

Living Well After Cancer

A guide for people with cancer, their families and friends



For information & support, call **13 11 20**

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First published February 2010. This edition November 2021.

© Cancer Council Australia 2021. ISBN 978 0 6489506 3 9

Living Well After Cancer is reviewed approximately every three years.

Check the publication date above to ensure this copy is up to date.

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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 Subcommittee initiative. We thank the reviewers of this booklet: Prof Michael Jefford, Medical Oncologist and Director, Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, VIC; Lucy Bailey, Nurse Counsellor, Cancer Council Queensland; Philip Bullas, Consumer; Dr Kate Gunn, Clinical Psychologist and Senior Research Fellow, Department of Rural Health, University of South Australia, SA; Rosemary Hodgkin, 13 11 20 Consultant, Cancer Council WA; Prof David Joske, Clinical Haematologist, Sir Charles Gairdner Hospital and Clinical Professor of Medicine, The University of Western Australia, WA; Kim Kerin-Ayres, Clinical Nurse Consultant, Cancer Survivorship, Concord Hospital, NSW; Sally Littlewood, Physiotherapist, Seymour Health, VIC; Georgina Lohse, Social Worker, GV Health, VIC; Melanie Moore, Exercise Physiologist and Clinical Supervisor, University of Canberra Cancer Wellness Clinic, ACT; June Sawva, Senior Clinician Dietitian, Nutrition and Dietetics, Monash Cancer Centre, Monash Health, VIC; Dr Elysia Thornton-Benko, Specialist General Practitioner and Research Fellow, University of New South Wales, NSW; Prof Janette Vardy, Medical Oncologist, Concord Cancer Centre and Professor of Cancer Medicine, The University of Sydney, NSW; Lyndell Wills, Consumer. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

Note to reader

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

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

Cancer Council

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



Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.



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About this booklet

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

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.

Having the information and support you need about follow-up care and ways to improve your health and wellbeing can help you deal with the after effects of cancer treatment.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 85). You may also like to pass this booklet to your family and friends. It may help them to understand your experience and their own feelings at this time.

How this booklet was developed – This information was developed with help from a range of health professionals and people who have completed cancer treatment. It is based on Australian guidelines¹⁻⁴ and findings from research studies about cancer survivorship.



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



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Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Tips



Cancer survivorship

Improvements in diagnosing and treating cancer mean that more people are surviving and living with cancer. Nearly 1.2 million people living in Australia today have been diagnosed with cancer during their lifetime.

Am I a cancer survivor?

The term “cancer survivor” is used to describe a person from the time of diagnosis onwards. For many people, survivor is a strong and positive word. Other people do not like being labelled and prefer to look towards a future that is not focused on cancer.

You may see yourself as a survivor as soon as you are diagnosed with cancer, when active treatment stops or when there are no more signs of cancer in the body. Or you may find it difficult to relate to the term survivor. Instead, you may think of yourself as someone who has had cancer or is living with cancer.

However you like to refer to yourself, you may wonder: what now? Research has shown that getting information about what to expect after finishing primary cancer treatment can help you prepare for life after cancer. This is known as the survivorship phase.

What is survivorship care?

Survivorship care aims to look after your emotional and physical wellbeing once primary cancer treatment is finished. This may include help dealing with treatment side effects and maintaining a healthy lifestyle after treatment.

- ▶ Some survivors live with cancer for many years. See our *Living with Advanced Cancer* booklet for more information.

Finding a “new normal”

When treatment ends, you may expect that life will soon return to normal. Or you may see the diagnosis as an opportunity to make changes to your life. Over time, cancer survivors often find a new way of living. This process is commonly called finding a new normal and it may take months or years.

A life-changing experience

Most people say cancer is a life-changing experience. Although having cancer can be very challenging, some people find positive aspects. They may discover an inner strength they didn't know they had, develop new friendships during treatment or find other sources of support.

Cancer may prompt you to reconsider your outlook on life. This shift is often gradual; even positive change can take time. You may:

- place more value on spending time with family or friends and choose to focus on the more meaningful relationships in your life
- spend more time doing activities you enjoy, start new activities or visit new places
- reconsider your career goals and work values, and decide to work fewer hours or take on a different role
- have a new focus on healthy living.

“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

Adjusting to life after treatment

The cancer experience doesn't stop when treatment ends. Give yourself time to adjust to life after treatment. It can be helpful to take each day as it comes and

Reflect on your life



Think about your goals and priorities. It may be helpful to write down how you're feeling in a journal or to ask yourself:

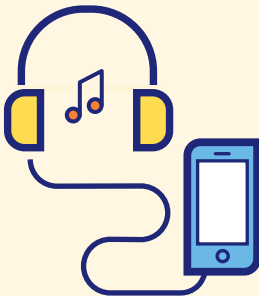
- What makes me feel fulfilled?
- What makes me feel happy?
- What gives my life meaning?
- What is most important?

Look after yourself



Take the time you need to get used to any changes in your body. 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.

Take time for yourself



Make time each day to do something you find relaxing or enjoyable. This could be reading, listening to music, spending time in nature or taking a bath.

Talk about your emotions



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

accept that you may have both good and bad days. Everyone is different, but you may find some of the following suggestions useful.

Manage your wellness



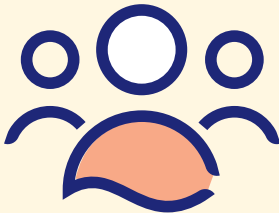
Think about ways you can manage your own wellness and make changes to improve your quality of life. Eating healthy food and being physically active can help your body cope with physical and emotional stress, and make you feel as though you are doing something practical to help yourself (see pages 58–73).

Clear your mind



Complementary therapies, such as relaxation, yoga, mindfulness meditation and visualisation, may increase your sense of control, relieve stress and anxiety, and improve mood.

Seek support



Connecting with others who have been through a similar experience may be helpful. Join a support group, attend a survivorship program, listen to survivorship webinars or read stories from other survivors. See pages 79–82 for sources of support.

Manage side effects



You may have ongoing side effects after treatment. Talk to your health care team about ways to improve or manage any symptoms (see pages 35–57).

Myths about the end of treatment

I should be back to normal – You may have thought you would just resume your life exactly where you left off before the cancer diagnosis. The reality is often more 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 treatment before they return to their usual activities.

I should feel well – On the outside, you may look healthy. On the inside you may still be recovering physically and emotionally. Many cancer survivors have ongoing health concerns because of the cancer or treatment side effects.

I should not need any more support – You may feel a bit lost when you stop seeing your treatment team, family and friends so often. Some survivors are surprised to find they need more support than ever after treatment ends.

I should feel grateful – Survivors can sometimes feel pressure to be grateful for having survived cancer. Instead, the impact of cancer on your life and future may make you feel upset, angry or resentful.

I should be celebrating – You may think that you should be happy because you survived the diagnosis and feel guilty or confused if you're not happy all the time.

I should feel positive – Friends and family may pressure you to think positively all the time. Although it is unrealistic to think positively all the time (see page 11), this can be a source of worry for survivors.

I should be the person I was before cancer – Many survivors say that cancer changes them. You may have a sense of loss for the person you once were or thought you'd be. It can also be difficult when the people around you expect you to return to how you were.

I should be making plans – You may feel both excited and anxious when treatment ends. Many survivors need time to reflect on what has happened before they can think about the future.

I should make big changes – You may feel guilty if you return to your pre-cancer way of life instead of making big changes to your way of life.



Understanding your feelings

While most people adapt well over time to life after cancer treatment, many people experience ongoing fears or concerns. You may find you need a lot of support with how you're feeling.

Common reactions to finishing treatment

Relief – You might be relieved that treatment has finished and seems to have been successful. You may welcome the chance to focus on the things you like to do.

Isolation – You may feel lost or nervous when regular appointments with your 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 – You may worry that the cancer will come back (see pages 15-20).

Uncertainty – You may avoid making plans for the future because you feel uncertain about your health. This is very challenging, but you can learn to manage it effectively.

Frustration – You may feel frustrated because you think your family and friends expect too much from you. Or you may feel discouraged because you can't do the things you want to do.

Hopeful – You may feel hopeful about the future, and happy to be getting back to your regular routine.

Survivor guilt – You may feel guilty or question why you survived cancer when others didn't. This can be confronting.

Anxiety – You may be anxious before follow-up appointments and feel these appointments “bring it all back”. Waiting for test results can also be an 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 35–57). Many survivors are worried about their finances or being a burden to their family. Other survivors worry about returning to work and dealing with questions from colleagues (see pages 75–78).

Lack of confidence – You may feel differently about your body and health. You may not trust your body and think it has let you down. You may not be physically able to do some of the things you did before treatment. Or you may worry about the impact on your ability to remember things and process information (see page 44). Many people feel vulnerable and self-conscious about their body image and sexuality (see pages 49–53).

Heightened emotions – You may become tearful or emotional very quickly, particularly when someone asks how you are. It is normal to feel like this.

Anger – You may be 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.

Recognising your feelings

Acknowledging how you are feeling may help you to work through your emotions. Try to develop a sense of your personal coping style (the things that work best for you). Remembering how you have coped with difficult situations in the past may give you some clues about helpful ways to cope with your emotions. 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

It is common to feel low or depressed after treatment ends. Cancer survivors often experience worry or periods of feeling down for months or even years after treatment.

Cancer survivors may feel sad or depressed because of the changes that cancer has caused, fear that the cancer will come back or worries about the future. Many people feel disconnected from their life before cancer. Others 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 manage these periods.

Warning signs of depression

At any stage after a cancer diagnosis, it is natural to have days when you feel sad or worried. Sometimes a person may begin to feel “stuck” in their distress and become depressed or anxious. Depression is more than feeling down for a few days. Seek help from your general practitioner (GP) if you:

- find it difficult to function on a daily basis
- have lost the desire to do things that previously gave you pleasure
- feel very sad and low most of the day, nearly every day
- begin to rely on alcohol or drugs
- eat more or less than usual
- are sleeping too much or having a lot of trouble sleeping
- feel restless, agitated, worthless, guilty, anxious or upset
- think you are a burden to others
- worry that you might hurt someone
- think about self-harm or taking your own life.

Some of these symptoms can also be caused by other medical conditions. Talk to your doctor about how you are feeling and ask for help (see opposite page). Anxiety and depression are quite common among people who have had cancer, but there is no need to face this experience alone.

“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

“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 ways to treat depression, which don't necessarily involve medicines. Treatment may include therapy provided by a GP, psychologist, psychiatrist, social worker or counsellor. Some people are able to get a Medicare rebate for these sessions under a Mental Health Treatment Plan. Ask your GP if you are eligible. You can also call 13 11 20 to find out if your local Cancer Council runs a counselling program.

Some people find online programs or smartphone apps helpful in managing depression and anxiety. Examples include moodgym.com.au, mycompass.org.au or mentalhealthonline.org.au.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au. In addition to getting professional help, the tips on the next page may help you.



If you are having intense thoughts about hurting yourself or others, seek immediate assistance by calling Lifeline 13 11 14. In an emergency, call Triple Zero (000).



How to manage your mood

- Take care of yourself. Eat a well-balanced diet, drink plenty of water and limit alcohol (see pages 58–73).
- Do some regular physical activity. This can help with feelings of anger, stress, anxiety and depression, manage fatigue and improve sleep. Even a short daily walk will help.
- Connect with other people doing things you enjoy.
- Spend time with a pet.
- Share your fears and concerns with someone close to you. This can help you feel less alone.
- Spend time outside in the fresh air. A change of scenery might lift your spirits.
- List activities you would like to do and plan to do one of these activities each day.
- Write down your feelings or express yourself in painting, colouring, music or singing.
- Establish a routine. Get up at the same time each morning. 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. Try to focus on the present moment, rather than worrying about upcoming check-ups or tests. You may find Cancer Council’s *Finding Calm During Cancer* podcast helpful with this.
- Keep a record of positive things that happen each day. These don’t have to be big things, it could just be an encouraging smile from a neighbour.
- ▶ See our *Emotions and Cancer* booklet for more practical tips.

Fear of cancer coming back

It is common to feel anxious or frightened about the cancer coming back (recurrence). Most cancer survivors are likely to experience this fear to some degree, and it may come and go for many years. You can learn ways to manage this fear (see the tips on the next page).

Worrying about recurrence 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. Over time, this fear usually fades, but it can return at certain times, such as:

- before follow-up appointments, tests and scans
- special occasions, such as birthdays or holidays
- anniversaries of the date you were diagnosed, had surgery or finished treatment
- 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 cancer-related fundraising campaigns or advertisements.

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



Ways to manage the fear of recurrence

- Talk to your treatment team about your risk of recurrence and how this will be managed. Ask about the symptoms to look out for and how to distinguish normal aches, pain or sickness from cancer symptoms.
 - Focus on things you can control, such as being actively involved in your follow-up appointments and making positive changes to your lifestyle to reduce the risk of recurrence (see pages 58–73).
 - Recognise the signs of stress and anxiety, such as a racing heartbeat or sleeplessness. Manage these in a healthy way, for example, you could try yoga, mindfulness meditation, taking slow, deep breaths or going for a walk.
 - Speak with a counsellor or psychologist if the fear of recurrence is overwhelming. They may be able to teach you some strategies to help manage your fears.
 - Joining a support group may help. See page 80 for more information.
 - Consider getting involved in a creative activity such as drawing, painting or writing. Some people find this helpful in working through their emotions.
 - Side effects of treatment can make it harder to cope emotionally. Talk to your doctor about ways to manage any ongoing treatment side effects you are experiencing.
- For more information, listen to our “Managing Fear” podcast episode.

“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

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 things, including the type and stage of cancer, genetic factors, type of treatment and time since treatment. Your specialist can discuss your risk with you.

Survival statistics

Even when there is no evidence of active cancer in the body, 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 talk about the “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 91 out of 100 people (91%) 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 (cancer that is small and has not spread) are likely

to have a much better outlook than people diagnosed with advanced disease (cancer that has spread to other parts of the body). With cancer treatments improving all the time, your outcome (prognosis) is likely to be better than the statistics currently available as they take many years to obtain.

Fear of getting a different cancer

Some survivors develop a second cancer that is different to the first cancer. The following things may increase your risk of developing another type of cancer:

- past or continuing exposure to cigarette smoke or other cancer-causing agents (including asbestos, heavy metals, diesel engine exhaust, solvents and pesticides)
- skin damage caused by exposure to ultraviolet (UV) radiation from the sun or solariums
- getting older
- 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 eating an unhealthy diet, drinking too much alcohol, being overweight, and not getting enough exercise.

Some of these things you can change and others you can't. Talk to your doctor if you are concerned about any risk factor. For ways to reduce your cancer risk, see *Looking after yourself* on pages 58–73. The tips on page 16 may help you deal with the fear of developing a second cancer.

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

Living with advanced cancer

For some people, cancer does come back after treatment. Advanced cancer usually can't be cured, but it can often be controlled. Sometimes treatment can shrink the cancer, stop or slow the spread of advanced cancer, or relieve side effects. This can help maintain quality of life for several years.

This booklet is for people who have finished primary cancer treatment. For information about dealing with the emotional, practical and physical aspects of a cancer recurrence, see our *Living with Advanced Cancer* booklet, listen to *The Thing About Advanced Cancer* podcast or call Cancer Council 13 11 20.

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, such as blood in your bowel movements, or diarrhoea or constipation that lasts for more than a week
- problems or changes with urinating
- persistent indigestion or difficulty swallowing
- abnormal bleeding or bruising
- unusual changes in the breasts or testicles
- abdominal (belly) pain or bloating that doesn't go away
- unexplained changes in your general health, such as weight loss or gain, night sweats, loss of appetite and loss of energy (fatigue).

Take part in cancer screening

Screening is organised testing to find cancer in people before any symptoms appear. Australia has free national screening programs for bowel cancer (people aged 50–74), breast cancer (women aged 50–74) and cervical cancer (women aged 25–74). These are currently the only cancers in which organised screening has been shown to be effective. Trials are ongoing to develop screening programs for other cancers.

Whether these screening programs are still appropriate for you will depend on the type of cancer treatment you had. For more information, talk to your GP or call Cancer Council 13 11 20.

Join a clinical trial

Doctors and other health professionals conduct clinical trials to look at ways to improve the care and quality of life of cancer survivors.

Areas studied include:

- how to best support the mental health of cancer survivors and deal with the fear of recurrence
- wellbeing and healthy lifestyle programs for survivors
- how to best treat common side effects such as fatigue, early menopause and lymphoedema
- understanding more about the causes of common side effects
- improving follow-up care for survivors.

You may want to consider joining a clinical trial when your cancer treatment finishes. Over the years, clinical trials have improved treatments and led to better outcomes for cancer survivors.

You may find it helpful to talk to your specialist, treatment team or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

For more information and to find a list of current trials, visit australiancancertrials.gov.au.

► See our *Understanding Clinical Trials and Research* booklet.

Key points about adjusting to life after treatment

Finding a “new normal”

- Cancer is often a life-changing experience and it may prompt you to reassess your priorities.
- Some survivors need support for a short period of time after their treatment finishes, others need ongoing support.
- Over time, survivors often find a new way of living – a new normal.

Understanding your feelings

- It's common to have many different feelings after treatment ends.
- Common feelings include relief, isolation, fear, uncertainty, frustration, hope, anxiety, worry, lack of confidence and anger.
- Feeling low after treatment finishes is common. You may want to seek professional support. Talk to your GP if you are feeling down or depressed.

Fear of cancer coming back

- Fear of recurrence is common. Most survivors learn to manage this fear either on their own or with professional help.
- 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.
- If you notice new or concerning symptoms, make an appointment with your doctor. For some people, cancer does come back and they will need further treatment.
- There are ways to reduce your risk of cancer recurrence (see pages 58-73).
- People of certain ages can take part in free national screening programs to help find bowel, breast and cervical cancers.

Follow-up care

After your treatment has finished, it is important to have regular appointments with your cancer specialists, cancer nurse or GP to monitor your health, manage any long-term side effects from treatment and check that the cancer hasn't come back or spread. Sometimes it may seem hard to attend appointments, but it is worth the effort.

Your cancer treatment summary

Ask your cancer specialist or nurse for a written summary of your cancer and treatment. They should also send a copy to your GP and other health care providers. This summary should include:

- the cancer type and features
- date of diagnosis
- test results and staging information
- overview of cancer treatment (types and dates).

Telehealth appointments

You may be able to have some appointments with your health professionals at home over a video link or on the phone. This is known as telehealth. It can reduce the number of times you need to travel to appointments. This may be particularly helpful if you live in a rural or regional area and have to travel a long way for appointments.

Although telehealth can't replace all face-to-face appointments, you can use it to talk about a range of issues including test results, prescriptions and side effects.

For more information, talk to your treatment team, read our *Telehealth for Cancer Patients and Carers* fact sheet or call 13 11 20.

Survivorship care plans

Some treatment centres now develop survivorship care plans for people as they approach the end of treatment. These plans usually:

- provide a cancer treatment summary (see opposite page)
- set out a clear schedule for follow-up appointments and screening tests, including contact details for the health professionals involved in your treatment and ongoing care
- list any symptoms to watch out for and possible long-term side effects
- identify your medical, emotional, psychological or social needs after treatment and ways to manage them
- explain the roles and responsibilities of different members of your health care team and who to contact if you are worried
- suggest ways to adopt a healthy lifestyle after treatment.

A survivorship care plan can help improve communication between you, your family and all the health professionals involved in your care (see pages 26–27). The plan is not a fixed document, but should be reviewed regularly as your needs change. You can ask your health professionals to update your plan during consultations.

If you have not been given a survivorship care plan, ask your treatment team if they can prepare one. Another option is to develop your own plan and review it with your treatment team. The Australian Cancer Survivorship Centre provides a template you can download and fill out. Visit petermac.org/cancersurvivorship and search for “Survivorship Care Plan template”.



If you've been treated for early breast, bowel or prostate cancer, visit mycareplan.org.au to generate your own online survivorship care plan. Some other cancer types will be added in the future.



Rehabilitation (rehab) can help you regain physical strength and get back to your daily activities. It may include physical therapy (e.g. in a pool or gym), or specialist care if you need help with speaking, eating, walking and other tasks. Talk to your health care team about whether this would help your recovery.

Follow-up appointments

How often do I need check-ups?

This is different for everyone. Your follow-up schedule depends on the type of cancer and treatment, the side effects experienced, and any other health conditions you are managing.

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. For information about what to expect at every stage of cancer care, including after treatment, visit cancer.org.au/cancercareguides.

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

What happens at follow-up appointments?

During check-ups your doctor or nurse may:

- assess your recovery
- ask how you're feeling and coping with life after cancer
- do a physical examination
- monitor and treat any ongoing side effects and talk to you about any late side effects of treatment (see page 35) to watch out for
- look for any signs that the cancer may be coming back

- check any new symptoms
- 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 (see next two pages).

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

Some people may need blood tests and scans, for example, mammograms for women treated for breast cancer, or prostate specific antigen (PSA) tests for men treated for prostate cancer. If you live a long way from your treatment centre, ask if you can have the tests in your local area. Not everyone will need or benefit from ongoing tests and scans. For many cancer types, having blood tests for tumour markers and imaging scans has not been shown to help identify a return of cancer.

It is important to tell your doctors about any new or ongoing symptoms so that they can help you manage them. For example, tell them if you feel low in mood or energy, aren't sleeping, have a reaction to any medicines, or have pain or fatigue.



Managing your own health is an important part of survivorship. With the support of your health care team, there are many steps you can take to look after your own wellness, including monitoring your body for any signs that the cancer has returned, managing any side effects and making healthy lifestyle choices (see pages 58–73).

“I now realise how important it is to build a relationship with my health care professionals and to actively look after my health.” EMMA

Who do I see for follow-up care?

You may have follow-up appointments with your cancer specialist, cancer nurse, GP or a combination. If you continue to see your specialist, you will still need to see your GP for regular health checks (e.g. blood pressure, cholesterol levels and weight). People treated for cancer may have a higher risk of other illnesses, such as heart disease and stroke, compared with the general population. Having a regular GP can help you manage your overall health and ensure you receive the support you need.

Your GP or specialist can refer you to a range of allied health professionals (see opposite page) to help you manage some of the side effects of treatment and improve your quality of life. Ask for a referral to a professional with experience working with cancer survivors. Some people also find complementary therapies helpful (see page 36).

If you have ongoing side effects after cancer treatment, talk to your GP about developing a GP Management Plan and Team Care Arrangement to help you manage the condition. This means you may be eligible for a Medicare rebate for up to five visits each calendar year to allied health professionals.



The Australian Cancer Survivorship Centre provides resources on survivorship care plans, dealing with common survivorship issues such as fatigue, and caring for a cancer survivor. You can find these at petermac.org/cancersurvivorship.

Other health professionals who can help

general practitioner (GP)	helps manage treatment side effects and may manage some surveillance tests; conducts regular health checks; provides advice about healthy lifestyle choices; manages any other physical or mental health issues you may have
cancer nurse specialist	provides care, information and support throughout treatment and recovery; helps with symptom management and wellbeing after treatment; liaises with other members of the treatment team
continence nurse	assesses and educates people about bladder and bowel control
counsellor, psychologist	help you manage your emotional response to treatment and recovery; can provide strategies to help you make any desired changes to your life
dietitian	helps with nutritional concerns, any ongoing problems with food and eating, or supervised weight loss or gain
exercise physiologist	prescribes exercise to help improve your overall health, fitness, strength and energy levels
lymphoedema practitioner	educates people about lymphoedema prevention and management; provides lymphoedema treatment
occupational therapist	assists in adapting your living and working environment to help you resume usual activities after treatment
physiotherapist	can develop a program to improve muscle strength, restore movement and help you get back to activities
sex therapist	helps you and your partner with sexuality issues after treatment
social worker	links you to support services and helps you with social, practical and financial issues
speech pathologist	helps with communication and swallowing issues; can give you strategies to help you eat and drink safely

Preparing for appointments

Ask questions – 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 83–84). If your doctor uses medical terms you don't understand, ask them to explain them in plain English. If you have several questions, ask for a longer appointment when booking.

Record the details – Taking notes can help you remember what was discussed. If you would like to record the discussion, ask your doctor first. It is a good idea to have a family member or friend go with you to appointments for emotional support or to take part in the discussion. You may wish to ask them to make notes or simply listen.

Report on health issues – Tell your doctor or nurse if you have:

- difficulty doing everyday activities
- any new symptoms or new aches or pains that seem unrelated to an injury, or existing aches or pains 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 (see page 36).

Discuss other issues – You may want to talk to your health care team about other issues, such as changes to your sex life, how cancer has affected your relationships, returning to work or financial difficulties.

Treatment history – 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, treatment and any ongoing side effects, 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 also common. These things may happen because:

- you fear you'll be told the cancer has come back
- going back to hospital brings back bad memories
- you feel vulnerable just when you were starting to feel more in control
- friends or family make comments that upset you.

Check-ups may feel easier once you've had a few and things are going okay. In the meantime, finding ways to cope with your anxiety before check-ups may help.



Coping with check-ups

- Share your concerns with people close to you so they can provide support.
- Plan to do something special after the check-up.
- Allow extra travel time so you don't feel rushed. This can help you to feel calm and focused.
- 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 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.
- Ask if you can go to the doctor's consulting rooms if you are not comfortable going to the hospital or treatment centre.
- Try to book tests about a week before your next doctor's appointment so you don't have to wait a long time for the results.

Key points about follow-up care

General

Follow-up care is usually different for each person. It depends on the type of cancer and treatment you had, and any long-term side effects you have.

Survivorship care plans

- 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.
 - If you don't have a survivorship care plan, ask your cancer specialist or nurse for a copy of your treatment summary. This will provide a guide for your GP and other health care providers.
-

Check-ups

- 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 may perform a physical examination as part of the check-up.
 - Some people will also have blood tests and scans, but not everybody needs these.
-

Health professionals

- 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 a range of allied health professionals to help you manage some of the side effects of treatment.
-



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 think about 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. If you still need support, let them know how it would be best for them to provide it.

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
- confused, especially if your relationship has changed
- upset that they are not in regular contact with the health care team
- pleased that cancer is no longer the main topic of conversation
- worried about what the future holds
- afraid that every little ache or pain means that the cancer has returned
- scared they will get cancer themselves
- a need to protect you and not let you do things for yourself.

Encourage your family and friends to seek support. They can call Cancer Council 13 11 20 or the Carer Gateway on 1800 422 737.

► See our *Caring for Someone with Cancer* booklet.

Will my family have a higher risk of cancer?

If you've had cancer, it doesn't mean that your children will also get it. Most cancers are caused by a build-up of abnormal cells. These cell changes cannot be passed on to your children, so they won't have a higher than normal risk of developing cancer.

However, having a strong family history of cancer may increase the risk of developing some cancers. This may be caused by inheriting a faulty gene linked to cancer, or by shared

environmental or lifestyle factors.

A family history of cancer means that there are a number of closely related family members diagnosed with the same cancer or with more than one cancer, often at a younger age.

Only about 5% of all cancers are linked to inherited faulty genes. If you are concerned about this, talk to your doctor. They may refer you to a family cancer clinic or genetic counselling service.

When others don't understand

After treatment finishes, your family and friends may not fully understand what you've been through. They 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. Family roles and responsibilities may have changed during treatment, and you may need to discuss these changes.

Friends and family may say things like "but you look fine" and "the cancer has gone, hasn't it?" It's natural for them to want the distress and disruption of cancer to go away.

Your family and friends may have difficulty accepting that you still need support or that some treatment side effects can persist for a long time or never go away. 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. Ask for their support and patience. It may help to tell them that your recovery is ongoing, and that you need time to adjust to what you've been through and work out the next steps.

Coping with children's needs

Like many adults, children may struggle with the changes to family life 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.

Talking to children about cancer can be difficult. Children's reactions and needs will vary depending on their age. But most young people find honest discussions reassuring.



Tips for talking with children

- Try to be as open and honest as possible. may encourage children to talk about their own fears.
- Acknowledge the impact of cancer on your family. This is particularly important for teenagers. Canteen can help young people aged 12–25 cope with life after a cancer diagnosis in the family. Call 1800 835 932 or visit canteen.org.au.
- Be open about how you feel, so the children understand if you're not bouncing back.
- Depending on the age and understanding of the children, talk to them about your fears (e.g. anxiety before a follow-up visit). This
- Spend time together doing things they enjoy.
- Explain any changes made to your family's lifestyle. Let your children know if these are going to be permanent.
- ▶ See our *Talking to Kids About Cancer* booklet and listen to our "Explaining Cancer to Kids" podcast episode.

Key points about impact on family and friends

Common reactions

- 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.
- Sometimes, family and friends don't understand that you need time to recover and adjust to any changes cancer has brought.
- Acknowledge the support that family and friends have already provided. Let them know if you still need help.

Support for family and friends

- Encourage your family and friends to seek support. Cancer Council provides a range of support services for family and friends. Call 13 11 20.
- If you or your family are worried that the cancer runs in the family, talk to your GP or oncologist. You may be referred to a family cancer clinic or a genetic counselling service.

Talking to children

- 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 or redkite.org.au.

Managing side effects

It can take time to recover from the side effects of cancer treatment. Side effects can be both physical and emotional, and impact on your ability to return to your usual day-to-day activities. Talk to your doctors about any side effects you have so you can develop a plan to manage them. This chapter outlines some side effects common to cancer survivors and offers suggestions on how to cope with them. For more information and support, call Cancer Council 13 11 20.

How long side effects may last

Some treatment side effects go away quickly; others can take weeks, months or even years to improve. Some may be permanent. Most side effects can be managed with support from your health care team. Your body will cope with the treatment and recovery in its own way. It is important not to compare yourself to others.

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 and what you can do to help prevent them.

Managing the side effects of treatment can feel overwhelming, but there are many sources of support (see pages 26–27).



Side effects after cancer treatment often relate to the type of cancer and the part of the body treated, so it can be useful to read the booklet about the type of cancer you had treatment for.

How complementary therapies can help

Complementary therapies – These therapies are widely used alongside conventional treatments. Examples include acupuncture, aromatherapy, massage, mindfulness meditation, relaxation, tai chi, art therapy and music therapy.

Many complementary therapies have been shown to be safe to use alongside conventional cancer treatments. Others are being scientifically tested.

Complementary therapies may help you manage side effects of treatment, increase your sense of control, decrease anxiety and improve your quality of life.

Let your doctor know about any complementary therapies you are using or thinking about trying. This includes over-the-counter medicines, herbal supplements and vitamins. Depending on the conventional medicines you are taking, some complementary therapies may cause reactions or unwanted side effects.

Your doctor may be able to refer you to a qualified therapist who is experienced in working with cancer

survivors and understands the role of complementary therapies in cancer care.

Make sure to tell the complementary therapist about your cancer diagnosis and treatment. Some therapies may need to be adjusted to avoid interactions with your conventional medicines or treatments.

Alternative therapies – These therapies are different from complementary therapies. They are used instead of conventional treatments.

Many alternative therapies have not been scientifically tested, so there is no proof they stop cancer growing or spreading. Others have been tested and shown not to be effective.

While side effects of alternative treatments are not always known, some are serious. Cancer Council does not recommend the use of alternative therapies. Visit cancer.org.au/iheard to get the facts.

► See our *Understanding Complementary Therapies* booklet for information about how different complementary therapies can help.

Sleeping problems

Getting enough sleep is important for maintaining your energy levels, managing fatigue and improving mood. Difficulty sleeping is common among people who have had cancer. It may be caused by pain, breathlessness, anxiety or depression. Some medicines and hormonal changes can make sleep difficult. If you already had sleep problems before cancer treatment, these can become worse.



Ways to improve sleep

- Get up at the same time each morning and avoid daytime naps.
- Exercise regularly but not right before bed (see pages 65–67).
- If you smoke, quit – smoking can affect your ability to fall and stay asleep.
- Limit or avoid drinking alcohol and caffeine. Avoid spicy food if it gives you indigestion.
- Set up a pre-sleep routine to help you relax. Try to go to bed around the same time most evenings to establish a stable sleep/wake routine.
- Listen to our relaxation and meditation podcast *Finding Calm During Cancer* or call 13 11 20 for a free copy of our relaxation and meditation recordings. Done regularly, these exercises may help you sleep better.
- Put screens (mobile phone, tablet, computer or TV) away an hour before bedtime and avoid using them in the bedroom.
- Keep the bedroom dark, quiet and a comfortable temperature.
- If medicines interfere with your sleep, discuss alternatives with your doctor.
- Speak with your GP about whether counselling or cognitive behaviour therapy (CBT) would help.
- ▶ Listen to our “Sleep and Cancer” podcast episode.

Fatigue

Now that treatment is over, you may think you should be full of energy, but this often isn't the case. Feeling very tired and lacking energy for daily activities (fatigue) is a common side effect of cancer and its treatment. You may have muscle aches and pains, get worn out quickly, have trouble concentrating or find it difficult to do daily activities. Cancer-related fatigue is different from tiredness, as it doesn't always go away with rest or sleep.

Many people say that fatigue has a big impact on their quality of life in the first year after treatment. You may 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.

Causes of fatigue

Many cancer survivors don't tell their doctor about fatigue because they think that nothing can be done about it. However, your treatment team or GP may be able to help. For example, your fatigue may be caused by a low red blood cell count (anaemia), an underactive thyroid, loss of muscle strength and fitness, depression or the side effects of medicines, which your doctor may be able to manage. You may need a referral to a specialist or a fatigue clinic (if available).

“I do become tired and I have to be careful, but if I pace myself, I can achieve what I want to achieve.” SUE



How to manage fatigue

- Be realistic about what you can do. Your body is still recovering and it will take time for your energy levels to return.
- Exercise regularly to help boost your energy levels, restore muscle mass and reduce fatigue. Consider seeing an exercise physiologist or physiotherapist so they can develop a tailored exercise program for you (see pages 65–67).
- Break tasks up into smaller, more manageable pieces. Focus on doing a little bit each day rather than a lot all at once.
- Plan your day. Set small manageable goals and take regular breaks. Leave plenty of time to get to appointments.
- Adapt your activities. 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 activities.
- If you have children or grandchildren, sit down to play. Try activities like reading, board games, colouring, puzzles and drawing.
- Ask for, and accept, offers of help. Family and friends can help with shopping, school pick-ups or mowing the lawn.
- Say no to things you don't feel like doing. If you have trouble saying no, ask someone to do it for you.
- Eat nutritious foods and limit alcohol. Aim to eat a healthy, well-balanced diet and drink plenty of water (see pages 68–72).
- Take regular short breaks throughout the day. Rest when you need to.
- ▶ See our *Fatigue and Cancer* fact sheet and listen to our “Managing Cancer Fatigue” podcast episode.

Pain

Pain can have a big impact on your life and prevent you from doing the things you want to do. After treatment, pain may continue for months or years. This is called chronic pain and it affects some cancer survivors. Causes include:

- scars or nerve damage after surgery
- nerve damage from cancer drug therapies leading to numbness and tingling in hands and feet (peripheral neuropathy, see page 45)
- irritated, sensitive skin in the area where you had radiation therapy
- joint and muscle pain from hormone therapies
- a build-up of lymph fluid (lymphoedema, see pages 42-43).

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 health issue, such as arthritis.

Managing pain

Learning how to manage your pain may let you return to many of the activities you enjoy and improve your quality of life. Discuss your pain with your doctor so they can try to work out the cause and develop a pain management plan. In cases where no fixable cause of the pain is found, the focus will shift to improving your ability to function despite the pain.

Pain medicines called analgesics are widely used to help reduce pain. Non-steroidal anti-inflammatory drugs or paracetamol are the main drugs used to relieve pain in survivors. While opioids are sometimes prescribed for chronic pain, research shows that using opioids for a long time is not safe. There are other ways to relieve pain (see opposite page).

If your pain is not well controlled, ask your doctor about referring you to a pain management specialist in a multidisciplinary pain clinic.



Ways to relieve pain

- Do some daily stretching and walking to help you deal with the pain. It is important to pace your activities throughout the day, and include rest or stretch breaks.
 - See a physiotherapist or exercise physiologist. They can develop a program to improve muscle strength and increase your ability to function, which may help relieve pain.
 - Talk to a physiotherapist or occupational therapist. They can suggest ways to address physical or practical problems that are causing pain.
 - Learn different ways to think about the pain so it has less impact. Some types of talking therapies provided by psychologists and counsellors can help.
 - Cognitive behaviour therapy (CBT) has been shown to improve mood, and decrease stress and anxiety.
 - Try relaxation techniques, such as deep breathing, hypnotherapy, meditation or listening to music. They may improve how well other pain-relief methods work, help you sleep, and focus your attention on something other than the pain.
 - Use massage or hot packs to relieve muscle spasms, stiffness and contractions. Cold packs may be used to numb the pain.
 - Acupuncture may help by stimulating nerves to release the body's natural chemicals, which help reduce pain.
 - Try creative therapies such as art therapy or journal writing. These can help you express your feelings and work through the pain.
 - Medicines that are normally used for other conditions can help relieve some types of chronic pain. They include antidepressants and steroids.
- See our *Understanding Cancer Pain* booklet and listen to our "Managing Cancer Pain" podcast episode.

Lymphoedema

When lymph fluid builds up in the tissues under the skin, it can cause swelling (oedema). This is known as lymphoedema. It can happen if lymph nodes have been removed during surgery or damaged by infection, injury or radiation therapy. Lymphoedema may appear during treatment or months or years later.

Lymphoedema can occur after treatment for many different cancers, but is more common in people treated for gynaecological (vulvar, vaginal, ovarian, uterine and cervical), breast and prostate cancers or melanoma. Whether or not you develop lymphoedema after treatment depends on the location of the cancer, its stage and the type of treatment you had. Not everyone who is at risk will develop it.

Symptoms of lymphoedema

Having lymphoedema can make movement and some types of activity difficult. Swelling usually happens in an arm or leg, but it can also affect other areas of the body. The main signs of lymphoedema include:

- visible swelling
- an aching or tingling feeling
- not being able to fully move the affected limb
- clothing, shoes or jewellery feeling tighter than usual
- pitting of the skin (when gentle pressure leaves a small dent).

How to find a lymphoedema professional

To find a health professional who specialises in the management of lymphoedema, visit the Australasian Lymphology Association's website at lymphoedema.org.au and click on "Find a Practitioner". This may be an occupational therapist, physiotherapist or nurse with special training.

► See our *Understanding Lymphoedema* fact sheet.



How to prevent or manage lymphoedema

- Treat lymphoedema early so you can deal with the problem quickly and avoid symptoms becoming worse.
- If you are at risk of developing lymphoedema, see a lymphoedema practitioner for regular check-ups rather than waiting for signs to appear. They may monitor the amount of fluid in your body using a painless electric charge (bioimpedance spectroscopy).
- Keep physically active to help the lymph fluid flow. Do regular exercise such as swimming, cycling or using light weights.
- Keep the skin healthy and unbroken to reduce the risk of infection. Avoid cuts, scratches, bites and injections in the affected area. If you shave, use an electric razor to minimise cutting the skin.
- Moisturise your skin daily to prevent dry, irritated skin. If you have lymphoedema, ask your lymphoedema practitioner about suitable creams and lotions.
- Protect your skin from the sun (see pages 61–63).
- Maintain a healthy body weight. Being overweight can be a risk factor for developing lymphoedema.
- Avoid wearing jewellery or clothing that puts pressure on the affected area or leaves marks on your skin.
- Take care cutting your toenails or see a podiatrist to look after your feet.
- Wear a professionally fitted compression garment, if advised by your lymphoedema practitioner.
- Seek medical help urgently if you think you have an infection in the affected area.

“Although I’d had lots of lymphoedema education, I actually missed the signs and didn’t realise I had it until I developed cellulitis.” SUZANNE

Changes in thinking and memory

Many cancer survivors say they have difficulty concentrating and remembering things. This is called cancer-related cognitive impairment. Other terms used to describe this include “chemo brain” and “cancer fog”. These changes may make you feel anxious, upset or frustrated.

Thinking and memory changes may be caused by the cancer or cancer treatments, medicines, anxiety or depression, or other health issues. 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 thinking or memory problems you are having, and if they are affecting your day-to-day life or your work.



Managing changes in thinking and memory

- Get plenty of sleep. Deep sleep is important for memory and concentration.
 - Use a diary or online calendar to keep track of appointments or set reminders on your phone.
 - Carry a small notepad or download an app to your phone so you can jot down things you need to remember.
 - Use your brain as much as you can – learn a language or musical instrument, do crosswords and puzzles, take up a new hobby.
 - Do some gentle exercise each day. This can help you feel more alert (see pages 65–67).
 - Do tasks one at a time rather than multi-tasking. Use a whiteboard to help plan your day.
 - Put personal items (e.g. wallet, keys) in a dedicated place at home and at work so you can find them easily.
- See our *Understanding Changes in Thinking and Memory* fact sheet and listen to our “Brain Fog and Cancer” podcast episode.

Tingling or numbness in hands or feet

Having tingling (“pins and needles”) or numbness in the hands or feet is a common side effect of some types of chemotherapy drugs. This is called peripheral neuropathy. It may last for a few months after treatment finishes or it may be permanent. In some cases, peripheral neuropathy can get worse a few months after chemotherapy has finished.

The impact of peripheral neuropathy varies from one person to another. It can be painful, annoying and frustrating and, for some people, make it hard to return to hobbies and other activities. Although there is no proven treatment to repair nerve damage, there are some medicines that can help you deal with the symptoms.



Taking care with numb hands or feet

- See a physiotherapist or occupational therapist for exercises to help you carry out your daily activities.
 - Test the water temperature with your elbow before putting your hands or feet in to avoid burns.
 - Use gloves while doing housework or gardening, a thimble when sewing and oven mitts when cooking.
 - Wear well-fitting shoes with non-slippery soles.
 - Clear walkways of hazards and remove loose rugs.
 - Use non-slip rubber mats in the shower and bath.
 - Be careful carrying things as you may have a greater risk of dropping them.
 - 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.
- See our *Understanding Peripheral Neuropathy and Cancer* fact sheet.

Other common cancer-related effects

Cancer survivors can experience a range of other physical issues after treatment. Some common side effects are discussed below. If you would like more information about managing these or any other issues, 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 help improve your balance and muscle strength.

Bowel or bladder changes

Changes to how your bowel or bladder works can be very distressing and have a significant impact on quality of life. Some medicines and cancer treatments can cause constipation, diarrhoea or incontinence. After treatment, some people have a stoma that allows urine (wee) or faeces (poo) to be collected in a bag. These changes may be temporary or ongoing, and may require specialised help or products. If you have any of these issues, talk to your GP, specialist doctor, specialist nurse or dietitian. Drinking more water and changing what you eat may also help.

Incontinence – This 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. There are ways to better manage or perhaps even cure incontinence, for example, 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.

Radiation proctitis – Radiation therapy to the pelvic area can damage the lining of the rectum, causing inflammation and swelling known as radiation proctitis. Your treatment team will try to reduce the risk of developing radiation proctitis. It is usually a short-term side effect but may be ongoing in some people. Radiation proctitis can cause a range of symptoms including blood in bowel motions; frequent passing of loose, watery faeces (diarrhoea); the need to empty the bowels urgently; and loss of control over the bowels (faecal incontinence).

The risk of developing radiation proctitis is low, but you may develop some of these symptoms for other reasons. Let your treatment team know if you develop any of these symptoms. They can refer you to a bowel care nurse for support. If you have ongoing bowel problems, your treatment team may refer you to a gastroenterologist.



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 (wee) or faeces (poo), 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.

Heart health

Radiation therapy to the chest area 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 some targeted therapies; radiation therapy combined with chemotherapy (chemoradiation); having treatment at a younger age; 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, the symptoms to look out for, and whether you need regular heart checks. If you develop heart problems later in life, make sure you let your doctors know about the cancer treatment you had.

Regular exercise, managing your cholesterol, blood pressure and weight, and stopping smoking can help you look after your heart health. See *Looking after yourself* on pages 58–73 for more information.

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 weight-bearing exercise (e.g. brisk walking), eating calcium-rich foods (e.g. yoghurt, milk, tofu, green vegetables), getting enough vitamin D, limiting alcohol and not smoking will also help keep your bones strong. For more information, call Healthy Bones Australia on 1800 242 141 or visit healthybonesaustralia.org.au.

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 get better 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.

Mouth or teeth problems

You may have mouth sores or tooth decay, 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.

► See our *Mouth Health and Cancer Treatment* fact sheet.

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:

- removal of a body part and use of a prosthesis
- visible scars and skin tightness
- hair loss or hair growing back differently
- trouble speaking
- problems with eating or drinking
- breathing changes or shortness of breath
- weight loss or gain
- bowel or bladder changes (see pages 46–47)
- changes to your sex life and intimacy (see pages 51–53)
- early menopause or infertility (see pages 53–56)
- a sense of feeling prematurely old.

You may be self-conscious about any changes. It will take time to get used to seeing and feeling the differences in your body. 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. Family and friends probably want to provide support and reassurance that they still love you. 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 peer support programs.



Adjusting to changes in appearance

- Be gentle with yourself and acknowledge your feelings.
- Give yourself time to get used to any physical changes. Some changes may improve with time.
- Focus on yourself as a whole person (body, mind, personality), not just the part of you that has changed.
- Talk openly about what has changed. Some people might be avoiding you because they don't know what to say.
- Do activities that you enjoy or make you feel good about yourself, such as walking, listening to music, working or studying, having a massage, relaxing outside or volunteering.
- Buy some new clothes or accessories that make you feel comfortable and more confident about the way you currently look.
- Book into a free Look Good Feel Better workshop. Call 1800 650 960 or visit lgfb.org.au.
- For practical suggestions about dealing with physical changes, call Cancer Council 13 11 20.

Impact on sexuality and intimacy

Treatments for some types of cancer can directly affect your physical ability to have sex or to enjoy it. More generally, many cancer treatments can affect your desire to be intimate with others. These changes may be temporary or ongoing and can be difficult to deal with.

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. Talk openly with your partner about 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 enjoy sex again. Most people can have a fulfilling sex life after cancer, but you may need to find different ways to give and receive sexual pleasure. Like any new skill, this will take time and practice. Some people say that because they try new things, their sex lives actually end up being much better after cancer.

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.



Managing changes in your sex life

- Seek professional advice and support. Talk to your doctor or nurse or ask for a referral to a sex therapist or counsellor. They can suggest ways to manage changes that affect your sex life.
- Try hormone creams and vaginal moisturisers to help relieve vaginal discomfort and dryness.
- Ask your doctor about medicines to help with erection problems.
- If surgery or radiation therapy has narrowed or shortened the vagina, you may be advised to use vaginal dilators to help keep the walls of the vagina open and supple. Using dilators can be challenging. Your doctor, nurse or physiotherapist can tell you where to get dilators and how to use them.
- Show affection by touching, hugging, massaging, talking and holding hands.
- Be intimate at the best time for you (e.g. when your pain is low or energy levels high).
- Talk to your GP if your low libido might be related to depression (see pages 11–13).
- Spend more time on foreplay and try different ways of getting aroused. Do whatever makes you and your partner feel good.
- Use a water-based 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 and to control penetration.
- If sexual penetration is painful or difficult, explore other ways to feel pleasure.
- If you feel comfortable, stimulate yourself. This may reassure you that you can still feel aroused.
- ▶ For more information, see Cancer Council's *Sexuality, Intimacy and Cancer* booklet and listen to our “Sex and Cancer” podcast episode.

How cancer treatment can affect sexuality

General	Females	Males
<ul style="list-style-type: none"> • reduced interest in sex (low libido) • tiredness and fatigue • changed body image • feeling sexually unattractive • incontinence • painful intercourse • depression or anxiety • strain on or changes to your relationships 	<ul style="list-style-type: none"> • trouble reaching orgasm • vaginal dryness • shorter and narrower vagina • loss of sensation • pelvic pain • menopausal symptoms (see next page) 	<ul style="list-style-type: none"> • trouble getting or keeping an erection (erectile dysfunction or impotence) • changes in ejaculation, such as dry orgasm

Menopause

Menopause means the ovaries no longer produce eggs and periods stop. 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 therapy and surgery to remove the ovaries (oophorectomy), can cause early menopause.

If you are younger, reaching menopause much earlier than expected may affect your sense of identity or make you feel older than your age or friends. 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 56 for more information about fertility.

When cancer treatment causes early menopause, the impact on how you feel, your body image and your relationships can be significant. It may take time to accept these changes. Talking to your GP, a family member, friend or counsellor may help.

Symptoms of menopause

Most menopause symptoms are related to a drop in your body's oestrogen levels. When menopause occurs suddenly because 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 a dry or tight vagina; loss of interest in sex (low libido); hot flushes and night sweats; aching joints; trouble sleeping; dry or itchy skin; and feeling more anxious or overwhelmed.

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.

Side effects of androgen deprivation therapy

Males who have androgen deprivation therapy (ADT) to treat prostate cancer may experience side effects such as hot flushes, erection problems, mood changes, fatigue, loss of muscle strength, loss of bone density (osteoporosis), high cholesterol and weight gain.

Studies show that regular exercise can help manage the side effects

of ADT. Our *Exercise for People Living with Cancer* booklet includes examples of aerobic, flexibility and strength-training exercises. It may also help to speak to a dietitian for advice on healthy eating.

For more information, talk to your specialist, GP or a sex therapist and see our *Understanding Prostate Cancer* booklet.



Ways to manage menopause symptoms

- Meditation and relaxation techniques may help reduce stress and lessen symptoms. Listen to our *Finding Calm During Cancer* podcast for some exercises.
- Maintain a healthy weight and eat a healthy diet with lots of fresh fruit, vegetables and wholegrains (see pages 69–72).
- Regular exercise can help improve mood, heart health, bone and muscle strength, and energy levels.
- Try cognitive behaviour therapy (CBT). This has been shown to improve menopausal symptoms, including anxiety, sleep, hot flushes and sexual issues.
- Check your cholesterol levels as they can rise after menopause, increasing your risk of heart disease and stroke. If your levels are high, 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 48).
- Menopause hormone therapy (MHT) 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. Talk to your doctor about the risks and benefits of MHT for your situation.
- 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.
- If vaginal dryness is a problem, take more time before and during sex to become aroused and for the vagina to become more lubricated. Use a water-based or silicone-based lubricant that has no added perfumes or colouring.
- For more information, talk to your doctor, ask for a referral to a specialist menopause clinic or visit menopause.org.au.

Fertility issues

Some cancer treatments can cause temporary or permanent infertility (inability to conceive a child). Some people are able to get pregnant or get their partner pregnant after finishing cancer treatment. 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 cancer specialist about the impact that your treatment might have on your health during pregnancy. Depending on the treatment you've had, they may advise you to wait between six months and two years before trying to conceive. Discuss the timing and suitable contraception with your specialist. If you do get pregnant, you may need careful monitoring during the pregnancy. It can be helpful to ask your obstetrician to talk with your cancer specialist.

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 fertility counsellor about how you are feeling might help.

► See our *Fertility and Cancer* booklet.



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 about treatment side effects

How long side effects last

- Side effects can be both physical and emotional, and have an impact on your day-to-day life. Most side effects can be managed.
- After treatment, side effects can take weeks, months or even years to get better. Some may be permanent.
- Some people have late side effects that develop months or years after treatment finishes.

Common side effects

- Fatigue is one of the most common physical side effects of treatment. It will take time for your energy levels to return.
- Some people have ongoing pain. Learning how to manage any pain may increase how much you can do and improve your quality of life.
- Some people develop swelling in the soft tissues under the skin. Exercises, massage and compression stockings may help.
- Many cancer survivors notice changes in the way they think and remember information. This is often referred to as “chemo brain”. It usually improves with time.
- Changes to how your body looks and works can affect how you feel about yourself. It can take time to get used to these changes.
- You may feel less interested in sex because of physical or emotional changes. Take things slowly and talk openly with your partner.
- Some cancer treatments can cause early menopause. The symptoms of menopause can usually be managed.
- Cancer treatments can cause infertility. This can be distressing regardless of whether you want to have children in the future.



Looking after yourself

It's important to look after your wellbeing after cancer treatment. For some people, this may mean making big lifestyle changes and embracing new health practices. For other people, it may be a small increase in exercise or a healthier diet. Coming up with a plan for how to look after yourself can help restore a sense of control.

Research suggests that a healthy lifestyle (in combination with conventional treatment) can stop or slow the development of many cancers. This chapter discusses ways to adapt your lifestyle to help reduce the risk of cancer coming back or a new cancer developing.

Some people who have had cancer may be at an increased risk of other health problems, such as heart disease, osteoporosis, stroke or type 2 diabetes. The lifestyle changes recommended for cancer prevention can also help reduce your risk of developing other health problems.

“I was completely overwhelmed by all the lifestyle advice I received from doctors once treatment was over. I decided to focus on one change at a time. I started by doing 100 steps in the backyard until I gradually built up to a 30-minute walk five days a week and strength training on two days. It took me almost six months to get there, but it was really satisfying to feel in control of my wellbeing.” BETH

Ways to reduce your risk of recurrence



Quit smoking

If you smoke, quit; and avoid second-hand smoke. There is no safe level of tobacco use – see next two pages.



Be SunSmart

Protect yourself from the sun (slip, slop, slap, seek, slide) – see pages 61–63.



Be a healthy body weight

Keep your weight within the healthy range and avoid weight gain as an adult – see page 64.



Be physically active and sit less

Aim for 150 minutes (2½ hours) of moderate intensity exercise or 75 minutes (1¼ hours) of vigorous exercise each week and 2–3 strength-training (resistance exercise) sessions each week – see pages 65–67.



Limit alcohol

Drink no more than 10 standard drinks a week and no more than 4 standard drinks on any one day – see page 68.



Eat well

Aim for 2 serves of fruit and 5 serves of vegetables or legumes a day. Eat a variety of wholegrain, wholemeal and high-fibre foods. Limit red meat and avoid processed meat – see pages 69–72.

Quit smoking

Smoking is the biggest preventable cause of cancer. It increases the risk of developing many types of cancer, including lung, bowel, ovarian, bladder, kidney, liver, oesophageal, pancreatic and stomach cancers.

If you smoke, Cancer Council strongly recommends that you quit. Stopping smoking has been shown to increase your expected survival time and reduce your risk of developing another type of cancer.

Choosing to quit smoking at any age will benefit your health. It 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 it hard to stop. Seek support and don't be put off if it takes several attempts before you're able to quit for good.



How to quit smoking

- Call Quitline on 13 7848 to talk to an advisor and request a free Quit Kit.
- Ask your doctor for advice about nicotine replacement therapy or prescription medicines to help you quit.
- Set a date to quit. Tell your family and friends so they can support you.
- Think of other attempts to quit as practice. Learn from what did and didn't help.
- Make your home and car a smoke-free zone.
- Keep a list of all the reasons you want to quit.
- Do something else if you feel tempted to smoke (e.g. go for a walk, listen to music).
- Download an app such as My QuitBuddy from the App Store or Google Play. This can help you track your progress.

What about electronic cigarettes (vaping)?

E-cigarettes are battery-operated devices that heat a flavoured liquid to produce a vapour that users inhale into their lungs. The liquid can contain a wide variety of substances, including cancer-causing chemicals. In Australia, it is illegal to sell or buy e-cigarettes containing nicotine without a prescription.

Research is continuing into the health effects of e-cigarettes. However, there is growing evidence that it is not safe to use them as they contain a range of substances that have been shown to be harmful to people's health. For up-to-date information regarding nicotine e-cigarettes, visit tga.gov.au/nicotine-vaping-products.

Be SunSmart

Skin cancer is the most common cancer in Australia and one of the most preventable. Most skin cancers are caused by exposure to the sun's ultraviolet (UV) radiation. Using sun protection will reduce your risk of skin cancer (see next two pages). It's also important to check your skin regularly and to ask your doctor how often you need a full skin check.

UV radiation from the sun causes skin cancer, but it is also the best source of vitamin D, which is needed for healthy bones. The body can absorb only a limited amount of vitamin D at a time. Getting more sun than recommended does not increase your vitamin D levels, but it does increase your skin cancer risk. Most people get enough vitamin D from incidental exposure to the sun, while using sun protection. When the UV Index is 3 or above (see next page for more information), this may mean spending just a few minutes outdoors on most days of the week.

People who've had skin cancer have a higher risk of developing more skin cancers. Talk to your doctor about how to protect your skin from the sun, check for new skin cancers, and maintain your vitamin D levels.

How to protect your skin

The UV Index shows the intensity of the sun's UV radiation. An index of 3 or above means that UV levels are high enough to damage unprotected skin, so

Slip on clothing



Wear clothing that covers your shoulders, neck, arms, legs and body. Choose fabric with a tight weave or with a high ultraviolet protection factor (UPF) rating and darker fabrics where possible.

Slop on sunscreen



Use an SPF 30 or higher broad-spectrum water-resistant sunscreen. Apply 20 minutes before going out and reapply every two hours, or after swimming, sweating or any activity that causes you to rub it off. For an adult, the recommended amount is 1 teaspoon for each arm, each leg, front of body, back of body, and the face, neck and ears – a total of 7 teaspoons of sunscreen for one full body application.

Slap on a hat



Wear a hat that shades your face, neck and ears. This includes legionnaire, broad-brimmed and bucket hats. Check to make sure the hat meets the Australian Standard. Choose fabric with a close weave that doesn't let the light through. Baseball caps and sun visors do not offer enough protection.

Slide on sunglasses



Protect your eyes with sunglasses that meet the Australian Standard. Wraparound styles are best. Sunglasses should be worn all year round to protect both the eyes and the delicate skin around the eyes.

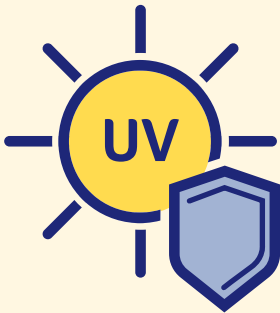
sun protection is recommended. Use a combination of the following measures to protect your skin. Make sun protection a part of your everyday routine.

Seek shade



Use shade from trees, umbrellas, buildings or any type of canopy. UV radiation is reflective and can bounce off surfaces, such as concrete, water, sand and snow, so shade should never be the only form of sun protection used. If you can see the sky through the shade, even if the direct sun is blocked, the shade will not completely protect you from UV.

Sensitive skin after treatment



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, and if there are any extra things you should do to protect your skin or you need more frequent skin checks.

Check daily sun protection times



Each day, use the free SunSmart app to check the recommended sun protection times in your local area. The times will vary according to where you live and the time of year. Visit sunsmart.com.au for more information.

You can also find sun protection times at the Bureau of Meteorology (bom.gov.au/uv or the BOM Weather app) or in the weather section of daily newspapers.

Be a healthy body weight

Some cancer treatments can affect your weight. People often 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. Whether you have lost or gained weight, it is important to work towards a healthy weight.

Being overweight or obese is a risk factor for many types of cancer (including cancer of the bowel, kidney, pancreas, oesophagus, uterus, liver and breast), heart disease and diabetes. Keeping your weight within the healthy range can help reduce the risk of cancer recurrence and improve survival. The health risk associated with your body weight can be estimated using your waist measurement (see below) and body mass index (BMI). To calculate your BMI, go to healthdirect.gov.au/bmi-calculator.

Waist measurement and health risk

Having fat around the abdomen or waist, regardless of your body size, can increase your risk of developing cancer, heart disease and diabetes. Some cancer types are also associated with increased fat around the hips and buttocks. Knowing your waist measurement can help you work out your risk. Place a measuring tape around your waist at the narrowest point between the lower rib and the top of the hips. Make sure to breathe normally. Use the table below to determine your health risk.

Health risk	Male waist	Female waist
increased	94 cm or more	80 cm or more
greatly increased	102 cm or more	88 cm or more

“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

Be physically active and sit less

Physical activity is a broad term that covers any activity that moves your body and increases your breathing and heart rate. Physical activity has a range of benefits for cancer survivors. It can:

- reduce the risk of some cancers (but not all) coming back, including breast, bowel and endometrial (uterine) cancers
- help prevent weight gain – being overweight or obese is a risk factor for many cancers
- help with recovery from treatment (rehabilitation) by increasing energy levels, improving sleep, increasing muscle strength, improving mobility and balance, relieving stress, and decreasing fatigue, anxiety and depression
- reduce the risk of developing other health problems, such as heart disease, osteoporosis and type 2 diabetes.

Recommended amounts of activity

Once cancer treatment is finished and you return to your usual day-to-day activities, aim to be as physically active as your abilities allow. The Clinical Oncology Society of Australia² recommends that people with cancer do:

- at least 150 minutes (2½ hours) of moderate intensity aerobic exercise or 75 minutes (1¼ hours) of vigorous intensity aerobic exercise every week
- 2-3 strength-training (resistance exercise) sessions a week to build muscle strength.

*Australia's Physical Activity and Sedentary Behaviour Guidelines*³ encourage adults to aim to do 300 minutes (5 hours) of moderate activity or 150 minutes (2½ hours) of vigorous activity every week. For maximum cancer prevention benefits, aim to gradually increase your activity to 60 minutes of moderate physical activity or 30 minutes of vigorous activity every day.

Many people lose muscle mass and strength during cancer treatment and find it harder to complete tasks of normal daily living. Strength-training (resistance exercise) can help you regain physical strength and get back to your daily activities. It can be done at home, an exercise clinic or gym. Resistance-based exercises can be done using your own body weight or equipment such as resistance bands, hand and ankle weights, or gym-based machines.

Taking care when exercising

Before taking part in any exercise program, it is important to talk to your specialist or GP about any precautions you should take. Ask about the amount and type of exercise that is right for you.

Your doctor may refer you to an exercise physiologist or physiotherapist to develop an exercise program to meet your specific needs. You may be able to attend one-to-one or group-based sessions, or your exercise professional may develop a program for you to follow at home. They will also show you how to exercise safely and monitor the intensity of your exercise (e.g. by measuring your heart rate).



Moderate intensity aerobic exercise includes brisk walking, swimming, jogging, cycling and golf. Vigorous intensity aerobic exercise includes fast jogging, running, swimming or cycling and playing team sport such as football or netball.



How to be more active

- Doing any physical activity is better than doing none. To avoid overexerting yourself, start physical activity slowly and build up gradually.
- Walk with a friend or pet, join a walking group or walk to the corner shop instead of driving. If you are exercising outdoors, remember to protect your skin (see pages 62–63).
- Break up long periods of sitting or screen time by standing up and moving every half-hour.
- Take the stairs instead of the lift or escalators.
- Do some vigorous housework and activities around the home each day, 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.
- Record your activity or steps completed each day. This can help keep you motivated.
- Join a group class such as dancing, Pilates, yoga or tai chi.
- Take your children or grandchildren to the park or kick a ball around the backyard.
- Try short periods of aerobic-based exercise (e.g. walking, cycling or swimming), stretching, or resistance-based exercises (e.g. using hand weights, resistance bands or your own body weight).
- Join a cancer survivorship exercise program or a local gym. Call 13 11 20 to find out about survivorship programs in your area (see pages 79–80).
- ▶ For some simple exercises to do at home, see our *Exercise for People Living with Cancer* booklet or free online exercise videos at cancercouncil.com.au/exercise.

Drink less alcohol

Drinking alcohol increases the risk of developing some cancers, including cancer of the mouth and throat, oesophagus, bowel, stomach, liver and breast. Even drinking small amounts of alcohol can increase cancer risk, and the risk increases with every drink. Alcohol contains a lot of energy (kilojoules or calories), so it can contribute to weight gain. Drinking alcohol also increases the risk of other diseases, such as heart disease and type 2 diabetes.

Cancer Council recommends you limit how much you drink to reduce your cancer risk. If you choose to drink alcohol, stick to the National Health and Medical Research Council guidelines and have no more than 10 standard drinks a week and no more than 4 standard drinks in one day. One standard drink has 10 grams of alcohol, but remember that drinks served at home and bars are often more than a standard drink.



Ways to reduce your alcohol intake

- Choose a non-alcoholic drink such as sparkling mineral water with fresh lemon or lime slices.
- Alternate alcoholic drinks with a glass of water.
- Set yourself a limit and stop once you've reached it.
- Wait until your glass is empty before topping it up to keep count of your drinks.
- Explore no alcohol beers, wines, spirits and mocktails.
- Have some alcohol-free days each week.
- Eat while you drink to slow your drinking pace.
- Catch up with friends over coffee or go for a walk.
- Download the Drinks Meter or Daybreak apps to help monitor your drinking.
- ▶ For information and support, call the National Alcohol and Other Drug Hotline on 1800 250 015.

Eat well

It is important to eat a balanced diet from the five food groups – fruit, vegetables and legumes, wholegrains, meat (or alternatives) and dairy (or alternatives). Limit foods containing saturated fat, added salt and added sugars, and avoid sugary drinks.

Fruit, vegetables and legumes

Eating fruit, vegetables and legumes (e.g. beans, lentils, peas) is important for your health. They are a great source of fibre, vitamins and minerals. Fruit and vegetables also contain natural substances, such as antioxidants and phytochemicals, which can protect cells in the body from damage that may lead to cancer. Eating fruit, vegetables and legumes can help you achieve and maintain a healthy weight because they are low in kilojoules and high in fibre.

The *Australian Dietary Guidelines*⁴ (eatforhealth.gov.au) recommend eating at least two serves of fruit and five serves of vegetables or legumes daily. Aim to eat a variety of different-coloured fresh fruit and vegetables. They are best eaten whole (not juiced), and it's good to eat both cooked and raw vegetables. Frozen and tinned vegetables are just as nutritious and are a good alternative to fresh produce – look for varieties without added sugars, salt or fats.

Wholegrain, wholemeal and high-fibre foods




Dietary fibre can help to ensure a healthy digestive system and reduce the risk of bowel cancer. Eating a diet high in fibre and wholegrain foods can also lower your risk of developing type 2 diabetes and heart disease, and help you maintain a healthy body weight.

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 wholegrain or wholemeal varieties. Wholegrain foods include wholemeal breads, rolled oats, wholemeal pasta, brown rice, barley, popping corn, cracked wheat (burghul) and quinoa. Wholegrain foods contain the outer layer of the grain, which contains fibre, vitamins, minerals and phytochemicals. Wholemeal foods are made from wholegrains that have been crushed to a finer texture. Nutritionally, wholemeal and wholegrain foods are very similar.

Some people continue to have bowel problems after cancer treatment. If you find that dietary fibre makes any bowel problems worse, you may need to eat low-fibre foods. A dietitian can recommend suitable foods for your situation.

How much is a serve?

Fruit, vegetables, legumes	Wholegrain foods	Meat (raw)
 <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 • ½ cup legumes • 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 • ½ cup cooked porridge 	 <ul style="list-style-type: none"> • 100 g lamb loin chop • 100 g steak • ½ cup diced red meat • ½ cup mince

Managing dietary changes

Treatment for some cancers can affect how you eat, swallow, digest food and absorb essential nutrients. You may need to try different foods and ways of eating to find out what works for you.

A dietitian can help tailor an eating plan to manage any ongoing issues. They can also provide advice about suitable nutritional supplements to help maintain your strength.

It may take time and support to adapt to your new way of eating. You may feel self-conscious or worry about eating in public or with friends. These reactions are natural.

It may help to talk about how you feel with your family and friends, your GP, a counsellor or someone who has been through a similar experience.

► See our *Nutrition and Cancer* booklet for more information.

Red meat and processed meat

Red meat includes beef, lamb, pork, veal, goat, venison and kangaroo. Lean red meat is an important source of dietary iron, zinc, vitamin B12 and protein. But 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 a day or two serves on 3–4 days a week.

There is strong evidence that eating processed meats, such as ham, bacon and prosciutto, is associated with an increased risk of bowel cancer. Cancer Council recommends you avoid eating processed meats.

There is no conclusive evidence that eating a vegetarian diet has a positive impact on survival after cancer treatment. However, eating more fruit, vegetables, legumes and wholegrain foods will probably improve the quality of your diet.



Ways to eat well after cancer

- Eat a variety of nutritious foods every day.
- Add vegetables, legumes, fruit, wholegrain and high-fibre foods to your meals.
- Limit your intake of red meat (see page 71).
- Choose lean cuts of meat and trim as much fat as possible before cooking.
- Swap a serve of red meat for another variety of protein. Sources of protein include fish, chicken, eggs, legumes, tofu, nuts, wholegrains, soya and dairy products.
- Avoid processed meats like ham, bacon and deli meats or eat only occasionally.
- Try reduced-fat milk, yoghurt and cheese. Choose varieties that are also low in added sugars or salt.
- Eat fish a couple of times a week.
- Add fruit and yoghurt to wholegrain cereal or serve some vegetables such as mushrooms with your eggs and wholegrain toast.
- Adapt your recipes to include more vegetables and legumes (e.g. add grated carrot and zucchini, celery, capsicum, beans or lentils to pasta sauces).
- Limit the portion size of your meals and snacks.
- 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, salt and kilojoules.
- Don't add salt to food during cooking or before eating. Add flavour with herbs and spices.
- Grill, poach, slow roast and stir-fry rather than deep fry.
- Steam or microwave vegetables to maintain their nutritional goodness.

Key points about looking after yourself

Reduce cancer risk You can reduce your cancer risk after treatment and improve survival by adapting your lifestyle.

Quit smoking

- Quitting smoking can have a significantly positive impact on survival.
- There is no safe level of smoking.
- Support is available to help you quit.

Be SunSmart Protecting your skin from the sun when the UV level is 3 or above will lower your risk of skin cancer.

Be a healthy body weight Whether you have lost or gained weight during treatment, it is important to get back to a healthy weight.

Be physically active and sit less

- Physical activity is important to reduce your cancer risk and help manage your weight.
- It also helps boost energy levels, decrease fatigue and relieve stress.

Drink less alcohol

- 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.

Eat well

- Eating a variety of fruit, vegetables, legumes, wholegrain, wholemeal and high-fibre foods, 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.
- Limiting your intake of red meat and avoiding processed meats can reduce your risk of bowel cancer.

Practical concerns

After cancer treatment, you may have concerns about financial issues, insurance policies and work.

Financial assistance

For many people, cancer treatment can be a financial strain. This can be caused by extra costs or loss of income. Support is available:

- Your local Cancer Council may be able to organise legal, financial and workplace advice (see opposite page).
- Ask your social worker about whether any financial or practical assistance is available to you. If you have to travel for follow-up appointments, ask about patient travel assistance.
- Call the National Debt Helpline on 1800 007 007 for free, confidential and independent financial counselling.
- Ask your utility company, loan provider or local council how they can help you manage payment of your bills or loans. Check if you qualify for any rebates, concessions or hardship programs.
- Talk to your superannuation fund about applying for an early release of your superannuation on the grounds of severe financial hardship. Find out how this will affect your retirement and whether your superannuation has any insurance policies that you could claim on.
- ▶ See our *Cancer and Your Finances* booklet and *Superannuation and Cancer* fact sheet.

“I called Cancer Council and ended up speaking to a financial counsellor. She helped me sort things out with the bank.” VINCENT

Legal, financial and workplace support

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

hardship variations; insurance claims and disputes; managing workplace issues; navigating a return to work; and transitioning to retirement. Some services are not available in all states and territories.

We can put you in touch with professionals who can help you with: credit and debt issues; mortgage

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

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 any diagnosis of cancer.

In general, you should be able to buy insurance for things that are not cancer-related (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 buying a new insurance policy.

► See our *Life Insurance* fact sheet.

Working after treatment ends

Having a job is an important part of life for many people. Aside from income, work can provide satisfaction, social contact, a sense of normality, and a way of maintaining self-esteem.

“I had planned to work beyond 65, but now I’m thinking I’ll retire sooner. I have different priorities now. I’ve been given a second chance.” JULIE

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 ability to perform 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. This may mean, for example, that your employer allows you to return to work in stages, is flexible with start and finish times, gives you time off to attend medical appointments, or provides tailored work tools.

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 say 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 may impact on your ability to do the job. 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 for you 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 if you have 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 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 information and 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
- 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
- see our *Cancer, Work & You* booklet and visit workaftercancer.com.au.

Key points about practical concerns

Financial assistance

- The cost of cancer treatment can strain your finances.
- Talk to a social worker or financial counsellor if you are struggling with debts or call the National Debt Helpline on 1800 007 007 for assistance.

Insurance

- 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 medical history and the insurer.

Working after treatment

- A written return to work plan can be a helpful guide for you and your employer.
- Talk to your employer about returning to work part-time or on lighter duties. As your health improves, you may want to ease back into your previous workload.
- Let your employer know about any changes you need to help you carry out the essential parts of your job.
- You don't have to tell a potential employer that you've had cancer unless it affects your ability to do the job.
- If you are unable to return to your previous position, consider attending a rehabilitation or retraining program to prepare for another job.
- You should not be treated differently in the workplace because of your cancer diagnosis. The *Disability Discrimination Act* protects anyone who has had cancer.

Support and information

- Cancer Council's Referral Services may be able to connect you with professionals for legal, financial planning, small business, and workplace advice. Some services may not be available in all areas. Call 13 11 20 for more information.
- See our *Cancer, Work & You* and *Cancer and Your Finances* booklets for more information.

Seeking support

Many people find they need support after treatment finishes. What services are available may vary depending on where you live. Some services will be free, but others might have a cost.

Survivorship programs

Survivorship programs provide information about recovery from cancer and its treatment, as well as practical information about life after cancer. Many offer group education programs for survivors that can help you meet others in a similar situation. You may find it helpful to share tips and ideas with other participants. Some programs are open to carers, family, friends and work colleagues.

Cancer Council – Your local Cancer Council may offer programs providing information about living well after cancer (e.g. ENRICHING Survivorship, Healthy Living After Cancer, Wellbeing After Cancer, Life Now, Cancer Wellness Program).

Topics covered may include nutrition, exercises to help improve quality of life, mindfulness and adjusting to life following cancer treatment. You may also find it helpful to watch Cancer Council's survivorship webinars. Call 13 11 20 to find out what services are available in your area.

“Really enjoyed the program ... I liked that it wasn't ‘you have to make major changes’ because you don't stick to it, small changes over time.” ASHLEY

Treatment centres – Some hospitals, treatment centres and community organisations offer free education programs for cancer survivors. Ask your oncologist, social worker or cancer nurse for a referral to a local support group or survivorship program.

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 group, you may find that you are comfortable talking about your issues after treatment, relationships with friends and family, and hopes and fears for the future.

There are many ways to connect with other people in a similar situation. Cancer Council runs face to face and telephone support groups, or can put you in touch with someone who has had a similar cancer experience. You could also join our online discussion forum at cancerCouncil.com.au/OC.

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

“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

Support from Cancer Council

Cancer Council offers a range of services to support people after cancer treatment. Services may vary by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Legal and financial support



If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council 13 11 20 to ask if you are eligible.

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access survivorship, nutrition and exercise programs.

Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit cancerCouncil.com.au/OC.

Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer Council Australia	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Guides to Best Cancer Care	cancer.org.au/cancercareguides
Australasian Lymphology Association	lymphoedema.org.au
Australian Association of Social Workers	aasw.asn.au
Australian Cancer Survivorship Centre	petermac.org/cancersurvivorship
Australian Music Therapy Association	austmta.org.au
Australian Physiotherapy Association	australian.physio
Cancer Australia	canceraustralia.gov.au
Carer Gateway	carergateway.gov.au
Dietitians Australia	dietitiansaustralia.org.au
Exercise & Sports Science Australia	essa.org.au
Healthdirect Australia	healthdirect.gov.au
Occupational Therapy Australia	otaus.com.au
Services Australia	servicesaustralia.gov.au
Speech Pathology Australia	speechpathologyaustralia.org.au

International

American Cancer Society Cancer Survivors Network	csn.cancer.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	cancer.gov
Office of Cancer Survivorship (US)	cancercontrol.cancer.gov/ocs

Question checklist

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

Fear of 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?
 - If the cancer returns, how will I know?
 - What are the signs I should look for?
 - Could I join any clinical trials or research studies about managing the emotional impact of cancer?
-

Follow-up care

- Will you give me a survivorship care plan?
 - Can I have a copy of my cancer treatment summary?
 - Who should I go to for my follow-up appointments?
 - How long will I receive follow-up care?
 - What tests do I need to have? What will the test results tell us?
 - Can I attend follow-up appointments using telehealth or have tests close to home?
 - 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?
 - Can I have the flu, COVID-19 or other vaccines?
-

Family and friends

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

continued on next page

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 late effects? Do I need any tests to monitor this?
- Am I likely to have long-term problems with pain?
- How can I control any pain?
- What can I do to stop feeling so tired all the time?
- Are there things I can do to help me sleep better?
- Where can I get help for dealing with how I am feeling? Can you refer me to a psychologist or counsellor?
- Would a Mental Health Treatment Plan be of help?
- 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?
- Can you tell me how a GP Management Plan or Team Care Arrangement can help me manage any ongoing side effects?

Looking after yourself

- 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?
- Are there any complementary therapies that might help me?
- What advice do you have about returning to work?
- Who can I talk to about my finances, legal matters and other practical concerns?
- Are there any support services you can refer me to?
- How can I connect with other cancer survivors?
- Are there any apps, podcasts or online programs that might be helpful?

Glossary

active treatment

Treatment that aims to control or cure the cancer. Does not include maintenance treatments given long term to reduce the chance of the cancer coming back.

advanced cancer

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

alternative therapy

A therapy that is used in place of conventional treatment, often in the hope that it will provide a cure.

analgesic

A medicine used to relieve pain.

antidepressant

Medicine to help relieve the symptoms of depression.

BMI (body mass index)

A way to find out if a person is a healthy weight for their height.

cancer-related cognitive impairment

Thinking and memory problems that may be experienced after cancer treatment, including difficulty concentrating and focusing. Also called chemo brain or cancer fog.

cancer specialist

A doctor who specialises in the study and treatment of people with cancer. May be a medical oncologist, surgeon, radiation oncologist or haematologist.

cancer survivor

A person from the time of their diagnosis with cancer.

chemotherapy

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

chronic pain

Pain that can range from mild to severe and lasts a long time, usually more than three months. Also known as persistent pain.

cognitive behaviour therapy (CBT)

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

complementary therapy

Any of a range of therapies used alongside conventional treatment to improve general health, wellbeing and quality of life.

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.

erectile dysfunction

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

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

Appointments with health professionals to follow your progress after treatment.

hormone therapy

A treatment that blocks the body's natural hormones. It is used when the cancer is growing in response to hormones.

infertility

The inability to conceive a child.

late effects

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

libido

Sex drive/sexual desire.

lymphatic system

A network of vessels, nodes and organs 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 fluid

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

lymph nodes

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. 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 after the initial treatment to prevent the cancer coming back.

menopause

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

menopause hormone therapy (MHT)

Drug therapy that supplies the body with hormones that it is no longer able to produce naturally. Previously known as hormone replacement therapy (HRT).

metastasis (plural: metastases)

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

mindfulness

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

mindfulness meditation

A type of meditation based on the concept of being "mindful".

oestrogen

One of the major sex hormones in females. It is produced mainly by the ovaries. After menopause, the hormone is produced in the fat cells.

opioids

The strongest pain medicines available. They include morphine, fentanyl, codeine, oxycodone and methadone.

osteoporosis

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

pain management plan

A personalised plan to manage pain, developed by a person's GP and the pain management team.

peripheral neuropathy

Weakness, numbness, tingling or pain, usually in the hands and feet,

caused by damage to the nerves located away from the brain and spinal cord (peripheral nerves).

podiatrist

A trained health professional who can help you look after your feet.

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 signs and symptoms 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. Most side effects can be managed.

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 of the body to allow urine or faeces to leave 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, emotional, psychological or social 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
-

References

1. Clinical Oncology Society of Australia Model of Survivorship Care Working Group, *Model of Survivorship Care: Critical Components of Cancer Survivorship Care in Australia Position Statement*, Clinical Oncology Society of Australia, 2016.
2. Clinical Oncology Society of Australia, *COSA Position Statement on Exercise in Cancer Care*, Clinical Oncology Society of Australia, Version 3, December 2020.
3. Australian Government Department of Health, *Australia's Physical Activity and Sedentary Behaviour Guidelines*, viewed 13 October 2021, available from: health.gov.au/resources/collections/collection-of-physical-activity-and-sedentary-behaviour-guidelines-for-all-ages.
4. National Health and Medical Research Council, *Australian Dietary Guidelines*, National Health and Medical Research Council, Canberra, 2013.



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.



Cancer Council

13 11 20

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

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

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

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

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council Queensland
cancerqld.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council NSW
cancercouncil.com.au

Cancer Council SA
cancersa.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Tasmania
cancer.org.au/tas

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.*

