancer or treatment side-effects (see pages 36–59). The after-effects of treatment may make everyday life difficult.

I should not need any more support – Some survivors are surprised to feel that they need more support than ever after treatment ends.

I should feel grateful – Survivors can sometimes feel pressured to be grateful.

However, the impact of cancer and its treatment on your life and future may make you feel upset, angry or resentful.

I should feel positive – Survivors can feel a great deal of pressure from friends and family to think positively all the time. Although this is unrealistic, it can be a source of worry and guilt.

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're not.

I should be the person I was before cancer – Many survivors say that cancer changes them. Some need time to adjust to physical changes. Others feel different, even though they look the same. Many survivors feel a sense of loss for the person they once were or thought they'd be.

Finding a new way of living

The transition to life after cancer treatment can take time. Take each day as it comes. Accept that you may have both good and bad days.



Reflect

Assess your life. Ask yourself:

- What fulfils me?
- What is important?
- What gives my life meaning?

Consider keeping a journal.

Many people find it helps to write down how they're feeling.



Look after yourself

Take the time you need to adjust to changes in your body or physical appearance. Do things at your own pace and rest between activities. Remember, your body is still healing. If you are worried about going out, ask someone to go with you.



Relax

Do something you find relaxing, such as reading, listening to music or taking a bath. Learn some form of relaxation or meditation, such as mindfulness, visualisation, yoga or deep breathing.



Talk about your emotions

Acknowledge your feelings. It may help to share any concerns or worries with family and friends, your doctor, a psychologist or counsellor.



Take control

Look at ways you can manage your own wellness and make lifestyle changes to improve your quality of life. This could include changing your diet, being more physically active or stopping smoking (see pages 60–73). Seeing a psychologist, counsellor or life coach may help you to develop goals and strategies to make any desired changes to your life.

Seek support

Learning about other people's experiences may help. Join a support group, attend a survivorship program or read stories from other survivors. Connecting with other cancer survivors may help you cope and feel more positive about the future. For more information, see pages 79–80.



Manage side effects

You may have ongoing side effects after treatment. Talk to your health care professionals about your symptoms to see if they can be improved or managed better (see pages 36–59).



Understanding your feelings

While most people adapt well over time 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 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 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 lonely if your relationships have changed or people don't understand what you've been through.

Fear of the cancer coming back – Fear of recurrence is common. Most survivors learn to manage this fear (see pages 17–23).

Uncertainty – Many survivors are reluctant to plan for the future because they feel uncertain about their health. This is very challenging, but you can learn to manage it effectively.

Frustration – Some people feel frustrated because they think their family and friends expect too much from them. Others feel frustrated because they can't do the things they want to do.

Survivor guilt – Some people feel guilty or question why they survived their cancer when others didn't. This can be confronting.

Anxiety about follow-ups – Many people feel anxious before 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 treatment side effects: how long they’ll last and whether they’ll affect your life (see pages 36–59). Many survivors are worried about financial pressures or being a burden to their family. Other survivors worry about returning to work and dealing with questions from colleagues (see pages 75–77).

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. Or you may not be physically able to do some of the things you did before treatment. Many people feel vulnerable and self-conscious about their body image and sexuality (see pages 52–55).

Feeling down/depressed – You may feel sad or down about your cancer experience and its impact on your life (see pages 12–15).

Heightened emotions – You may become tearful and emotional very quickly, particularly when someone asks how you are. This is very normal, but it can be embarrassing for some people.

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 do not expect negative emotions once their treatment ends and find this confusing.

Accepting your feelings

Acknowledging how you are feeling may help you to work through your emotions. It is common for people with cancer to feel quite distressed at some point in their cancer experience. Most cancer survivors find that they do feel better over time.

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 doing more exercise or improving their diet.

Feeling down or depressed

Feeling low or depressed after treatment ends is common. Cancer survivors often experience worry, fear of recurrence, or periods of feeling down, for months or even years after treatment.

Some people feel sad or depressed because of the changes that cancer has caused, or because they are frightened about the future. Many people feel disconnected from their life before cancer. They may wonder 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.

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

Signs of 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 general practitioner (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
- unintended weight gain or loss
- feeling very tired, slowed down or lacking 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
- wishing you were dead
- 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.

🗨️ Although some people bounce right back, once treatment was over, I questioned my values and reasons for being here. 🗨️ *Emma*

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 medicine. Treatment 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 GP if you are eligible. Call 13 11 20 to see if your local Cancer Council runs a counselling program.

Some people find online programs helpful in dealing with depression and anxiety, e.g. moodgym.com.au, mycompass.org.au or mentalhealthonline.org.au. You can find a list of health and wellbeing apps at healthdirect.gov.au/health-and-wellbeing-apps.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety at beyondblue.org.au. If you'd like to talk to someone about how you are feeling, call Lifeline on 13 11 14 or [beyondblue](http://beyondblue.org.au) on 1300 22 4636. In addition to getting professional help, the tips on the opposite page may help you.

“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



Managing your mood

- Take care of yourself. Eat a well-balanced diet with lots of fresh fruit and vegetables, and drink plenty of water.
- Avoid excessive amounts of caffeine and alcohol.
- Try to do some physical activity every day – this will help you sleep better and improve your mood.
- Set small and achievable goals and review your priorities. Don't expect too much from yourself.
- Share your fears and concerns 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. Learn to be kind to yourself.
- 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" every day.
- Practise letting your thoughts come and go without getting caught up in them.
- Consider complementary therapies, such as massage, yoga, meditation or reflexology (hand and foot massage).
- Keep a record of positive things that happen each day.
- For more information see Cancer Council's *Emotions and Cancer* booklet.



Key points

- For many people who have finished cancer treatment, life has changed and is not quite the same as it was before their diagnosis.
- 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, once treatment is over.
- Many people find they need time to reflect on their cancer experience. With time, they find a new way of living – a “new normal”.
- It's common 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 financial pressures or returning to work, lack of confidence, and anger.
- Many survivors find they need ongoing support after their treatment finishes.
- Acknowledging and talking about how you're feeling may help you manage your emotions.
- It's common to have some worries and periods of sadness for months or years after treatment.
- Feeling low after treatment finishes is common. Talk to your GP, a counsellor, psychologist or psychiatrist if you are feeling down or depressed.



Fear of the cancer coming back

Feeling anxious or frightened about the cancer coming back (recurrence) is a common challenge and one of the greatest concerns for cancer survivors. Most cancer survivors are likely to experience this fear to some degree and it may come and go for many years.

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
- when other people are diagnosed with cancer
- when you have 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).

“Once treatment was finished, it was quite daunting. I was fearful that the cancer would come back somewhere. Eight years later, it hasn't come back, which is fantastic.”  Pete



Managing the fear of recurrence

- Focus on what you can control, e.g. being actively involved in your follow-up appointments and making positive changes to your lifestyle (see pages 60–73).
- Talk to your specialist about your risk of recurrence and learn more about your type of cancer.
- Psychological interventions specifically addressing the fear of cancer recurrence 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. Manage these in a healthy way, e.g. you could try yoga or mindfulness meditation.
- Speak with a counsellor or psychologist if the fear of recurrence is overwhelming. They may be able to teach you some strategies to help you manage your fears and have a more positive frame of mind.
- Social support has been found to play a protective role in the fear of recurrence.
- Joining a support group may help. See page 80 for more information.
- Consider getting involved in a creative activity. Some people find this helpful in working through their emotions and anxieties.
- Not all symptoms are a sign of cancer, they may indicate other health problems, e.g. diabetes, arthritis, high blood pressure.
- Talk to your doctor about how to distinguish normal aches, pain or sickness from cancer symptoms.
- See your GP 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 live. Cancer is most likely to recur in the first five years after treatment ends. Generally, the more time that goes by, the less likely it is that the cancer will come back (see *Survival statistics* below).

The risk of cancer coming back is different for each person and depends on many factors, including the type and stage of cancer, genetic factors, type of treatment and time since treatment. Talk to your doctor about your risk of recurrence.

For information on how to reduce your risk of cancer recurrence, see *Taking control of your health* on pages 60–73.

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. It does not mean you will only survive for five years. For example, about 90 out of 100 people (90%) with breast cancer will be alive five years after they are diagnosed. Many of these people live much longer than five years after diagnosis.

How accurate are the statistics?

Five-year cancer survival rates are a guide only. They generally include everyone with a particular type of cancer, at all stages and grades of the disease. For most cancers, 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 (cancer that has spread to other parts of the body).

Statistics take many years to calculate and are usually slightly out of date. For example, if you were diagnosed with cancer in 2017, the doctor may use survival rates for people diagnosed in 2009 (followed for five years until 2013). With cancer treatments improving all the time, your outcome (prognosis) is likely to be better than it would have been in 2009.

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.

Living with advanced cancer

For some people, cancer does come back after treatment. This can be devastating. Treatment for advanced cancer aims to control the cancer for as long as possible. In some cases this may be months or years.

For more information about dealing with the emotional, physical and practical aspects of a cancer recurrence, see *Living with Advanced Cancer*. Call **13 11 20** or visit your local Cancer Council website.

Fear of getting a different cancer

Some survivors worry about developing a different type of cancer. While this is not common, some people develop a second cancer that may not be related to the first cancer.

See *Managing the fear of recurrence* on page 18 for some tips that may help you deal with the fear of developing a different cancer.

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

- exposure to cigarette smoke or other cancer-causing agents
- skin damage caused by overexposure to ultraviolet (UV) radiation from the sun or artificial sources such as solariums
- ageing
- being born with an inherited gene that increases the chance of developing some cancers (about 5% of cancers)
- having some forms of cancer treatment, particularly as a child
- lifestyle factors such as smoking, eating an unhealthy diet, drinking too much alcohol, being overweight, and not getting enough exercise.

Talk to your doctor if you are concerned about any risk factors. See *Taking control of your health* on pages 60–73 for ways to reduce your cancer risk.

“ 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 GP 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 that lasts for more than a few weeks)
- urinary problems or changes
- unusual changes in your breasts or testicles
- abdominal pain or bloating that doesn't go away
- abnormal bleeding or bruising
- unexplained changes in your general health, such as weight loss, loss of appetite and loss of energy (fatigue).

To help detect cancer early, free national screening programs are available for breast (women aged 50–74), cervical (women aged 25–74) and bowel (men and women aged 50–74) cancers. For more information, talk to your doctor, call Cancer Council 13 11 20 or visit cancerscreening.gov.au.

“ I'm more aware of my own body and the need to get any changes checked out straightaway. ” Sam



Key points

- Many cancer survivors worry that the cancer will come back. This fear can affect both their emotional and physical wellbeing.
- This concern may be worse at certain times, such as special occasions, follow-up appointments, and hearing about other people diagnosed with cancer.
- Many survivors find this fear lessens with time. However, this is not always the case.
- There are things you can do to help you manage your fear of recurrence and have a more positive frame of mind.
- 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. Many people live much longer than five years after they are diagnosed.
- For some people, cancer does come back and they will need further treatment.
- Most people who get cancer only get one type. However, some people will develop another type of cancer.
- There are ways to reduce your risk of cancer recurrence (see pages 60–73).
- People of certain ages can take part in free national screening programs for the early detection of bowel, breast and cervical cancers.
- If you notice new or concerning symptoms, make an appointment with your doctor.



Follow-up care

After your treatment has finished, you will have regular check-ups. These will allow your health care team to monitor your health and wellbeing. Follow-up care differs depending on the type of cancer and treatment, the side effects experienced, and any other health conditions you are managing.

To help prepare for the time after treatment, you may find it helpful to write down any questions you have and discuss them with your treatment team (see suggested questions on pages 82–83).

Survivorship care plans

Many treatment centres now work with people as they approach the end of their treatment to develop survivorship care plans.

These care plans usually:

- provide a summary of your treatment
- set out a clear schedule for follow-up care, including contact details for the health professionals involved in your treatment and any screening tests
- list any symptoms to watch out for and possible long-term side effects
- identify any medical or psychosocial problems that may develop after treatment and ways to manage them
- suggest ways to adopt a healthier lifestyle after treatment.

A survivorship care plan can help improve communication between you, your family and all the health care professionals involved in your care (e.g. your GP, treatment centre, psychologist, exercise physiologist, dietitian and physiotherapist).

A survivorship care plan is not a fixed document, it should be reviewed regularly as your needs change. You can ask your health care professionals to update your plan during consultations.

If you have not received a plan, it may be helpful to develop your own survivorship care plan and review it with your doctor. For more information, visit petermac.org/cancersurvivorship or journeyforward.org.

Your treatment summary

If you don't have a survivorship care plan, ask your surgeon, oncologist or specialist nurse for a written summary of your cancer and treatment. 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
- test results and staging information
- overview of treatment (e.g. surgery, radiation therapy, chemotherapy, targeted therapy).

Taking charge of your care

Self-management is an important part of survivorship. With the support of your health care team, there are many steps you can take to manage your own wellness, including monitoring your body for any signs that the cancer has returned, managing any side effects and adopting a healthier lifestyle (see pages 60–73).

Common questions about follow-up

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
- talk to you about any late treatment side effects to watch out for
- look for any signs that the cancer may be coming back
- check any new symptoms
- do a physical examination
- ask if you have any concerns or questions
- discuss your general health and give healthy lifestyle advice
- outline how the cancer and its treatment might interact with any other health problems
- refer you to other health professionals and services, as necessary (such as a dietitian, psychologist or physiotherapist).

If you are on maintenance treatment (e.g. hormone therapy for breast or prostate cancer), talk to your treating team about how long the therapy will continue and any side effects to look out for.

Some people may need blood tests and scans, e.g. mammograms for women treated for breast cancer or prostate specific antigen (PSA) tests for men treated for prostate cancer. Not everyone will need or benefit from ongoing tests and scans.

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.



The Australian Cancer Survivorship Centre provides resources on survivorship care plans, dealing with long-term side effects such as fatigue, and caring for a cancer survivor. You can access these at petermac.org/cancersurvivorship.

How often do I need check-ups?

The frequency of your check-ups will depend 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 or optimal care pathways exist for your follow-up care.

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

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.

If you continue to see your specialist, you will still need to see your GP or specialist nurse to monitor your overall health, e.g. your blood pressure, cholesterol levels and weight. You may also need to see other allied health professionals such as a dietitian, psychologist, physiotherapist or exercise physiologist.

Preparing for check-ups

It may help to write down any questions you have and take this list with you to your appointments (see the list of suggested questions on pages 82–83). If your doctor uses medical terms you don't understand, ask them to explain them 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 help you 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 make 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 existing 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
- started taking any new medicines or using complementary or alternative treatments.

You can also talk to your health care team about other issues. For example, you may want to discuss 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 psychologist, counsellor, speech pathologist, social worker, occupational therapist, lymphoedema practitioner, physiotherapist, exercise physiologist, dietitian or specialist nurse.

Give each health professional you see a copy of your survivorship care plan or treatment summary. If you don't have one of these, tell them 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 worried before routine check-ups. Anxiety, poor appetite, sleeping problems, mood swings and increased aches or pains are common in the lead-up to an appointment.

You may feel anxious before routine 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
- friends or family make comments that upset you.

You may find check-ups get 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. See the next page for some coping strategies to help ease your anxiety.



Coping with check-ups

- Take a close friend or relative with you to your check-ups.
- Share your fears with people close to you so they can provide support.
- Plan to do something special after your follow-up appointment.
- Try to see your check-ups as a positive way you can care for yourself.
- Learn mindfulness and meditation skills, or practise deep breathing to help manage the signs of stress and anxiety.
- 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 go to the doctor's consulting rooms if you are not comfortable going to the hospital or treatment centre.
- Try to book tests close to your next doctor's appointment.

“It is a major psychological hurdle to be positive after treatment. It is a relief for it to be over, but during check-ups, you always wonder if the treatment worked. Also, if you get sick, it doesn't always mean it is cancer or related to the treatment. It might just be the flu.”  Ben



Key points

- 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 experiencing.
- It's a good idea to work with your treatment team to develop a survivorship care plan. This will set out a clear schedule for your follow-up care.
- Many cancer survivors say they feel anxious before their routine check-ups.
- Having a clear follow-up plan and asking your doctor what to expect at your follow-up appointments may help you feel less anxious.
- Check-ups may get easier the more you have. Talk to your doctor about things you can do to help manage your anxiety before check-ups.
- Your doctor will discuss how you're feeling and perform a physical examination as part of the check-up. Some people will also have blood tests and scans, but not everybody needs these.
- If you don't have a survivorship care plan, ask your surgeon, oncologist or specialist nurse 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, a specialist nurse or a combination of health professionals.
- You may also want to see other health professionals such as a physiotherapist, psychologist, dietitian or specialist cancer nurse.



Impact on family and friends

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

Your cancer diagnosis may make people around you question their own priorities and goals. And, 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
- convinced that everything will go straight back to normal for you
- happy to focus on others and themselves again
- exhausted
- confused, especially if your relationship has changed
- upset that they are not in regular contact with the health care team
- 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.

“People usually don't mean to make things worse. Their reactions are likely to come from their own difficulties in handling feelings such as fear and anxiety.”  Dani

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 your outlook and priorities 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 you may still need support or that some symptoms, such as tiredness or memory problems, can persist for long periods of time. Other effects from treatment may never go away.

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 like to talk to them about how you're feeling. It may help to tell them that your recovery is ongoing, and that you need time to adjust and think about what you've been through. It may be useful to ask family and friends 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. Children's reactions and needs will vary depending on their age. However, discussions that are handled sensitively and honestly can be reassuring for young people.



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. To find out about support to help teenagers cope with life after cancer, visit canteen.org.au.
- 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 talk about their own fears.
- Reassure your children that regular check-ups will help monitor the cancer.
- Be open about how you feel, so the children understand if you're not bouncing back.
- Spend time together doing something they enjoy.
- Explain any changes made to your family's lifestyle, and let your children know if they are going to be permanent.
- Call Cancer Council **13 11 20** or look online for a copy of *Talking to Kids About Cancer*.



Key points

- Family and friends also need time to adjust after your treatment is over.
- 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 need time to adjust to emotional and physical changes they may be experiencing at the end of treatment.
- Acknowledge the support that family and friends have already provided. Let them know if you still need help.
- 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 that the cancer is inherited, talk to your GP or oncologist. You may be referred to a family cancer clinic or a genetic counselling service.
- Children may find it especially hard to understand how you have changed and why things can't go back to the way they used to be.
- Talking to children at their level, and being as open and honest as possible may help.
- For support helping your children cope with cancer, talk to your treatment team or visit **canteen.org.au**.



Coping with side effects

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

Some side effects go away 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)
- sleeping difficulties
- pain
- numbness or tingling in feet or hands (peripheral neuropathy)
- persistent swelling (lymphoedema)
- forgetfulness or memory problems (chemo or cancer brain)
- changes in bladder or bowel functioning
- heart problems
- mouth or teeth problems
- bone density loss (osteoporosis)
- joint pain
- problems with eating or drinking
- changed body image, e.g. hair loss, weight loss or gain
- changes in sexuality and sexual function
- menopausal symptoms for women
- fertility problems.

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. Talk to your doctor about whether you are at risk of developing late effects from your treatment. If you are concerned about a new symptom, 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 very tired and lacking energy for daily activities, is a common physical side effect of cancer and its treatment. Fatigue is different from tiredness, as it doesn't always go away with rest or sleep.

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 strength 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.

If you have a chronic medical condition following cancer treatment, talk to your GP about developing a Chronic Disease Management Plan or Team Care Arrangement to help you manage the condition.



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.

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.

Symptoms of fatigue

Signs of fatigue include:

- lack of energy – you may want to stay in bed all day
- difficulty sleeping – see page 40 for more information
- finding it hard to get up in the morning
- difficulty completing tasks, especially in the afternoon, when energy levels can be unexpectedly low
- feeling anxious or depressed, particularly if fatigue persists
- muscle weakness – 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).

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 a low red blood cell count (anaemia), an underactive thyroid gland, depression or the side effects of drugs, which your doctor may be able to address. You may also find the tips on the opposite page helpful.



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, and accept, offers of help** – Family and friends can help with school pick-ups, shopping or mowing the lawn.
- **Plan your day** – Make a task list and do the most important activities when you have the most energy.
- **Take it slow** – Work at your own pace and take regular breaks. Leave plenty of time to get to appointments.
- **Exercise regularly** – Light to moderate exercise can boost energy levels and reduce fatigue (see pages 66–67).
- **Make time to relax** – Try activities like walking on the beach, spending time in the garden or listening to music.
- **Adapt your play** – If you have children, sit down to play. Try activities like reading, board games, puzzles and drawing.
- **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.
- **Say no** – Don't feel pressured to do things that you don't feel like doing. If you have trouble saying no, ask someone to do it for you.
- **Stop smoking** – Smoking reduces your energy. If you smoke, consider quitting (see pages 68–69).
- **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.
- **Eat nutritious foods** – Aim to eat a healthy, well-balanced diet (see pages 62–65).
- **Seek help** – Talk to your GP if your fatigue is caused by depression (see pages 12–14).

Sleep disturbance

Difficulty sleeping is common among people who have had cancer. Sleep can be affected by symptoms related to cancer treatment, such as pain, breathlessness, anxiety or depression. Some medicines can also disrupt sleep (e.g. hormone therapy for breast cancer). People who have pre-existing sleep problems can have additional sleep difficulties after their cancer treatment. If you have ongoing problems with sleeping, talk to your GP.



Managing sleep disturbance

- Get up at the same time each morning, including weekends.
- Exercise regularly but not right before bed (see pages 66–67).
- Limit or cut out the use of alcohol, caffeine, nicotine and spicy food.
- Avoid daytime naps.
- Only go to bed when tired.
- Set up a pre-sleep routine to help you relax.
- Call **13 11 20** for a free copy of Cancer Council's relaxation and meditation CDs. Done regularly, these exercises may help you sleep better.
- Avoid using electronic devices such as computers or smartphones before bed or in the bedroom.
- Ensure the room is dark, quiet and a comfortable temperature.
- If you wake up during the night, get up for a while.
- If medicines interfere with your sleep, discuss alternatives with your doctor.
- Cognitive behaviour therapy (CBT) has been shown to be effective in addressing sleep problems. Ask your GP for more information.

Pain

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

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

How you manage your pain depends on the type of pain you have. Pain may be a side effect of cancer treatment or it may be caused by an unrelated problem, such as arthritis.

Learning how to manage your pain may allow you to return to many of the activities you enjoy and improve your quality of life. Discuss your pain with your doctor so that the cause of the pain can be worked out and the best treatment plan developed. In cases where no fixable cause of the pain is found, the focus will shift to improving your ability to function despite the pain.

Common methods of pain relief

Persistent pain can be treated in a variety of ways:

- A physiotherapist or exercise physiologist can develop a program to improve muscle strength and increase your ability to function, which may help relieve pain.
- Movement is very important: daily stretching and walking can help you deal with the pain. It is important to pace activities throughout the day, including rest and stretch breaks.

- Cognitive behaviour therapy (CBT) can help people think about their pain differently. It has been shown to increase people's sense of control, improve mood, and decrease stress and anxiety.
- Some complementary therapies may also help, especially those that require your active participation (see box opposite). Always let your treating therapist know that you have had cancer.
- Pain-killing drugs, called analgesics, are widely used to relieve pain caused by cancer. However, they have a more limited role in relieving pain experienced by cancer survivors. Paracetamol or non-steroidal anti-inflammatory drugs are the main drugs used to relieve pain in survivors. Opioids such as codeine and morphine have been shown not to work very well to control chronic pain.
- Medicines normally used to treat depression or epilepsy have been found to help for some types of pain.
- Rarely, some people have surgery or an anaesthetic injected into their body (nerve block).
- If your pain is not well controlled, ask your doctor about referring you to a multidisciplinary pain clinic.
- For more information about cancer-related pain, call Cancer Council 13 11 20 for a free copy of *Overcoming Cancer Pain*.

Using pain-killers safely

All medicines including non-prescription pain-killers, may have side effects, particularly if they are not taken as directed:

- Talk to your doctor, nurse or pharmacist about any pain medicines you are taking, side effects to look out for, and any possible interactions with other medicines, vitamins or herbal remedies.
- Follow the directions for use and only take the recommended dose. This will reduce the risk of misuse or accidental overdose.

- Let your doctor know if you have any side effects. They may need to adjust your medicines.
- Most people taking opioids won't become addicted. The risk of becoming addicted depends on the dose and length of treatment. Some people are at increased risk.
- You may experience withdrawal symptoms when you stop taking a drug, but this is not addiction. For this reason, your doctor will reduce your dosage gradually. Talk to your doctor if you are concerned about drug dependence.

Other methods of pain relief

- A physiotherapist or occupational therapist can suggest ways to address physical or practical problems that are causing your pain.
- 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.
- Massage or hot packs may relieve muscle spasms, stiffness and contractions.
- Acupuncture may help by stimulating nerves to release the body's natural chemicals, which help reduce pain.
- Other therapies may help, e.g. hydrotherapy or electrotherapy. For more information, see a physiotherapist.
- Let your doctor know about any complementary therapies you are 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.



Lymphoedema

Lymphoedema is swelling that occurs in the soft tissues under the skin due to a build-up of lymph fluid. If lymph nodes have been removed during surgery or damaged by infection, injury, or radiation therapy, the lymph fluid may not drain properly.

Swelling usually occurs in an arm or leg, but it can also affect other areas of the body. The likelihood of developing lymphoedema after treatment depends on the extent of the surgery, other cancer treatment and your body weight. Lymphoedema can take months or years to develop. Not everyone who is at risk will develop it.

Lymphoedema may be permanent, but it can usually be managed, particularly if diagnosed early. The main signs of lymphoedema include visible swelling, which may be associated with feelings of tightness or heaviness, an aching or tingling feeling, not being able to fully move the affected limb, or pitting of the skin.

Lymphoedema requires lifelong self-care and management. The focus of treatment is to improve the flow of lymph fluid through the affected area. This will help reduce swelling and improve the health of the swollen tissue. Reducing the swelling will lower your risk of infection, improve your wellbeing and make movement easier.

Gentle exercise, compression stockings, and a type of massage called lymphatic drainage can all help to reduce the swelling. It is important that you consult a lymphoedema professional who can tailor a treatment plan for you based on the location and stage of the lymphoedema and any other health conditions you may have.



How to prevent and/or manage lymphoedema

- Treat lymphoedema early so that you can deal with the problem quickly and avoid symptoms becoming worse.
- Keep the skin healthy and unbroken to reduce the risk of infection. Avoid cuts, scratches, bites and injections in the affected area.
- Moisturise your skin daily to prevent dry, irritated skin.
- Engage in activities like swimming, bike-riding or using light weights to aid the flow of lymph fluid.
- Maintain a healthy body weight.
- Protect your skin from the sun (see pages 69–71).
- Avoid wearing jewellery or clothing that constricts the affected area or leaves marks on your skin.
- Take care cutting your toenails or see a podiatrist to look after your feet and nails.
- Raise your legs if watching TV. Avoid sitting for long periods.
- Wear a professionally-fitted compression garment, if advised by your lymphoedema practitioner.
- To find a lymphoedema practitioner, visit the Australasian Lymphology Association's website at lymphoedema.org.au, or ask your doctor for a referral.
- Seek medical help urgently if you think you have an infection in the affected area.
- For more information, download the *Understanding Lymphoedema* fact sheet from your local Cancer Council website.

“ My experience is that lymphoedema is very manageable if you notice the signs early. ” Suzanne

Memory and thinking changes

Many cancer survivors say they have difficulty concentrating, focusing and remembering things. This is called cancer-related cognitive impairment. Other terms used to describe this include “chemo brain” and “cancer fog”.

Researchers still aren't sure exactly what causes the memory and concentration changes experienced by some cancer survivors, but there is ongoing research to try to find out.

Memory and thinking changes may be caused by:

- the cancer itself
- cancer treatments, such as chemotherapy, radiation therapy, immunotherapy, hormone therapy, surgery and anaesthesia
- medicines such as steroids, anti-nausea drugs or pain-killers
- fatigue and sleep problems
- emotional concerns, such as stress, anxiety or depression
- infections
- vitamin or mineral deficiencies (e.g. iron, vitamin B, folic acid)
- other health problems, including anaemia
- tumours, cancer or metastases in the brain
- ageing.

These problems usually improve with time, although for some people it may take a year or more to see improvements. Tell your doctor about any memory or thinking 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 and thinking problems

- Get plenty of sleep. Deep sleep is important for memory and concentration.
- Do some gentle exercise, including strength training, each day to help you feel more alert (see pages 66–67).
- A psychologist can help with a cognitive training program. These mental exercises may help improve thinking, memory and concentration.
- Some people find puzzles and brain training apps helpful.
- Use your mobile phone, calendar or daily planner to keep track of appointments, tasks, social commitments, birthdays, etc.
- Plan activities so you do things that require more concentration when you are more alert. You may find it helpful to have a daily schedule.
- Discuss these problems with your partner, family or workplace and ask for their support or assistance.
- Do tasks one at a time rather than multi-tasking.
- Set aside time each day to read and respond to emails.
- Let phone calls go straight to your answering machine or voicemail. You can listen to them when ready and prepare how you will respond.
- If you are working and have your own office, close the door when you don't want to be interrupted.
- Carry a small notepad or download an app to your phone so you can jot down things you need to remember.
- Before your appointments, write down a list of items you would like to discuss. Don't be afraid to write down notes during the appointment or to take a support person with you.
- Put personal items (e.g. wallet, keys) in a dedicated place at home and at work so you can find them easily.

Tingling or numbness in hands or feet

Tingling or numbness in the hands or feet (peripheral neuropathy) is a common side effect of chemotherapy. It may last for a few months after treatment finishes or it may be permanent.

Peripheral neuropathy can be painful, annoying and frustrating. It may make it difficult for you to return to normal hobbies and activities. There is no proven treatment to repair nerve damage. Talk to your GP about treatments that may help you deal with the symptoms. You can also see a physiotherapist or occupational therapist for exercises to help you carry out your daily activities.

The lack of feeling in your hands and feet can cause safety problems, such as a greater risk of falling over. See the box below for some ways to protect yourself and others.



Taking care with numb hands or feet

- Check the water temperature in your home to avoid burns.
- Use gloves to protect your hands while doing housework or washing dishes.
- Wear well-fitting shoes with non-slippery soles.
- Clear walkways of hazards and avoid using rugs.
- Use non-slip rubber mats in showers and baths.
- Regularly check your feet for minor injuries or see a podiatrist.
- If feeling in your feet is severely affected and you can't feel the pedals in the car, ask someone else to drive for you.

Other physical problems

Cancer survivors can also experience a range of other physical problems after treatment. Some common problems are discussed below. If you would like more information about managing these or any other problems, call Cancer Council 13 11 20.

Balance or mobility problems

Surgery or cancer treatment may have affected your balance or ability to walk or move around. Balance training guided by an exercise physiologist, physiotherapist or occupational therapist may assist with these problems.

Bowel or bladder changes

Changes to how your bowel or bladder works can be very distressing and difficult to adjust to. Some medicines and cancer treatments can cause constipation, diarrhoea or incontinence. Some people have a stoma because of their treatment. These changes may be temporary or ongoing, and may require specialised help or products. If you experience any of these problems, talk to your GP, specialist doctor, specialist nurse or dietitian. Drinking more water and dietary changes may also help.

Incontinence is when a person is not able to control their bladder or bowel. Temporary or permanent incontinence can be a side effect of treatment for cancer of the bladder, bowel, prostate, penis, ovaries, uterus, cervix or vagina.

For many people, incontinence is an embarrassing problem. However there is help available, and ways to better manage or



The blood vessels in the bowel and bladder can become more fragile after radiation therapy to the pelvic area. This can cause blood to appear in your urine or bowel movements, months or even years after treatment. Always seek advice from your specialist or GP if you notice new or unusual bleeding. Keep in mind that it may not be related to your treatment.

perhaps even cure the incontinence, e.g a physiotherapist can teach you exercises to strengthen your pelvic floor muscles. For more information and support, call the National Continence Helpline on 1800 33 00 66 or visit continence.org.au or bladderbowel.gov.au.

Heart problems

Radiation therapy to the chest and some types of chemotherapy may damage the heart muscle and lead to an increased risk of heart problems after treatment. Risk factors include certain types of drugs, such as anthracycline chemotherapy drugs and HER2-targeted agents; radiation therapy combined with chemotherapy; younger age at treatment; diabetes; high blood pressure (hypertension); obesity; and smoking.

If you have received high-risk chemotherapy or targeted therapy drugs, radiation therapy to the chest or whole body, or combined radiation therapy and chemotherapy, talk to your doctor about your heart health and the symptoms to look out for. If you develop heart problems later in life, make sure you alert your doctors to the cancer treatment you received.

Bone density loss (osteoporosis)

Cancer and its treatment, particularly radiation therapy, can have long-term effects on your bone strength. Menopause and some types of hormone therapy may also cause bones to weaken and break more easily. Talk to your doctor about having a bone density test or taking medicine to prevent your bones from becoming weak.

Regular exercise, eating calcium-rich foods (e.g. yoghurt, milk, tofu, green vegetables) and getting enough vitamin D will also help keep your bones strong. For more information call Osteoporosis Australia on 1800 242 141 or visit osteoporosis.org.au.

Mouth or teeth problems

You may have problems with your mouth or teeth, find it difficult to swallow, or have a dry mouth. 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. It is important to have regular dental check-ups after cancer treatment, especially if you had surgery or radiation therapy to the head or neck region.

Hearing problems

Radiation therapy to the head or neck and 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. These problems may go away when treatment ends or they may be permanent. Tell your GP if you notice any change in your hearing or if these symptoms don't go away.

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) or body shape
- hair loss or hair growing back differently
- speech difficulties
- problems with eating or drinking
- breathing changes or shortness of breath
- weight loss or gain
- bowel or bladder changes (see page 49)
- changes to your sex life and intimacy (see opposite page)
- early menopause or infertility (see pages 56–58)
- a sense of feeling prematurely old.

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 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, a psychologist 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.



Adjusting to changes in appearance

- Be gentle with yourself and acknowledge your feelings.
- Give yourself time to get used to any physical changes. Focus on yourself as a whole person, not just the part of you that has changed.
- Talk about and acknowledge the changes. If you don't, people may avoid you because they don't know what to say.
- For practical suggestions about dealing with physical changes, call **13 11 20**.

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 pages 56–57)
- 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 they avoid all forms of intimacy, including hugs, kisses and sharing feelings, because they're afraid this may lead to sex when they don't feel physically up to it.

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 feel confused or uncertain about how to react. Let your partner know how you're feeling and any fears you have about sex. Ask your partner how they're 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.

Some people worry that they will never be able to have an intimate relationship again. For most people, sex is more than arousal, intercourse and orgasms. It involves feelings of intimacy and acceptance, as well as being able to give and receive love. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

Common sexual problems after cancer treatment

General	Women	Men
<ul style="list-style-type: none"> • Loss of interest in sex • Tiredness and fatigue • Changed body image • Feeling sexually unattractive • Incontinence • Painful intercourse • Depression or anxiety • Relationship changes or pressures 	<ul style="list-style-type: none"> • Difficulty reaching orgasm • Vaginal dryness • Reduced vaginal size • Loss of sensation • Pelvic pain • Menopausal symptoms (see page 56) 	<ul style="list-style-type: none"> • Difficulty getting or maintaining an erection • Ejaculation difficulties



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.
- If you're having erection problems, ask your doctor if medicine can help.
- If radiation therapy or surgery has narrowed or shortened the vagina, you may be advised to use a vaginal dilator to help keep the walls of the vagina open and supple.
- Show affection by touching, hugging, massaging, talking and holding hands.
- Do some physical activity to boost your energy and mood. Talk to your GP if your low libido is caused by depression (see pages 12–15).
- Be intimate at the best time for you (e.g. when your pain is low or energy levels high).
- Take some pain-killers before having sex if you have ongoing issues with pain.
- Spend more time on foreplay and try different ways of getting aroused: shower together, have a weekend away, dance, wear something sexy. Do whatever makes you feel good about yourself.
- Use a water or silicone-based lubricant during sex. Avoid products with perfumes or colouring to reduce irritation.
- Try different positions during sex to work out which is the most comfortable for you.
- If sexual penetration is painful or difficult, explore different ways to orgasm or climax.
- 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.
- For more information, see Cancer Council's *Sexuality, Intimacy and Cancer* booklet.

Menopause

Menopause means that a woman's ovaries no longer produce eggs and her periods stop. For most women, menopause is a natural and gradual process that starts between the ages of 45 and 55.

Some cancer treatments, including certain chemotherapy drugs, radiation therapy 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. If your family is complete or you didn't want children, you may still have mixed emotions or worry about the impact of menopause on your relationship. See page 58 for more information about fertility. Some women find menopause difficult because they feel it has taken away part of their identity as a woman.

Symptoms of menopause

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, sweating (especially at night), dry or itchy skin, loss of confidence, mood swings, anxiety, trouble sleeping, tiredness, loss of libido and vaginal dryness. Many of these symptoms will eventually pass, although this may take months or a few years. Some women who have already been through menopause find that these symptoms return during or after treatment.



Managing menopause symptoms

- Meditation and relaxation techniques may help reduce stress and lessen symptoms.
- Maintain a healthy weight and eat a healthy diet with lots of fresh fruit, vegetables and wholegrains.
- Ask your doctor for advice about diet changes or herbal remedies.
- Cholesterol levels can change after menopause, which can increase your risk of heart disease. Talk to your doctor about lifestyle changes or cholesterol-lowering drugs.
- Menopause can increase your risk of developing thinning of the bones (osteoporosis, see page 51).
- 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.
- If vaginal dryness is a problem, take more time before and during sex to give yourself time to become aroused and for the vagina to become more lubricated.
- Look for a vaginal moisturiser at the chemist to help with vaginal discomfort and dryness.
- See your doctor about trying an oestrogen cream, which may relieve vaginal dryness. If you need to avoid products containing oestrogen, talk to your doctor about non-hormonal medicines that may help with menopausal symptoms such as hot flushes and night sweats.
- For more tips about sexuality and intimacy, see page 55.
- Ask whether your hospital has a menopause clinic. If you need help adjusting to menopause symptoms after cancer treatment, talk to your doctor about a referral.

Fertility problems

Some cancer treatments can cause temporary or permanent infertility (inability to have a child). Although chemotherapy and radiation therapy can reduce fertility, after treatment some women may be able to become pregnant and some men may be able to father a child. Other people take steps to preserve their fertility before treatment starts by storing eggs, sperm or embryos.

If you are thinking about trying to get pregnant after treatment, talk to your doctor about the impact that your treatment might have on your health during pregnancy. Your doctor may suggest you wait a certain period of time before trying to conceive, to give your body time to recover and to 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 psychologist or 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*.



If you have trouble conceiving after cancer treatment or would like to learn about ways to improve your chances of getting pregnant, 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. Some may be permanent.
- Side effects can be both physical and emotional, and vary depending on the cancer type and stage, and the treatment you had.
- If you have ongoing side effects, your GP can use your survivorship care plan to develop a Chronic Disease Management Plan.
- Fatigue is one of the most common physical side effects of treatment.
- Learning how to manage any pain may increase your ability to function and improve your quality of life.
- Persistent pain can be treated in a variety of ways, including exercises, stretches, cognitive behaviour therapy, and pain-killing drugs.
- Lymphoedema can occur if the lymph nodes are damaged or removed. It is managed by preventing or controlling the swelling, and avoiding infections.
- Many cancer survivors say they have difficulty concentrating. This is often referred to as “chemo brain”. It usually improves with time.
- Changes to your body after treatment can change how you feel about yourself.
- 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. This can be distressing regardless of whether you want to have children in the future.



Taking control of your health

Cancer survivors will benefit from maintaining or adopting a healthier lifestyle after their cancer treatment. This could include achieving a healthy body weight, eating a healthy diet, being physically active, protecting yourself from the sun, stopping smoking or cutting down on alcohol.

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 type 2 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. Make sure you see your GP for regular lifestyle health checks. Find out more at cutyourcancerrisk.org.au and see page 79 for information about healthy living programs run by Cancer Council.

Maintain a healthy body weight

Obesity is a risk factor for a number of different cancers. 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 waist circumference (see opposite) and body mass index (BMI). To calculate your BMI, go to healthdirect.gov.au and search for BMI calculator.

Keep in mind that some cancer treatments can affect your weight and waist circumference. Some people expect to lose weight during cancer treatment, but for many people it can have the opposite effect. Weight gained during cancer treatment can be difficult to lose because of fatigue and other challenges after cancer treatment. Whether you have lost or gained weight, it is important to work towards getting back to a healthy weight.

Treatment for some cancers can affect your ability to eat, digest food and absorb essential nutrients. You will need to try different foods and ways of eating to find out what works for you. You may need to change your eating habits, such as eating smaller meals more often throughout the day.

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, including cancer. Some cancer types are also associated with increased fat around the hips and buttocks.

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.

Health risk	Men	Women
Increased	94 cm or more	80 cm or more
Substantially increased	102 cm or more	88 cm or more

Seeing a dietitian

Dietitians can help you with nutritional concerns, any ongoing problems with food and eating, or supervised weight loss. They are available in all public hospitals, and some private hospitals and community health centres. Ask at your local centre or see 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 daa.asn.au. Ask about Medicare rebates.

Have a healthy, well-balanced diet **Eat more fruit, vegetables, wholegrains and fibre**

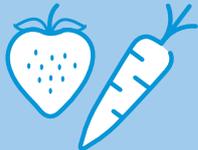
Fruit and vegetables are essential for a healthy, balanced diet. They are a great source of fibre, vitamins and minerals. Fruit and vegetables also contain natural protective substances, such as antioxidants, that can prevent damage to DNA and other cells, and destroy cancer-causing agents (carcinogens) and cancer cells. Fruit and vegetables are low in kilojoules – eating them can help you maintain a healthy body weight.

Dietary fibre can help to ensure a healthy digestive system and reduce the risk of bowel cancer. Eating a diet high in fibre, including fruit, vegetables and wholegrain cereals, can also lower your risk of developing type 2 diabetes and heart disease, and help you maintain a healthy body weight. Some people experience ongoing bowel problems after cancer treatment (e.g. surgery or radiation therapy to the pelvis). If you find that dietary fibre makes any bowel problems worse, you may need to eat low-fibre foods.

The *Australian Dietary Guidelines* (eatforhealth.gov.au) recommend eating at least two serves of fruit and five serves of vegetables daily. Aim to eat a variety of different-coloured fresh fruit and vegetables. They are best eaten whole (i.e. not in a juice or supplement form), and a combination of cooked and raw vegetables is recommended. Frozen and tinned vegetables are still nutritious and are a good alternative. Look for varieties without added sugars, salt or fats.

The *Australian Dietary Guidelines* recommend that most adults eat at least four serves of cereal or grain foods each day, with at least two-thirds of these being wholemeal or wholegrain varieties.

How much is a serve?

Fruit & vegetables	Cereal & grains	Meat (uncooked)
 <ul style="list-style-type: none"> • 1 medium-sized piece of fruit • 2 smaller fruits, e.g. plum, apricot • 1 cup diced fruit • ½ cup cooked vegetables • 1 cup raw salad vegetables 	 <ul style="list-style-type: none"> • 1 slice of wholegrain bread • ½ cup cooked brown rice or wholemeal pasta • ⅔ cup wholegrain breakfast cereal 	 <ul style="list-style-type: none"> • 100 g lamb loin chop • 100 g steak • ½ cup diced red meat • ½ cup mince

Limit your intake of red meat and avoid processed meats

It is important to eat a balanced diet that is high in plant foods, such as fruit, vegetables and wholegrain cereals, but there is no need to give up meat. Lean red meat is an important contributor to dietary iron, zinc, vitamin B12 and protein.

Eating too much red meat increases your risk of bowel cancer. To reduce your cancer risk, Cancer Council recommends people eat no more than one serve of lean red meat per day or two serves 3–4 days a week (see page 63).

There is strong evidence that eating processed meats, such as ham, bacon and deli meats, is associated with an increased risk of bowel and stomach cancers.

There is no conclusive evidence that being a vegetarian has a positive impact on survival after cancer treatment. However, increasing your consumption of fruit, vegetables and wholegrain foods will probably improve the quality of your diet. If you are considering reducing the amount of meat in your diet, it is important to include a variety of other proteins. These include eggs, legumes, pulses, nuts, wholegrains, soya and dairy products.



Cancer Council's *Nutrition and Cancer* booklet has more information about eating well after cancer treatment. For a free copy, call **13 11 20** or visit your local Cancer Council website.



How to improve your diet

- Eat a variety of nutritious foods every day.
- Eat plenty of fruit, vegetables, legumes, wholegrain and high-fibre foods.
- Try reduced-fat milk, yoghurt and cheese, that are also low in added sugars or salt.
- Limit your intake of red meat (see opposite page).
- Choose lean cuts of meat and trim as much fat as possible before cooking.
- Cut out processed meats like ham, bacon and deli meats altogether or eat only rarely.
- For breakfast, add fruit and yoghurt to wholegrain cereal or serve some vegetables with your eggs and toast.
- Limit the portion size of your meals and snacks.
- Adapt your recipes to include more vegetables, beans and legumes, e.g. add grated carrot and zucchini, celery, capsicum, beans or peas to pasta sauces.
- Fill half your dinner plate with vegetables.
- Swap sugary drinks for water.
- Avoid snacks that are high in added fats, sugars and salt, such as chips, biscuits and chocolate. Replace them with nuts, fruit, yoghurt or cheese.
- Limit takeaway foods that are high in fat, sugar and salt.
- Don't add salt to food during cooking or before eating. Add flavour with herbs and spices.
- Grill, poach and bake rather than fry.
- Steam or microwave vegetables to maintain their nutritional goodness.
- Use a non-stick frying pan or a small amount of polyunsaturated oil (e.g. olive oil) when pan-frying.

Be physically active

Being physically active and limiting sedentary behaviour is essential for health and wellbeing. Research shows that physical activity can both reduce the risk of some cancers and help prevent some types of cancer coming back. Physical activity also helps to prevent weight gain and obesity, which are risk factors for a number of cancers.

Physical activity has a range of other benefits for cancer survivors. It can boost energy levels, increase muscle strength, improve mobility and balance, relieve stress, reduce the risk of heart disease, improve sleep, and decrease fatigue, anxiety and depression.

For maximum cancer prevention benefits, Cancer Council recommends aiming for at least 60 minutes of moderate activity or 30 minutes of vigorous activity every day. This can be broken up into smaller episodes of at least 10 minutes each. Moderate activity includes brisk walking, swimming and even household chores. Vigorous activity includes football, netball, running and aerobics.

Doing any physical activity is better than doing none. Start physical activity slowly and build up gradually. Many people lose muscle strength during cancer treatment and find it harder to complete tasks of normal daily living. Strength-training (resistance) activities can be very useful to reverse losses in muscle strength.

If you are unsure if you are well enough to exercise or worried about disrupting your recovery, talk to your doctor about the type and amount of activity suitable for you. They may refer you to an exercise physiologist or physiotherapist. Ask about Medicare rebates.



How to be more active

- Walk with a friend, join a walking group or walk to the corner shop instead of driving.
- Break up long periods of sitting or screen time by standing up every half-hour.
- Take the stairs instead of the lift or escalators.
- Do vigorous housework and activities around the home, such as vacuuming, gardening 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.
- Join a dance or yoga class.
- Take your children or grandchildren to the park or kick a ball around the backyard.
- Join an exercise group or a local gym.
- Try short periods of aerobic exercise (e.g. walking, cycling or swimming), stretching, strength training (resistance exercises), Pilates and tai chi.
- Talk to your GP before starting a new exercise program. A physiotherapist or exercise physiologist can develop a program that is right for you.
- If you are being physically active outdoors, remember to protect your skin (see pages 69–71).
- See Cancer Council's *Exercise for People Living with Cancer* booklet for more information.
- Call **13 11 20** to find out about survivorship programs in your area (see page 79).

“ I was not as active before cancer as I am now. I walk three or four times a week. It gives me extra energy and helps clear my mind. ” Rima

Quit smoking

If you smoke, Cancer Council strongly recommends that you quit. There is no safe level of tobacco use. Research shows that continuing to smoke increases your 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 and reduce your risk of developing a new second cancer.



How to quit smoking

- Call Quitline on **13 7848** to talk to an advisor and request a free Quit Pack.
- Ask your doctor for advice about subsidised medicines to help you quit.
- Set a date to quit. Tell your family and friends so they can support you.
- Think of yourself as someone who doesn't smoke.
- Make your home and car a smoke-free zone.
- Buy a reward with the money you would spend on tobacco.
- Keep a list of all the reasons you want to quit.
- Consider previous quit attempts as practice. Learn from what did and didn't help.
- Don't be tempted to "just have one".
- Avoid tempting situations or plan how you'll react if you are tempted.
- Distract yourself if you feel tempted, e.g. going for a walk, having a drink of water.
- Get support online – visit quitcoach.org.au or icanquit.com.au.
- Download a smartphone app such as My QuitBuddy to help you track your progress.

Quitting smoking can also improve your ability to be more physically active and help reduce alcohol consumption, both of which can help you maintain a healthy weight.

Many people who smoke 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 opposite page.

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

Use sun protection

Skin cancer is the most common cancer in Australia. The main risk factor associated with all types of skin cancer is overexposure to ultraviolet (UV) radiation from the sun. When UV levels are 3 and above, Cancer Council recommends you use a combination of sun protection measures when outdoors for more than a few minutes to reduce your skin cancer risk (see pages 70–71).

Some exposure to the sun is healthy. Vitamin D, which is needed to develop and maintain healthy bones, 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. Short incidental sun exposure, such as walking from the office to get lunch on most days of the week, can be a good way to maintain vitamin D levels.

Protecting your skin from the sun

When UV levels are 3 or above, be SunSmart. Find a way to make sun protection part of your everyday routine, e.g. by having sunscreen and a broad-brimmed hat within easy reach before going outside.

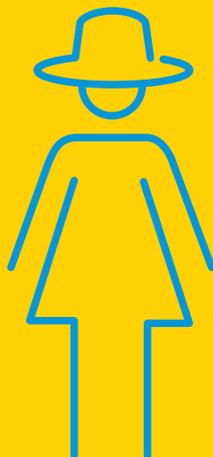
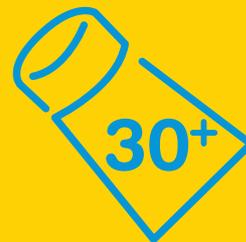
SLIP on clothing

Wear clothing that covers your shoulders, neck, arms, legs and body. Choose closely woven fabric or fabric with a high ultraviolet protection factor rating.



SLOP on sunscreen

Use an SPF 30+ or higher broad-spectrum sunscreen. Use a water-resistant product for sports and swimming. Apply a generous amount of sunscreen 20 minutes before going out and reapply every two hours, or after swimming or any activity that causes you to sweat or rub it off.



SLAP on a sun-safe hat

Wear a hat that shades your face, neck and ears. This could be a wide-brimmed, bucket or legionnaire-style hat. Adult hats should have at least a 7.5 cm brim. Hats for children aged under 8 years should have at least a 5 cm brim, and hats for children aged 8–12 should have at least a 6 cm brim.



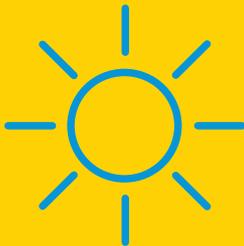
SEEK shade

Use shade from trees, umbrellas, buildings or any type of canopy. Shade is very effective at reducing UV exposure, however, UV radiation is reflective and can bounce off surfaces, such as concrete, water, sand and snow. It is wise to use other forms of UV protection as well, such as sunscreen and clothing.



SLIDE on sunglasses

Protect your eyes with sunglasses that meet the Australian Standard AS1067. Wraparound styles are best. Sunglasses should be worn all year round.



Sensitive skin

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.

Check sun protection times every day

Use the SunSmart UV Alert to check daily sun protection times in your local area. It is available as a free smartphone app, online (sunsmart.com.au or bom.gov.au/uv) or in the weather section of daily newspapers.



Limit or avoid alcohol

Many people drink alcohol to relax and socialise. However, drinking too much may lead to weight gain. Drinking alcohol also increases the risk of cardiovascular disease, type 2 diabetes, and some cancers. Even low levels of alcohol consumption can increase cancer risk, and the risk increases with every drink you consume.

Cancer Council recommends that you limit your alcohol consumption to reduce your risk of cancer. If you choose to drink alcohol, stick to the National Health and Medical Research Council guidelines and limit your intake to two standard drinks a day. One standard drink contains 10 grams of alcohol, but remember that drinks served at home, restaurants and bars are usually more than a standard drink – see alcohol.gov.au for a guide to standard drinks.



How to reduce your alcohol intake

- Use water to quench thirst and sip alcoholic drinks slowly.
- Alternate alcoholic drinks with a glass of water.
- Set yourself a limit and stop once you've reached it.
- Switch to light beer, dilute spirits with extra mixer and ice, or 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 each week.
- Eat while you drink to slow your drinking pace and fill yourself up.
- Offer to be the designated driver so that you limit your alcohol intake or don't drink.



Key points

- You can reduce your cancer risk after treatment and improve survival through healthy lifestyle choices.
- Whether you have lost or gained weight during treatment, it is important to return to a healthy weight.
- Eating a variety of vegetables, fruit, wholegrain breads, cereals, pasta, rice and other foods low in fat, salt and sugar helps to maintain a healthy body weight.
- Eating more dietary fibre can help lower the risk of bowel cancer and ensure a healthy digestive system.
- Limiting your intake of red meat and cutting out processed meats can reduce your risk of bowel cancer.
- Physical activity is important to reduce your cancer risk and help manage your weight. It also helps boost energy levels, decrease fatigue, relieve stress and improve overall wellbeing.
- Quitting smoking can have a significantly positive impact on your survival. There is no safe level of smoking. Support is available to help you quit.
- Being SunSmart every day and protecting your skin from the sun will lower 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.
- Talk to your GP about the support they can provide to help you take control of your wellness.



Legal, financial and workplace concerns

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

Financial assistance

For many people, cancer treatment can be a financial strain. This may be caused by extra out-of-pocket costs for medicine or travel expenses, or from loss of income. These extra costs can cause you and your family a lot of stress, but support is available:

- Your local Cancer Council may be able to organise legal and financial advice (see box on opposite page).
- Ask your social worker about any financial or practical assistance available to you.
- Call the National Debt Helpline on 1800 007 007 for free, confidential and independent financial counselling.
- Talk to your superannuation fund about applying for an early release of your superannuation savings on the grounds of severe financial hardship.
- Talk to your utility company, loan provider or local council about how they might be able to help you manage payment of your bills or loans.
- See Cancer Council's booklet *Cancer and Your Finances* for more detailed information.

Insurance

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, including your cancer diagnosis.

Legal, financial and workplace support

Cancer Council's Legal, Financial, Small Business and Workplace Referral Service may be able to help if you or someone in your family had cancer, and you need financial, legal or workplace advice.

We can connect you with professionals to assist you

with: credit and debt issues, mortgage hardship variations, insurance claims and disputes, managing workplace issues, and transitioning to retirement.

Call **13 11 20** to find out what services are available in your area and whether you are eligible for this assistance.

In general, you should be able to buy insurance for things that are not related to your cancer (like travel insurance for lost luggage, or life insurance for accidental death). It may be difficult to buy travel insurance that covers cancer-related medical problems, but you should be able to get coverage for non-cancer-related medical costs.

It is a good idea to check exactly what is covered before purchasing a new insurance policy. For more information about insurance, download a copy of the *New insurance policies* fact sheet from your local Cancer Council website.

Working after treatment ends

Work is an important part of life for many people. Aside from income, work can provide satisfaction, a sense of normality, a means of maintaining self-esteem, and a chance to socialise.

If you took time off work for treatment and are returning to an existing job, talk to your employer about a return to work plan. It's a good idea to speak with your doctor about your capacity to undertake your usual tasks.

For some people, returning to the same job may not be possible due to changes in ability and length of time away. The desire to reduce work-related stress or seek more meaningful work may also motivate people to change jobs.

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 new office equipment or making adjustments to your workstation.

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 I had cancer in job applications?

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 résumé, 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 this at the interview.

What if I can no longer work?

If cancer or its 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 132 717 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 and perform your usual role.

Anyone who has had cancer is protected by the Commonwealth *Disability Discrimination Act 1992*, which prevents employers from discriminating against people with disabilities in the workplace.

For further advice:

- speak to a social worker, union official or solicitor
- contact your state or territory anti-discrimination body or visit the Australian Human Rights Commission at humanrights.gov.au
- visit the Fair Work Ombudsman at fairwork.gov.au
- call 13 11 20 and ask for a free copy of *Cancer, Work & You* or download a copy from your local Cancer Council website
- download Cancer Council's online Workplace Fact Sheets from your local Cancer Council website. These fact sheets assist employers and workplaces to provide a supportive and fair work environment for people affected by cancer.



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.
- Insurance that covers cancer-related problems may be harder to get.
- Cancer survivors should be able to get travel insurance, but the terms and conditions will vary depending on your condition and the insurer.
- A written return to work plan can be a helpful guide for you and your employer.
- 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.
- Let your employer know about any workplace adjustments you may need to help you carry out your job.
- If you are unable to return to your previous position, consider attending a rehabilitation or retraining program.
- 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 Referral Service 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.
- See Cancer Council's *Cancer, Work & You* and *Cancer and Your Finances* booklets 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.

Survivorship programs

Free education programs for cancer patients and survivors are available in some treatment facilities or community centres. Your local Cancer Council may also offer online webinars.

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

Your local Cancer Council may offer programs providing information about living well after cancer (e.g. ENRICHing Survivorship, Healthy Living After Cancer, Wellness and Life After Cancer, Life Now). These may include sessions on nutrition, exercises to help improve quality of life, mindfulness and adjusting to life following cancer treatment. Call 13 11 20 to find out what services are available in your state or territory.

“ Really enjoyed the program. I feel after treatment there is a gap in support for getting back to normal life, I liked that it wasn't ‘you have to make major changes’ because you don't stick to it, small changes over time. ” Ashley

Talk to someone who's been there

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

In a support setting, 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 because they aren't trying to protect their loved ones.

Types of support

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

- **face-to-face support groups** – often held in community centres or hospitals
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **group education programs for survivors** – often delivered by your local Cancer Council, programs such as Wellness and Life After Cancer or ENRICHing Survivorship can help you meet others in a similar situation
- **online forums** – provide the opportunity to connect with other people anywhere and anytime, e.g. Cancer Council Online Community at cancercouncil.com.au/OC.



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



Cancer Council services

Cancer Council offers a range of services to support people after cancer treatment. Services may vary depending on where you live.

Cancer Council 13 11 20 – This service can continue to help you after treatment with answers to your questions about life after cancer. Trained professionals will answer any questions you have about your situation and link you to services in your area. For more information, see the inside back cover.

Practical help – Your local Cancer Council can help you access programs or offer advice to manage the practical impact of life after cancer. This may include access to exercise and nutrition programs, mentoring programs, and information on survivorship (see page 79).

Information resources – Cancer Council produces a wide variety of free information about cancer-related topics. This includes easy-to-read booklets and fact sheets on a range of emotional and practical issues relevant to living well after cancer. Call 13 11 20 or visit your local Cancer Council website.

Legal and financial support – Call 13 11 20 to find out what support is available in your local area.

“ I’ve just passed the five-year mark and had my final appointment with my oncologist – this has been a big relief. In the last year I’ve become involved as a volunteer providing telephone peer support with Cancer Connect. ” *Christine*



Question checklist

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

Fear of the cancer coming back

- Am I at risk of getting a different type of cancer or another serious health problem due to the cancer or its treatment?
- 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?

Follow-up care

- Is it possible to get a survivorship care plan?
- Can I have a copy of my cancer treatment summary?
- Who should I go to for my follow-up appointments?
- Why do I need check-ups?
- What will happen during my check-ups?
- How often do I need check-ups?
- What symptoms/problems should I watch out for?
- Who should I contact if I develop new symptoms?
- What happens if there are signs the cancer has come back?

Family and friends

- Where can my family get help and advice?
- Are my children at risk of inheriting my type of cancer?

Treatment side effects

- How long will it be before I feel better?
- 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 psychologist or counsellor?
- 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?
- Is there someone I can see about ongoing side effects?

Taking control of your health

- Is there anything I can do to improve my health?
- 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? Can you refer me to a physiotherapist or exercise physiologist?
- What advice do you have about returning to work?
- Are there any complementary therapies that might help me?
- Are there any support services you can refer me to?



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
CanTeen	canteen.org.au
Australian Cancer Survivorship Centre	petermac.org/cancersurvivorship
Breast Cancer Network Australia	bcna.org.au
beyondblue.....	beyondblue.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Voices Australia.....	cancervoicesaustralia.org
Carers Australia	carersaustralia.com.au
Flinders Centre for Innovation in Cancer.....	fcic.org.au/survivorship
Lifeline	lifeline.org.au
National Centre for Cancer Survivorship.....	nccs.org.au
Work After Cancer	workaftercancer.com.au

International

American Cancer Society Cancer Survivors Network....	csn.cancer.org
Children's Oncology Group	survivorshipguidelines.org
Journey Forward	journeyforward.org
Macmillan Cancer Support (UK).....	macmillan.org.uk
National Cancer Institute (US).....	cancer.gov
National Coalition for Cancer Survivorship (US)	canceradvocacy.org
Office of Cancer Survivorship (US).....	cancercontrol.cancer.gov/ocs
OncoLife Survivorship Care Plan	oncolife.oncolink.org



Glossary

active treatment

Aims to control or cure the cancer.

advanced cancer

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

analgesic

A medicine used to relieve pain.

antidepressant

Medicine to help relieve the symptoms of depression.

BMI (body mass index)

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. The doctor has told them that treatment has finished. They are free from any signs of cancer.

chemo or cancer brain

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

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments.

cognitive behaviour therapy (CBT)

A common type of counselling that helps people identify unhelpful thoughts and behaviours and change how they respond to negative situations or emotions.

complementary therapy

Supportive treatments that are used in conjunction with conventional treatment (e.g. acupuncture, massage, meditation, reflexology). They may improve general health, wellbeing and quality of life, and help people cope with side effects of cancer.

depression

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

diagnosis

The identification and naming of a person's disease.

electrotherapy

Applying mild electric currents to the body to stimulate nerves and reduce pain, e.g. transcutaneous electrical nerve stimulation (TENS).

erectile dysfunction

Inability to get and keep an erection firm enough for penetration. Also called impotence.

exercise physiologist

Prescribes exercise to help people with medical conditions improve their overall health, fitness, strength and energy levels.

fatigue

Extreme feeling of 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 treatment.

general practitioner (GP)

A doctor in general practice. Works in partnership with your specialists in providing ongoing care.

hormone replacement therapy (HRT)

Drug therapy that supplies the body with hormones that it is no longer able to produce naturally. Often used to treat the symptoms of menopause.

hormone therapy

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

infertility

The inability to conceive a child.

late effects

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

libido

Sex drive/sexual desire.

lymph

A clear fluid that circulates around the body through the lymphatic system, carrying cells that fight infection.

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. Includes the bone marrow, spleen, thymus and lymph nodes.

lymph nodes

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

lymphoedema

Swelling caused by a build-up of lymph fluid. This happens when lymph vessels or nodes can't drain properly because they have been removed or damaged.

maintenance treatment

Treatment given for months or years as part of the treatment plan.

menopause

When a woman stops having periods (menstruating). This can happen naturally; from cancer treatment; or because the ovaries have been removed.

metastasis (plural: metastases)

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

mindfulness

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

morphine

An opioid. A strong and effective pain-killing drug that is commonly used to treat people with cancer who have pain.

nerve block

Pain medicine that is injected directly into or around a nerve or into the spine to block pain.

oestrogen

A female sex hormone produced mainly by the ovaries.

opioids

The strongest pain-killing drugs available. Include morphine, fentanyl, codeine, oxycodone and methadone.

osteoporosis

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

peripheral neuropathy

Weakness, numbness, tingling or pain, usually in the hands and feet, caused by damage to the nerves that are located away from the brain and spinal cord (peripheral nerves).

physiotherapist

Uses physical methods, such as massage and exercise, to help restore movement and mobility, and prevent further injury.

primary cancer

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

prognosis

The expected outcome of a person's disease.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

recurrence

The return of a disease after a period of improvement (remission).

remission

When the symptoms and signs of the cancer reduce or disappear. This may not mean that the cancer is cured.

secondary cancer

See metastasis.

side effect

Unintended effect of a drug or treatment.

stage

The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

stoma

A surgically created opening to the outside of the body.

survival rate

The proportion of patients diagnosed with the same disease who are still alive after a particular period of time.

survivorship care plan

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

wellness

Seeking good physical, mental, spiritual, emotional and social wellbeing, not just the absence of disease.

Can't find a word here?

For more cancer-related words, visit:

- cancerCouncil.com.au/words
- cancervic.org.au/glossary
- 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 other Pink events, 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.



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.

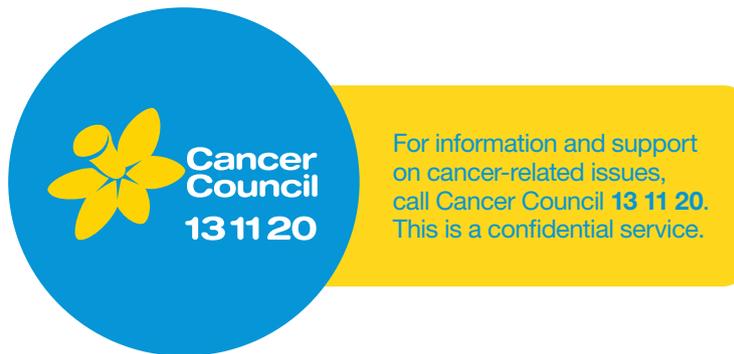
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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, you can contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancerCouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancerTas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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