Cancer Council

COPING WITH CANCER

Just Diagnosed

A guide for people with cancer, their families and friends

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call **Cancer Connect 13 11 20**

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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 booklet 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 8 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 and present.

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About this booklet

Many people feel shocked and upset when told they have cancer. It's often a confusing and overwhelming time. You may have many questions and wonder "what does this mean for me?" and "what happens next?".

This booklet can help you, your family, friends and carers understand more about cancer and what to expect in the days and weeks after diagnosis. It includes information about:

- cancer and further tests and scans you may have
- treatments for cancer and the health professionals you may see
- how to look after your general and emotional health
- how cancer may affect your relationships, work and finances.

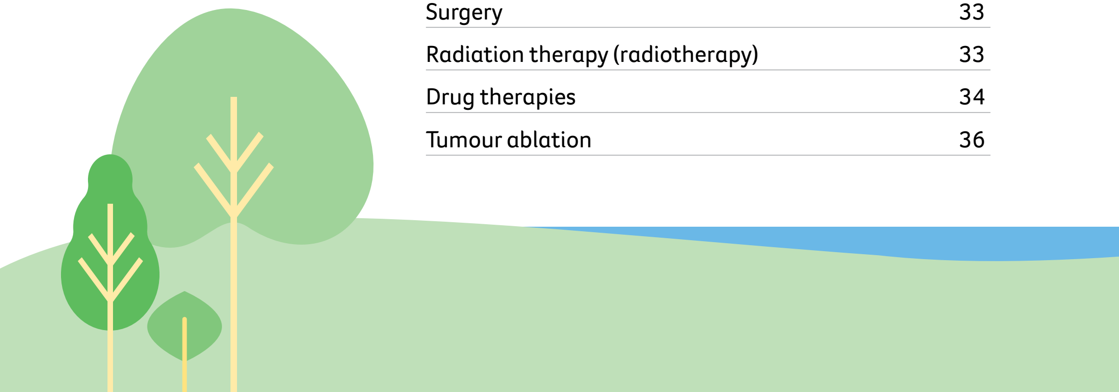
Cancer Council has more detailed information on each of the above topics and more than 40 different cancer types. You may want more information now or later – it's up to you.

This booklet provides general information only. Your doctors are the best people to talk to about your treatment and care. See page 54 for suggested questions for your cancer care team.

How this booklet was developed – This information was developed with help from a range of health professionals and people affected by cancer. Some parts of this booklet are based on international guidelines.[1]

If you're feeling overwhelmed or if you just have questions, our Cancer Connect service can be a good place to start. We can help you find the information and support that are right for you. Call **Cancer Connect 13 11 20** or visit cancerconnect.org.au.

Contents



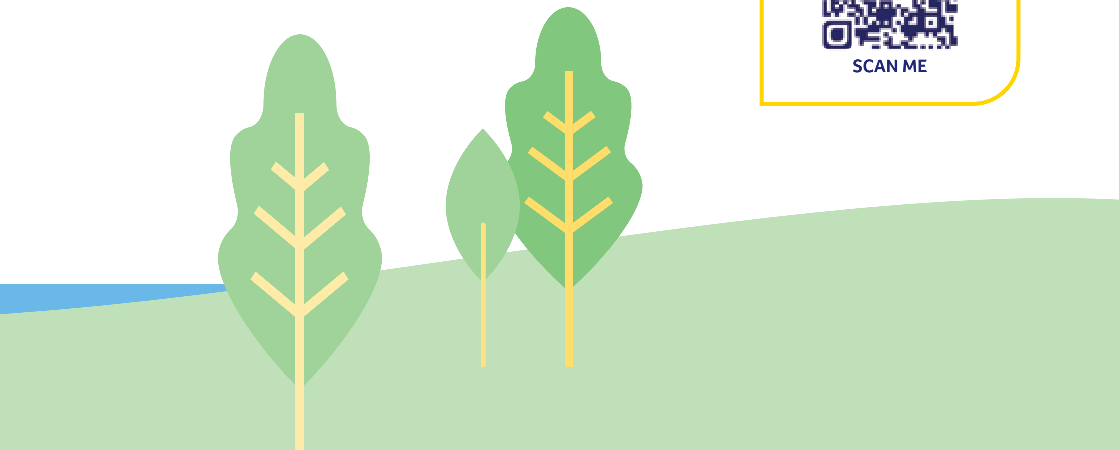
Key to icons

Icons are used throughout this booklet to indicate:

- 🔍 More information
- ! Alert
- 💡 Tips

Is this Cancer Council booklet helpful? Please follow this QR code for a quick 3-minute survey, or call 13 11 20 to provide your feedback.

SCAN ME



When you find out you have cancer

The days and weeks after a cancer diagnosis can be a distressing and frightening time. Many people feel shocked and uncertain about the next steps. It's natural to have many feelings. You don't have to face them alone. See pages 18–24 for ways to help you cope with the emotional impact of cancer.

What happens next?

After a diagnosis, people often wonder what will happen next. While everyone's experience differs, many people follow similar steps.

Tests and scans

It's likely that you'll need further tests and scans to find out more about the cancer and help the doctors plan treatment. See pages 11–17.

Preparing for treatment

Even small changes to your daily habits can help you cope better during cancer treatment. See pages 25–29 for tips on looking after yourself.

Treatment

Your doctor will talk to you about the best treatments for you. They will support you in making treatment choices. After the initial treatment, more treatment may be given. Some people take medicines for months or years to reduce the risk of cancer coming back (maintenance treatment). See pages 30–36 for information about common types of treatment.

Managing symptoms and side effects

Cancer and its treatments may cause unwanted effects on your body. Find out more in our information about the type of cancer you have.

After treatment

What happens after treatment depends on the cancer type and stage:

- **Monitoring –** For many people, there may be no obvious signs of cancer in the body. You'll have regular check-ups to be sure the cancer doesn't return. This is called monitoring or surveillance.
- **Palliative care –** If cancer won't go away, treatment and other support is given to help manage the symptoms of cancer and maintain quality of life. This is called palliative or supportive care.

What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. Normally, cells grow, die and are replaced in an orderly way. Sometimes, cells change and keep growing when they shouldn't, which can lead to cancer.

In some cancers, such as lung or breast cancer, these cells form a lump called a tumour. In other cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours grow slowly and don't spread. Cancerous (malignant) tumours can grow into nearby areas and spread to other parts of the body through the blood or lymph systems.

The primary cancer is named after the place in the body where the cancer starts. If it spreads to another part of the body, the new tumour is called a secondary cancer or metastasis. The cancer keeps the name of the place where it started. For example, if cancer spreads from the lungs to the liver, it's called metastatic lung cancer.

INFORMATION FROM CANCER COUNCIL

Information is available on more than 40 different types of cancer, as well as treatments and emotional and practical issues.

You can access our information in various formats:
- online
- booklets and fact sheets
- podcasts and videos.

Call **Cancer Connect 13 11 20** for free booklets, or visit **cancerconnect.org.au** to find all our resources.

Your health care team

When you notice symptoms that could be cancer, or have a screening test that shows something unusual, you'll usually see a general practitioner (GP). Your GP will arrange some tests and scans. If the results suggest that you may have cancer, you'll be referred to a specialist doctor for further tests. The specialist you see will depend on the type of cancer you have. After diagnosis, a team of health professionals will work with you throughout your treatment.

Health professionals you may see

GP/family doctor

Your GP supports you from cancer diagnosis and treatment to follow-up and survivorship. If you don't have a regular GP, it's a good idea to find one. A GP can:

- help you understand treatment options and prepare for treatment
- refer you to specialists and allied health professionals such as physiotherapists, dietitians or psychologists
- help arrange a second opinion if you want one
- continue to see you for day-to-day health issues and follow-up care
- get to know you and your medical history, and provide background to the cancer care team.

Cancer specialists

Cancer specialists diagnose cancer and guide your treatment and follow-up care. They may be a:

- **medical oncologist –** treats cancer with drug therapies (e.g. chemotherapy)
- **surgeon –** removes tumours and may perform some biopsies
- **radiation oncologist –** prescribes and oversees radiation therapy
- **haematologist –** diagnoses and treats diseases of the bone marrow, blood and lymphatic system.

Cancer specialists can:

- answer your questions about treatment
- work together as part of a multidisciplinary team (see page 10) to plan and deliver treatment
- be supported by junior medical staff (e.g. registrar), if you're treated in hospital.

Specialist nurses

A specialist nurse coordinates your care from diagnosis through treatment. They work closely with specialists and other health professionals. They may be called a cancer care coordinator, clinical nurse consultant or clinical nurse specialist. Specialist nurses are often your main contact for questions and concerns.

They can:

- provide information and support
- coordinate care for specific cancer types (in smaller hospitals, a general coordinator or the nursing unit manager may provide this support).

In rural areas, a cancer care coordinator may attend appointments with a visiting oncologist.

More than one nurse may be involved in your care (e.g. a surgical nurse, breast care nurse or stomal therapy nurse).

Psychologists and social workers

Various health professionals can help manage the emotional and practical impacts of cancer. You may see a:

- **psychologist –** helps you manage your feelings about diagnosis and treatment. They can provide counselling and advocacy at all stages of living with cancer. They may also support your family members and carers
- **social worker –** provides emotional and practical support, as well as advocacy, during times of crisis. They help access practical services (e.g. accommodation, transport, financial assistance, home care services). They can connect you with services that best meet your needs.

Physical and occupational therapists

To help with mobility, day-to-day tasks and speech, you may see a:

- **physiotherapist –** helps you to move and exercise safely to regain strength, fitness and mobility
- **exercise physiologist –** designs exercise programs to help improve health, fitness, strength and energy levels, especially for people with medical conditions
- **occupational therapist –** provides equipment, aids and advice about getting back to your daily activities
- **speech pathologist –** helps with speech or swallowing issues after treatment.

Other health professionals

You may also see a:

- **dietitian –** helps with nutrition concerns and recommends changes to diet
- **radiographer –** performs x-rays, mammograms and other scans
- **radiation therapist –** plans and delivers radiation therapy
- **genetic counsellor –** gives advice if you have a strong family history of certain cancer types
- **pharmacist –** dispenses medicines and explains doses and side effects
- **Aboriginal and Torres Strait Islander health professional –** supports Aboriginal and Torres Strait Islander peoples with culturally safe care and advice
- **multicultural navigator –** supports people from various communities; may be available in some hospitals and cancer centres.

Choosing your specialist

It's important to feel comfortable with your specialist. Some people are happy to leave the choice of specialist to their GP, while others want to be involved in this decision. Choosing specialists is not always possible (e.g. in the public health system), but if it is, you may consider:

- **Specialties –** Some doctors specialise in treating certain cancers.
- **Multidisciplinary care –** Health professionals who specialise in different parts of your care sometimes work together to plan treatment. This is called a multidisciplinary team (MDT). It may include surgeons, medical oncologists, radiation oncologists, cancer care coordinators, dietitians, psychologists and social workers.
- **Specialist treatment centres –** These centres treat many patients, including those with rare cancers.
- **Your preferences –** You may want to see all your doctors at the one hospital, even if it's far away, or go to your local hospital for some visits to cut down on travel.

MORE INFORMATION

For information on the health professionals you may see, read our *Understanding Cancer* booklet or fact sheet on the type of cancer you have.

For an overview of what to expect at every stage of your cancer care, visit cancer.org.au/cancercareguides. Here you will find short guides about diagnosis, treatment and beyond for many types of cancer.

Call **Cancer Connect 13 11 20** for free booklets. To find all our resources, visit **cancerconnect.org.au.**

NEXT STEPS

- ▶ After a cancer diagnosis, the doctors may arrange further tests and scans to learn more about the cancer and guide treatment decisions.

What tests and scans might you need?

You may have already had tests or scans to diagnose cancer, but extra tests are often needed after diagnosis to give doctors more information about the disease. Depending on the type of cancer, further tests and scans may be used to find out:

- **where the cancer started –** doctors may need to work out the source of the cancer; different cancers are treated in different ways
- **the stage of the cancer –** this shows the size of the cancer, if it has spread and how far
- **the grade of the cancer –** this shows how quickly the cancer may grow
- **your general health –** other health issues, such as heart problems, may affect how cancer is treated
- **other information about the cancer –** doctors may look for features in the cancer to help work out the best treatment.

Once your doctors know more about the cancer, they'll talk to you about which treatments may help you the most (see pages 30–36). You may have more tests and scans during and after treatment.

You probably won't need every test or scan mentioned in this chapter, but you'll need some. If you're unsure about a test or scan, ask your doctor to explain it. You can also ask your doctor if some or all tests can be bulk-billed or done in the public system to help with costs.

> *"My diagnosis was made after the biopsy. I felt relieved to finally have a label for my illness."* DEE

Common tests and scans

Blood and urine tests

It's likely that you'll have blood tests to check your general health and sometimes to find out more about the cancer.

You may also be offered a blood or saliva test to check for certain gene changes (see opposite page). The results can help your doctor work out which treatments may work for you. For some types of cancer, your urine (wee or pee) may be tested to check for cancer cells or blood.

Imaging scans

You may have several imaging scans to create pictures of the insides of the body. See pages 14–15 for more information about scans.

Biopsies

A biopsy is when a doctor removes a sample of cells or tissue from an area of the body. The sample is examined under a microscope to look for signs of cancer and what type of cell is affected.

If the cancer can be easily felt or seen, a doctor may use a needle or make a small cut in the skin to take a sample. Other ways to have a biopsy include:

- **with imaging guidance –** a specialist may use a scan to guide a needle into the cancer to get a sample
- **during a scoping test –** see opposite page
- **during surgery –** a surgeon makes a cut in the skin to remove a sample.

For a biopsy, you'll have a local anaesthetic to numb the area. If you're having surgery, you may have a general anaesthetic to put you to sleep.

Checking for tumour markers and gene changes

Samples of cancer cells, tissue, blood or saliva may be tested for tumour markers or gene changes. This information can help the doctor understand more about the cancer and how it can be treated.

Tumour markers – Some cancers release proteins (tumour markers). Tumour markers can help doctors learn more and monitor cancer, but they don't show if you have cancer.

Gene changes – Tests may look for gene changes that have been passed down through families (inherited changes) or that have developed during your life (acquired changes). Tests for inherited gene changes may be covered by Medicare (see page 38). If an inherited gene change is found, you may be referred to a genetic counsellor. Other gene tests help the doctor work out what treatments are most likely to work.

Scoping tests

For some cancers, doctors use a thin, flexible tube with a camera on the end (called a scope) to look inside your body and examine your organs. Different types of scoping tests are used to check different parts of the body. These include:

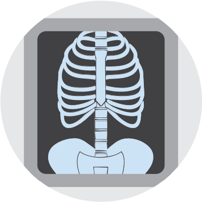
- **bronchoscopy –** inserted through the mouth to see airways and lungs
- **colonoscopy –** inserted through the anus to see the large bowel
- **cystoscopy –** inserted through the urethra to see the bladder
- **hysteroscopy –** inserted into the vagina and passed through the cervix to check the uterus (womb)
- **laparoscopy –** inserted through a small cut in the abdomen (belly) to check organs such as the stomach, pancreas or liver.

Your doctor will explain how to prepare for the scoping test and how long it will take. A small tissue sample may be removed during the procedure (biopsy, see opposite page). The sample will then be sent to a laboratory to confirm that it's cancer as well as the type and stage.

Imaging scans

These scans use special equipment to create pictures of the inside of the body. They help doctors work out the stage of the cancer and the best treatment for you. Scans are done in a hospital or radiology clinic.

X-ray



An x-ray uses a small amount of radiation to create pictures of the inside of the body. The scan takes only a few minutes and does not cause pain.

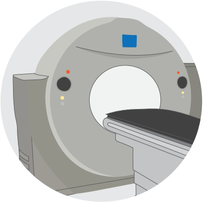
Fear of small spaces

For CT, MRI and PET–CT scans, you'll need to stay very still inside a large machine.

If you feel anxious in small spaces (claustrophobia), let your cancer care team know before your appointment.

They can give you medicine to relax during the scan.

CT scan



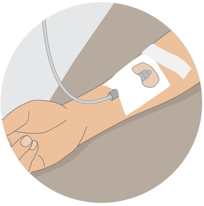
A computerised tomography (CT) scan uses x-ray beams to take many pictures of the inside of your body. These images are combined into one detailed, cross-sectional picture.

Before the scan, you may need to drink water or a special dye (called contrast). During the scan you may be injected with contrast. This makes the pictures clearer. You'll need to remove any metallic objects, such as jewellery, before the scan.

You'll lie still on a table that moves in and out of a large, doughnut-shaped scanner.

The scan takes only a few minutes. It's painless but the contrast can cause a warm or flushing feeling.

PET–CT scan



A positron emission tomography (PET) scan is sometimes combined with a CT scan to show the cancer in more detail.

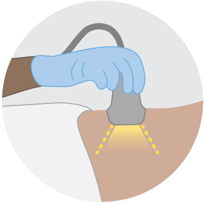
A low-dose radioactive glucose solution will be injected into your arm. You'll then wait about 30–90 minutes for the solution to move through your body.

You'll need to remove any metallic objects, such as jewellery, before the scan.

The scan takes 2–3 hours. A few hours after the scan, the solution will leave your body in your urine (wee). You may be told to avoid close contact with young children and pregnant women for a few hours.

Before your scan, tell the doctor if you have any allergies or have had a reaction to dyes during previous scans. You should also let them know if you have diabetes, kidney disease, or if you are pregnant or breastfeeding.

Ultrasound



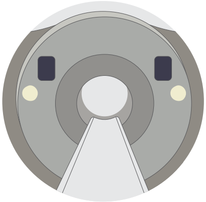
An ultrasound uses soundwaves to create a picture of the part of the body that is affected by cancer.

You'll lie on a table and uncover the area being checked. A cool gel is spread on the skin, and a small handheld device (a transducer) is moved over your skin. Sometimes the transducer may be inserted into the body (e.g. to check the uterus).

An ultrasound usually takes 10–20 minutes and doesn't cause pain, but it may be uncomfortable.

Before some ultrasounds, you may need to fast (not eat), or drink water to fill your bladder.

MRI scan



A magnetic resonance imaging (MRI) scan uses a magnet and radio waves to take detailed pictures of the body.

Before the scan, you may be injected with a special dye (called contrast) to help show any cancer in the areas being scanned. Tell your doctor if you have any metallic implants (e.g. pacemaker), as some make MRI scans unsafe. You'll also need to remove metal jewellery before the scan.

You'll lie very still on a table that slides into a tunnel-shaped scanner. The machine makes loud noises, so you'll be given earplugs. The scan is painless and takes about 30–60 minutes.

Bone scan

A bone scan helps show any abnormal areas of bone growth.

You'll be injected in the arm with a small amount of radioactive dye then wait for 2–3 hours while it moves through your bloodstream to your bones.

Your body is then scanned. Areas of bone with cancer cells usually absorb more dye and show up more clearly. A bone scan can take up to 5 hours (including waiting time).

The dye leaves your body in your urine (wee) after a few hours. You may be told to avoid close contact with children and pregnant women for the first few hours after the scan.

Waiting for tests and results

It can take time to have some tests and to receive the results. Some tests are complicated to perform or need specialists to review the results.

If your GP arranges a test, you may need to wait for an appointment with a cancer specialist. Your GP will tell you when the results are likely to be ready so you can make an appointment with the specialist to discuss the results and the next steps.

It's common to feel anxious while waiting for test results. If you need support, contact your GP or cancer care team, or call our Cancer Connect service on 13 11 20.

Prognosis

The first question that comes to mind after a cancer diagnosis is often "what's going to happen to me?". Your doctor may talk to you about the expected outcome of the cancer. This is called the prognosis.

No one can predict exactly how the cancer will affect you, but your doctor can explain what usually happens for people with the type of cancer you have.

To work out your prognosis, the doctor will consider:

- your test results
- the type of cancer
- the stage and grade of the cancer
- how likely it is that the cancer will respond to a specific treatment
- your age, fitness level and medical history.

In general, the earlier cancer is diagnosed, the better the chances that treatment will be successful. In some cases, advanced cancer can also respond well to treatment. Advanced cancer is cancer that has spread from one organ to other organs. It may also be called stage 4 or metastatic cancer.

Although the doctor will do their best to predict the outcome after cancer treatment, a prognosis is never certain. It can also change over time.

Some people don't want to know their prognosis, and this is completely natural. You can decide how much you want to know. Talk to your doctor about how you're feeling. If you have any questions or worries about your prognosis, talk to your cancer care team. You can also call 13 11 20 to speak to our Cancer Connect service.

MORE INFORMATION

To find out more about the further tests and scans you might have, see the Cancer Council resource on the type of cancer you have.

You can also listen to our podcast episode:
- "Tests and Cancer"

See page 50 for information and support services.

Call **Cancer Connect 13 11 20** for free booklets. To find all our resources, visit **cancerconnect.org.au.**

NEXT STEPS

- At any stage after a cancer diagnosis, you may experience times of distress and feel a range of strong emotions. See pages 18–24 for ideas about how to cope.
- Once your doctor knows more about the cancer, they'll talk to you about which treatments might help you the most. See pages 30–36.

Coping with emotions

When you’re told you have cancer, it’s common to feel a range of strong emotions. The diagnosis is often unexpected and may suddenly change your plans and hopes for the future. A cancer diagnosis can affect every part of your life – family, friends, work and finances.

After a cancer diagnosis, people may feel overwhelmed or numb. Other common emotional reactions include:

- **Shock and disbelief –** You may find it hard to accept that you have cancer, especially if you don't feel sick.
- **Fear, worry and anxiety –** You may feel anxious and uncertain about how cancer will affect you, your family and the future.
- **Anger, guilt and blame –** It's common to think "why me?" and feel angry. This anger may come out as being snappier than usual with family and friends. You may feel angry at yourself, or even feel some anger towards your health professionals about your diagnosis.
- **Sadness and depression –** It's natural to feel sad about how cancer might change your everyday life and what it means for the future. If you have continued feelings of sadness, trouble getting up in the morning or have lost motivation to do things that used to give you pleasure, you may have depression. Talk to your GP because counselling or medication can help.
- **Loss of control –** You may feel that you're losing control of your life. This can be particularly difficult for people who are used to being independent or have caring responsibilities.
- **Loneliness –** Cancer can feel isolating, even if you have people around you for support.

There's no right or wrong way to feel after a cancer diagnosis, and your emotions may change over time. For ways to help you cope with how you're feeling, see pages 20–21.

If you're finding it difficult to cope with the diagnosis, speak to your cancer care team or GP. They may suggest you see a psychologist or counsellor for support. You can also call 13 11 20 to talk it through with our Cancer Connect service.

Ways to cope

You might find some of the following strategies helpful in managing how you feel after a cancer diagnosis and during treatment.

Look after yourself

If your health allows, being active, eating healthy food and drinking plenty of water can help you cope with the emotional stress of cancer and its treatment. It can also help to focus on maintaining or improving your sleep. For ways to prepare for treatment, see pages 26–27.

Focus on one day at a time

Thinking of all the “what-ifs” can feel overwhelming. It can help to focus just on the next step. Taking things one day at a time can make challenges feel more manageable.

Seek support

Talk to a family member, friend or health professional. You could also call Cancer Connect on 13 11 20, visit the Online Community at cancercouncil.com.au/OC or join a support group. Accepting or asking for help around the home or with other responsibilities, like caring for children or community activities, can make things easier.

Find out what to expect

Learning about cancer and its treatment can help you make decisions and feel more in control. Take in information at your own pace, so you don’t feel overwhelmed. It might be useful to bring a family member or friend to appointments for support and to take notes. You can also ask to record the appointment with the doctor’s consent. Be sure to ask questions about anything you want to know.

If you're experiencing high levels of distress, talk to your cancer care team or call Cancer Connect 13 11 20. For 24-hour support, call Lifeline 13 11 14.

Take a break

Make time each day to relax. Try activities that help you to feel good such as reading, listening to music, taking a bath or having a massage. Staying connected with work, hobbies, or time with family and friends can help you take a break from cancer. It may be helpful to tell friends and family that it's okay not to talk about cancer sometimes too.

Draw on spirituality

Some people find meaning and comfort in their faith. Others see spirituality more generally. A cancer diagnosis can challenge deeply held beliefs. Talking with a spiritual care practitioner, religious leader or Elder can help.

Clear your mind

Complementary therapies, such as yoga and meditation, can help you feel more in control, reduce stress and anxiety, and improve mood.

Does "positive thinking" help?

After a cancer diagnosis, some people may encourage you to "stay positive". They may think that having a positive attitude improves the chances of a better outcome after cancer treatment.

But it's common to have negative and positive emotions, and this won't affect how your treatment works.

If you need support in coping with a diagnosis, you may be referred to a psychologist or a social worker. Joining a support group can also help.

Managing all the information

Many people feel overwhelmed by the amount of medical information they receive in the days and weeks after a cancer diagnosis. This may be called “information overload”.

It can be hard to take in complex information when also coping with shock, distress and cancer symptoms such as pain or fatigue. You can just take in information at your own pace; you don’t need to understand everything at once. You might find it helpful to:

- bring a family member or friend to appointments to take notes
- record the discussion (but make sure you ask your doctor first)
- ask your doctor for printouts of results and keep them in a folder
- email questions to your cancer care team ahead of your appointment.

Finding more information

Some people want to learn as much as possible about cancer and its treatment right away, while others prefer to take things slowly. If you would like to learn more, you can find reliable information through our Cancer Connect service. Call 13 11 20 or visit cancerconnect.org.au.

It can be tempting to search online for information about cancer – and many people turn to “Dr Google”. However, not all online information is accurate, up to date, or relevant to your situation. Be sure to use information from trusted sources, such as Cancer Council. See pages 52–53 for a list of trustworthy websites.

Sometimes you may hear the words the doctor is saying but find them hard to understand or believe. It’s okay to ask the doctor or other members of the cancer care team to explain anything that is unclear. See page 55 for the meanings of some common words.

In some cultures, people may believe that cancer is contagious, a test, caused by bad luck or always fatal. Some people may not want to talk about it openly and avoid using the word "cancer". If it's hard to talk about cancer within your community, you could ask a community leader or Elder to help you, or call Cancer Connect 13 11 20.

Telling family and friends

Telling people you have cancer can be hard. You might worry about how your family and friends will react, and want to protect them. Sharing this news in your own way can prevent confusion and give others a chance to support you. To prepare for these conversations, you could:

- pick a quiet time and place to talk, if possible
- decide if it's best to talk in person, or by phone or text
- ask someone close to join you when you tell others.

Keep in mind that people may get upset when you tell them about your diagnosis, and you might end up comforting them. This can be exhausting, so give yourself time and space, and consider telling only a few people at a time. And remember that it's okay not to tell everyone.

Telling children that a parent, sibling or another person has cancer can be extra tough. Our *Talking to Kids About Cancer* booklet has tips for having conversations with children and teenagers.

For information about telling your workplace about a diagnosis, see page 43.

If you don't want to tell people yourself, ask a close friend or family member to do it. They also might set up a group chat to share updates. If you're unsure what to say, you can speak to your hospital social worker or call Cancer Connect 13 11 20.

Help from others can make a big difference after a cancer diagnosis. People often want to support you but might not know how. Let them know what you need, such as a lift, shopping, or just a chat. You can use apps such as Gather My Crew (gathermycrew.org.au) to organise help.

If the cancer is advanced

Finding out the cancer is advanced (stage 4 or metastatic) when it's first diagnosed can be devastating. Treatment for advanced cancer is improving all the time, and sometimes it can be controlled for many months, years or a lifetime. Treatment will be focused on supporting people to do the things that are important to them. Setting personal goals, like spending time with family and friends, will be an important part of treatment. You may also be referred to a palliative care team.

MORE INFORMATION

To find out more about coping with cancer see:

- *Emotions and Cancer*
- *Talking to Kids About Cancer*
- *Living with Advanced Cancer*

Or listen to our podcasts:

- "Coping with a Cancer Diagnosis"
- "Cancer Affects the Carer Too"
- *Finding Calm During Cancer* series

Call **Cancer Connect 13 11 20** for free booklets. To find all our resources, visit **cancerconnect.org.au.**

See pages 49–51 for information and support services. Information is also available for Aboriginal and Torres Strait Islander peoples, in community languages and in Easy Read format.

NEXT STEPS

- It's important to take care of your general health while getting cancer treatment. Adopting healthy habits can also support your recovery.

Looking after yourself

Taking care of your general health before and during cancer treatment can help you to cope with cancer symptoms and treatment side effects. It can also support your recovery. If you're feeling unwell, it can be hard to make big changes to how you live, but even small changes can help.

Getting ready for treatment

Taking steps to improve your general health before treatment can help reduce side effects and support recovery. Even small steps can make a difference, so just do what you can.

You may need to wait a few weeks to start treatment, so you might have time to change some daily habits. See opposite page for suggestions. If you need to start treatment immediately, there are still usually simple changes you can make to improve your health.

Some cancer treatment centres and hospitals offer special programs to improve general health. These are called prehabilitation or “prehab” programs. These programs may be available for people having surgery or stem cell transplants.

If you don’t have access to these programs, your GP or cancer care team may suggest simple changes to your daily habits. If your GP refers you to an allied health professional (e.g. dietitian, physiotherapist, psychologist), you may be eligible for a Medicare rebate for 5–10 sessions each calendar year. Ask your GP for details.

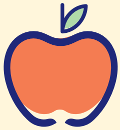
Taking care of your heart

Cancer and heart disease share many risk factors, and some cancer treatments can affect the heart. Making some simple changes to your lifestyle can help you to better manage treatment and protect your heart (see opposite page).

You may need to have heart and lung tests before some treatments. If you already have heart problems, you may need to see your cardiologist before starting cancer treatment.

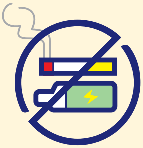
Tips for improving your general health

You may not be able to make big changes, but every small change to your daily habits can help.



Eat a balanced diet

Try to include foods from the 5 food groups – vegetables and legumes, fruit, wholegrains, meat and dairy and their alternatives. Eating well can help your body cope with side effects and speed up recovery. Avoid extreme diets or cutting out whole food groups at this time. Your doctor may suggest you see a dietitian.



Quit smoking and vaping

If you smoke or vape, aim to quit before starting treatment. Quitting smoking may improve your treatment results. See your doctor or call the Quitline on 13 7848 for support.

Start or keep moving

Being active can help reduce treatment side effects and support recovery. Talk to your doctor, exercise physiologist or physiotherapist about an exercise plan. Even small increases in your physical activity levels can be good for your health.

Drink less alcohol

Alcohol can increase the risk of complications. If you do drink, limit use and follow the Australian Government's guidelines (nhmrc.gov.au/health-advice/alcohol). If you do not drink alcohol, it's best not to start.

Talk to someone

A counsellor or psychologist can help manage emotions after diagnosis and treatment. Ask your GP about a mental health plan or call Cancer Connect 13 11 20 to find out about our support services.

Relationships, sex and fertility

Having cancer can affect your relationships with family, friends and co-workers in different ways. It's natural to feel stressed, tired and emotional, and this may strain relationships.

The experience of cancer may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening and do the same for those around you. Sharing how you feel with others can help. Call Cancer Connect 13 11 20 for support in managing personal relationships during cancer.

Effects on intimate relationships

Cancer can affect sex and intimacy in physical and emotional ways. How it affects you depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual activity may not always be possible, other ways of maintaining closeness and intimacy are important.

Contraception and fertility

If you're sexually active, you may need to use certain types of contraception to protect your partner or prevent pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility temporarily or permanently. If having children is important to you – now or in the future – discuss the options with your doctor before starting treatment. You may be referred to a fertility unit.

The Look Good Feel Better program can help you manage the appearance changes of cancer treatment and feel more confident. Call 1800 650 960 or visit lgfb.org.au.

Complementary therapies

Complementary therapies may be used alongside conventional medical treatments. Therapies such as massage, meditation and acupuncture may reduce anxiety and improve your mood. Tell your doctor about any therapies you are using or thinking about using, to be sure they are safe and supported by evidence.

Alternative therapies are those used instead of conventional medical treatments. These are unlikely to be scientifically tested, may prevent successful treatment of the cancer and can be harmful. Cancer Council does not recommend the use of alternative therapies as a cancer treatment. Talk to your cancer care team before trying any alternative therapies.

MORE INFORMATION

To find out more about looking after yourself see:

- *Nutrition for People Living with Cancer*
- *Exercise for People Living with Cancer*
- *Emotions and Cancer*
- *Understanding Complementary Therapies*
- *Understanding Heart Health and Cancer*

Or listen to our podcast series:

- *The Thing About Cancer*
- *Finding Calm During Cancer*

See pages 49–51 for information and support services.

Call **Cancer Connect 13 11 20** for free booklets. To find all our resources, visit **cancerconnect.org.au.**

NEXT STEPS

- Once the doctor has checked the results of tests and scans, they may talk to other health professionals about the best way to treat the cancer. Your doctor will then talk to you about your treatment options. See pages 30–36 for information about treatment.

What treatment might you have?

Cancer treatments have improved in recent years. Some cancers that used to be difficult to treat can now be treated or better managed.

Sometimes, treatment can remove the cancer completely. This is called “curative treatment”.

If the cancer has spread and curative treatment is not possible, treatment may focus on managing symptoms and slowing the spread of the cancer. This is called “palliative treatment”.

When cancer has responded well to initial treatment, further treatment may be used to stop it from growing. This is called “maintenance treatment”; it may be used over a long period of time.

Sometimes, only one treatment is used, but often therapies are combined to make them more effective. In some cases, a different type of treatment is given before or after the main treatment. This is called:

- **neoadjuvant treatment –** given before the main curative treatment such as surgery. For example, chemotherapy may be used to shrink a cancer and make it easier to remove with surgery.
- **adjuvant treatment –** given after main curative treatment to reduce the chance of the cancer coming back.

If you’re unsure about anything, it’s important to ask your specialist questions. For a list of suggested questions, see page 54. You may also want to get a second opinion. For more information, see page 32.

Making treatment decisions

When test results are ready, you'll have to make decisions about how the cancer will be treated. The doctor will recommend treatments based on several factors, including:

- the type of cancer you have
- where the cancer began
- whether it has spread
- your age and general health
- your preferences.

The doctor will also consider the available treatments and what clinical guidelines suggest. Clinical guidelines recommend tests and treatments for various types of cancer based on evidence. Your doctor may also discuss your treatment plan with other specialists as part of a multidisciplinary team (see page 10).

Sometimes, it's difficult to make decisions about treatment. You may feel that everything is happening too fast. Ask your doctor how soon your treatment needs to start, and take as much time as you can to understand your options before making a decision.

You can accept or refuse any treatment offered. Some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit. Others choose not to be treated.

If you live in a rural or regional area

Living in a rural and regional area may mean you need to think about where to have treatment. Australia has excellent regional cancer centres and hospitals that treat many different cancers, but specialists there may see fewer rare cancers. You also might have to wait longer to see a visiting specialist.

If you're worried about waiting times or access to certain treatments, ask your cancer care team about your options. They may suggest that you have specialised treatment in a larger centre. You may be able to get help with travel costs (see page 45). It also might be possible to use telehealth for some consultations.

If your local hospital or cancer centre can give you the same care, you might not be able to have treatment elsewhere in the public system. Your cancer care team will help you find the best option.

Getting a second opinion

If you have concerns or doubts about your diagnosis or treatment, you may want to talk to another specialist. This is called a second opinion.

A second opinion may reassure you that you're on the right track. It can help if you have to choose between a higher risk treatment with a better chance of success and a lower risk option that may be less effective.

Not everyone wants a second opinion. Some people feel nervous about asking for one, but doctors are used to it. They can't treat you differently because you ask to talk to another specialist. You can get a second opinion and still stay with your first doctor, or you may decide to change to the second doctor.

If you need help finding a doctor for a second opinion, ask your cancer specialist, GP or cancer care team. Keep in mind that getting a second opinion may delay the start of treatment. There may also be extra costs in seeing a second specialist.

Joining a clinical trial

A clinical trial helps show whether a new way of preventing, screening, diagnosing or treating cancer works better than current methods and is safe. If the new way is shown to work better than the existing method, it may become available.

All trials have rules about who can take part (eligibility criteria), and there may not always be a trial that suits your situation.

People join clinical trials for different reasons. You may want access to a new treatment that isn't yet available as part of standard care. You may also want to help improve cancer care for others.

Your doctor or nurse may suggest a clinical trial that may be suitable for you, or you can find information at australiancancertrials.gov.au. Waiting rooms often have information about current studies, or you may hear about a trial through support groups or in the media. If you find a trial that you're interested in, ask your doctor if it might be an option for you.

Surgery

What it is – Surgery removes cancer from the body or repairs a part of the body affected by cancer. It usually involves one or more cuts in the body (incisions). It may be called a procedure, operation or resection.

How it's given – Surgery can be done in 3 main ways:

- open surgery – the surgeon removes the cancer through one or more cuts (incisions) in the body
- keyhole surgery – the surgeon makes a few small cuts and inserts a camera to see the cancer and remove it safely. Also called laparoscopic or minimally invasive surgery
- robotic surgery – a type of keyhole surgery where the surgeon uses a robotic system to assist the procedure.

Depending on the type of cancer and surgery, it may be a day procedure or you may need to stay in hospital longer. You may have a general anaesthetic (puts you to sleep) or a local one (numbs part of your body).

Radiation therapy (radiotherapy)

What it is – Radiation therapy uses a controlled dose of radiation to kill cancer cells or damage them so they cannot grow, multiply or spread.

How it's given – Radiation therapy may be given in 2 main ways. For some cancers, both types are used:

- external beam radiation therapy – delivers radiation from outside the body using a machine called a linear accelerator
- internal radiation therapy – delivers radiation inside the body. A source of radiation is placed in the body next to or inside the cancer. This may be temporary or permanent. The most common type of internal radiation therapy is called brachytherapy.

Drug therapies

Many types of cancer are treated with medicines that circulate throughout the body. These are also called systemic or drug treatments. The main types are chemotherapy, targeted therapy, immunotherapy and hormone therapy.

Chemotherapy

What it is – Chemotherapy uses drugs that kill or slow the growth of cancer cells. It's sometimes called chemo.

How it's given – Chemotherapy is usually injected slowly into the bloodstream using a thin tube inserted into a vein in the arm (intravenous or IV). A central venous access device (CVAD) may be used so the tube can stay in place during the treatment course. This may be a PICC line or port-a-cath ("port"). Chemotherapy is given in cycles. This means you have the treatment, then a break before the next dose. It can also be given as tablets you swallow or as a cream.

Targeted therapy

What it is – Targeted therapy uses drugs that target specific features of cancer cells to stop the cancer growing and spreading. These drugs destroy cancer cells, while limiting damage to healthy cells.

Targeted therapy only works for some cancers with certain gene or cell changes. Tests are usually needed to see if the cancer will respond to targeted therapy (see page 13). It may be used alongside chemotherapy.

How it's given – Targeted therapy may be given as tablets or capsules you swallow or through a thin tube inserted into the arm (intravenous or IV). Sometimes, a central venous access device (CVAD) is used. Targeted therapy may also be given as an injection under the skin.

“My diagnosis of oesophageal cancer came as a complete shock. I had chemotherapy and radiation therapy to shrink the tumour and then went home to recover for 6 weeks before surgery.” JOHN

Immunotherapy

What it is – Immunotherapy uses the body’s own immune system to fight cancer. There are several different types of immunotherapy. The main types are called checkpoint inhibitors.

How it’s given – Checkpoint inhibitors are usually given through a thin tube inserted into a vein in the arm (intravenous or IV). These drugs are usually given in cycles. This means you have the treatment, then a break before the next dose.

Hormone therapy

What it is – Hormone therapy may be used to treat cancers that grow because of certain hormones (hormone-dependent cancers). It may be known as androgen deprivation therapy, endocrine therapy or hormone-blocking therapy.

How it’s given – Hormone therapy is usually taken as tablets you swallow or given as injections into the muscle or under the skin.

There are medicines available to help manage some side effects that may happen with treatment. Tell your cancer care team about any side effects or changes. There might be other medicines that can help you feel better.

Tumour ablation

What it is – Tumour ablation destroys the cancer without removing it from the body. Heat is usually used to treat the cancer (called thermal ablation). Sometimes, extreme cold is used instead (called cryotherapy).

How it's given – In thermal ablation, the heat is delivered to the tumour using radio waves (radiofrequency ablation or RFA) or microwaves (microwave ablation or MWA). A needle is inserted into the cancer and applies heat directly to the tumour, so it can be destroyed without harming healthy tissue. Cryotherapy is given in a similar way.

MORE INFORMATION

To find out more about cancer treatments, see our resource about the cancer you have or one of our treatment resources:

- *Understanding Chemotherapy*
- *Understanding Radiation Therapy*
- *Understanding Surgery*
- *Understanding Targeted Therapy*
- *Understanding Immunotherapy*
- *Understanding Clinical Trials*

Call **Cancer Connect 13 11 20** for free booklets. To find all our resources, visit **cancerconnect.org.au.**

Or listen to our podcast episodes:

- "Making Treatment Decisions"
- "New Cancer Treatments – Immunotherapy and Targeted Therapy"

See pages 49–51 for information and support services. Information is also available for Aboriginal and Torres Strait Islander peoples, in community languages, and in Easy Read format.

NEXT STEPS

- Finding your way around the health care system can be challenging, particularly when you have cancer. Understanding how the health care system works can help you get the care you need.

Finding your way in the health system

Health care systems can feel complex and hard to navigate, particularly when you're dealing with the physical, emotional and financial concerns of cancer. In Australia, you can have medical treatment in the public system or in the private system. Some people use a mix of public and private services.

Public health care

Australia's public health system helps you to have affordable care. Some services are free in the public system, but you will probably still need to pay some costs yourself (see page 44). You can choose to be treated in

Public hospitals

Public hospitals and some community-based services provide free or low-cost care for people with a Medicare card (see below). If you're being treated as a public patient in a public hospital, you can't choose your doctor or other members of your health care team. Treatment is based on your needs, so you may have to wait longer for care than a private patient, but this isn't always the case.

Medicare

The Australian Government fully or partly covers the cost of a range of many medical services including cancer care. Medicare may cover some or all the cost of:

- visits to GPs and specialists outside the hospital
- certain tests and scans used in cancer diagnosis (see pages 11–15)
- some medical services provided in private hospitals.

Medicare Safety Net

Once your gap payments for health care outside the hospital add up to a certain amount, Medicare will pay a higher benefit for the rest of that calendar year. For details, call Medicare on 132 011 or visit servicesaustralia.gov.au/what-are-medicare-safety-nets-thresholds.

What if you don't have a Medicare card?

If you're not a permanent Australian resident and don't have a Medicare card, you may need to pay the full health care costs. Some people can still get public health care, including refugees and eligible asylum seekers, as well as people from countries with reciprocal health care agreements (where 2 countries agree to provide visitors with health care).

the public system even if you have private health insurance (see page 40). It's your decision. You can also have some care in the public system and some in the private system.

Bulk-billing

Some GPs and specialists accept the Medicare benefit as full payment for a service. This is called bulk-billing, and it means you don't need to pay anything. To find GPs and specialists who bulk-bill, visit healthdirect.gov.au/australian-health-services. Not all doctors bulk bill, so you'll need to pay the difference between the Medicare fee and the doctor's fee. This is called a gap payment (see page 41).

Pharmaceutical Benefits Scheme (PBS)

Many cancer medicines are expensive. The PBS covers all or part of the cost of many prescription medicines for people with a current Medicare card.

If you're treated as a public patient in a public hospital, the PBS pays for most medicines. This means these drugs are free. You might need to pay a small amount (dispensing fee) for some medicines you take home. If you're a private patient, you may have to pay part of the cost of PBS medicines, but the overall cost will be capped under the PBS Safety Net (see below).

Some new cancer drugs are not funded by the PBS, but you still may be able to have them (see page 41).

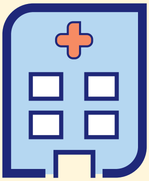
PBS Safety Net

The PBS Safety Net further reduces the cost of PBS medicines once you or your family have spent over a certain amount on medicines each year (the threshold). For details, call 1800 020 613 or visit servicesaustralia.gov.au/pbs-safety-net-thresholds.

Private health care

Some people prefer to be treated as a private patient so they can choose their own doctor and avoid potentially longer waiting times for treatment. Most people who use private health care have private health insurance.

Private hospitals and health services



Private doctors, hospitals and other providers set their own fees. Private health insurance may pay part of the bill. For some treatments, Medicare may also cover part of the cost.

You'll probably still need to pay some money yourself. This is known as a gap payment (see opposite page). You may also be charged for things such as your hospital room, operating theatre fees and medicines.

Before treatment starts, your cancer care team will explain what costs you need to pay. This is called informed financial consent (see page 42).

Check with your private health insurer about what your policy covers.

Private health insurance

Ask what your policy covers. If you've joined recently, there may be a waiting period. Private health insurance does not pay for out-of-hospital services that Medicare covers (e.g. GP visits). It doesn't usually cover radiation therapy, which is mostly given as outpatient treatment.

Thinking about the costs

Before being treated as a private patient, it's good to ask:

- your doctor for a written estimate of their fees, who else will care for you (e.g. an anaesthetist) and how you find out what their fees will be
- your private health insurer what costs they'll cover
- the hospital if there are any extra treatment and medicine costs.

Your private health insurer may have arrangements with certain doctors and hospitals (medical gap scheme). Using these services can cut costs.

Drugs not on the PBS

Doctors may recommend a drug that's not on the PBS. This is called a private prescription. These drugs are often very expensive, and you may need to pay the full price for them. This cost will not count towards the PBS Safety Net.

Some private health insurance policies may cover part of the cost of a private prescription. Check with your fund.

You also may be able to access non-PBS drugs by joining a clinical trial (see page 32) or through a compassionate access scheme. This is when a drug company is willing to provide a drug to a patient for free or at reduced cost.

Gap payments

Some doctors don't bulk-bill, so you'll have to pay the difference between the Medicare benefit and the consultation fee.

It's often up to the doctor to set their fee, and different doctors set different fees. When you make an appointment with your doctor, ask if there'll be a gap payment and what it will be. Keep in mind that a doctor with a larger gap payment is not necessarily any better than another doctor with a lower gap payment.

> *"If you want to have radiation therapy in the public system after private surgery, tell your surgeon at the time of surgery and you'll go on the waiting list. By the time you're ready for radiation therapy after surgery, you should have a place."* ONCOLOGY NURSE

Informed consent

To help you make a decision that's based on your values, your doctor must give you information about:

- what the proposed treatment involves and how it may help
- other treatment options
- possible side effects and risks
- any likely out-of-pocket costs (called informed financial consent).

Information is usually given in English. If you need an interpreter, tell your doctor or call the free interpreter service TIS National on 131 450.

When you understand this information and agree to treatment, this is called informed consent. You'll usually be asked to sign a document to show that you understand the information you are given and agree to treatment. If you're confused or need more information, talk to your doctor or someone in your cancer care team.

MORE INFORMATION

For a general overview of what Medicare and private health insurance may cover, visit privatehealth.gov.au.

You can also use the Medical Costs Finder for a guide on what certain cancer tests, scans and treatments might cost in your area. Visit medicalcostsfinder.health.gov.au.

For information and support, call our Cancer Connect service on 13 11 20.

NEXT STEPS

- ► Understanding how cancer can affect your finances and work is an important first step to reducing money worries.

How might work and finances be affected?

Cancer can make it hard to work or do everyday tasks. Many people are still in the workforce when they're diagnosed. Some keep working, while others need time off or stop working altogether. Some people change careers. People caring for family members may need extra help at home.

Managing work

Whether you can work during and after treatment depends on many factors, including how you're feeling and the type of work you do. Ask your doctor about how cancer and treatment may affect your work. They can provide a letter to your employer explaining the likely impact.

Telling your employer about your diagnosis is up to you. You don't have to by law, but you do need to let them know if anything could make it harder to do your work or pose a safety risk to you or others. It's illegal for employers to discriminate due to cancer and its treatment. You can talk to your employer about:

- **Workplace changes –** Your employer may need to make changes to help you keep working. These are called reasonable adjustments; examples include changing your hours or adjusting your workload.
- **Leave –** You may be able to take paid sick leave, annual leave or long service leave, or unpaid leave.

> *"At the time of the diagnosis, I was working as an office manager, but afterwards we reassessed our life. I now work in aged care, which I love."* JODIE

Working during treatment may offer more than income; it can provide routine, a sense of a normal life and social interaction. If you can't continue to work, try to find other ways to organise your day and stay in touch with others.

Managing your finances

Cancer can make earning money harder and it can increase your expenses. Even with Medicare or private health insurance, you may still have to pay some costs yourself.

Out-of-pocket costs you may have include:
- gap payments for GPs and specialists
- scans or tests not covered by the public system
- hospital or surgery fees
- medicines and dressings
- visits to physiotherapists, dietitians or other therapists
- travel, parking and accommodation
- child care
- general help at home.

Where to get financial support

Many people worry about money when dealing with cancer. There are different professionals who may be able to provide assistance. You can call Cancer Connect 13 11 20 to ask for support and they may be able to refer you to financial support services.

> *"You hear that once people are in a credit trap, they can't get out of it. I called Cancer Council and ended up speaking to a financial counsellor. She helped me sort things out with the bank."* VINCENT

Other sources of income

If you have to stop working because of cancer, you may be able to get financial support in different ways.

Government benefits – The Australian Government provides a range of payments through Centrelink for people with cancer and their carers. To check if you're eligible for payments, ask your social worker or visit servicesaustralia.gov.au.

Insurance – You may have personal insurance policies (e.g. income protection or total and permanent disability insurance) or insurance through your superannuation. If your policies cover your situation, it may be helpful to seek financial advice, as time limits to make a claim may apply.

Superannuation (super) – In Australia, you can access your super after the age of 60. You usually need to be retired if aged under 65. You may also be able to access super early in certain circumstances, such as to pay for medical treatment or severe financial hardship. Talk to your super provider or a financial professional for advice.

Help paying for travel and accommodation

Every state and territory government has a scheme to help with the cost of travelling long distances for specialist medical treatment. Many schemes also help with accommodation costs, if needed. The eligibility rules are different in each state and territory. In general, you must be a permanent resident of the relevant state or territory and also need to travel a significant distance to the closest specialist treatment. Ask a hospital social worker for more details or call Cancer Connect 13 11 20.

> *“When my treatment finished, I couldn’t wait to get back to work. I wanted to return to something normal. I went back part-time and that helped me take my mind off things.”* KATE

Planning ahead

There are some other legal steps, such as advance care planning, making a will and appointing a guardian, that can help your family if you become seriously ill. Having plans in place can give you peace of mind and make sure your wishes are known and followed. If you need help with making a will or other legal matters, Cancer Council may be able to refer you to a qualified lawyer. Call Cancer Connect 13 11 20.

MORE INFORMATION

To find out more about managing work, finances and other practical impacts of cancer, see:

- *Cancer and Your Finances*
- *Cancer, Work and You*
- *Insurance and Cancer*
- *Superannuation and Cancer*

See pages 49–51 information and support services. Information for Aboriginal and Torres Strait Islander peoples, in community languages, and in Easy Read format is also available.

Call **Cancer Connect 13 11 20** for free booklets. To find all our resources, visit **cancerconnect.org.au.**

NEXT STEPS

- Cancer affects the whole family. Your family member or you may take on the role of a carer.

Caring for someone with cancer

When someone close to you – a partner, family member, child, friend or neighbour – is diagnosed with cancer, they often need extra support. People who provide ongoing unpaid care and support to a person with an illness are known as "carers". You may not think of yourself as a carer, but as someone simply helping a person in need.

Caring includes a range of tasks from going to medical appointments and preparing meals, to offering emotional support and managing paperwork, such as paying bills.

Caring for someone with cancer can be meaningful and rewarding, but it can also be tiring and demanding. While you're busy looking after someone, you may ignore your own needs. But it's important to look after yourself too, and ask for help if you need it.

Looking after yourself

If you don't have a regular GP, it's a good idea to find one. A GP can help you to take care of your own health needs. It can help to share caring tasks with others (e.g. household chores, driving the person to appointments, updating family and friends). Using an app like Gather My Crew can help you to share the load (see page 52).

As time goes on, it might be a good idea to take a break from caring. Respite care can be for a couple of hours, overnight or for several days. Carer Gateway provides information on respite options, including emergency respite (see page 52).

> *"I decided I had to swim daily. I had a roster of friends who looked after my wife for an hour every morning."* ROB

Support for carers

- **Peer support –** You can connect with other carers through support groups and other peer support services. Call Cancer Connect 13 11 20 to find out about the options.
- **Financial help –** You may be able to get payments from the government. Call Cancer Connect 13 11 20 to find out more.
- **Practical help –** Carer Gateway and Cancer Connect may help with information, support services or referrals. See page 52.
- **Support for children and teens –** When a parent has cancer, a child or teenager may have to take on some caring duties. Cancer Hub offers support for families. See page 52.

MORE INFORMATION

To find out more about caring roles and support, see:

- ► *Caring for Someone with Cancer*

Or listen to our podcast episodes:

- ► "Cancer Affects the Carer Too"
- ► "How to Help Someone with Cancer"

See the next chapter for information and support services.

Call **Cancer Connect 13 11 20** for free booklets. To find all our resources, visit **cancerconnect.org.au.**

NEXT STEPS

- ► There are many sources of information and support for people with cancer and their carers, family and friends. When you feel ready, take some time to explore what's available. These services can help to make life a little easier.

Seeking support

Being diagnosed with cancer can feel frightening and isolating. But you're not alone. There are many sources of information and support to help you, your family and carers.

Cancer Connect – From diagnosis, through to treatment and beyond, our Cancer Connect service can help you find the information and support that is right for you. The service is free and confidential. Call 13 11 20 to speak with us, or visit our website at cancerconnect.org.au.

Cancer-specific support organisations – Depending on the cancer type you have, various organisations may offer support and information (see page 53 for contact details).

Government support – Federal, state or territory programs may help with income support, travel costs (see page 45), and medical aids and appliances.

Talk to your GP, nurse or social worker about your support options.

Other types of support

You also may be able to get help with:

- home care services (e.g. Meals on Wheels, visiting nurses, home help)
- support groups and programs
- counselling services.

The availability of services will vary depending on where you live. Some services will be free, while others may have a cost.

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

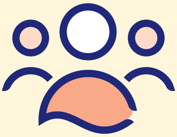
Cancer Connect 13 11 20

Our Cancer Connect service can help answer any questions you have about your situation and link you to local services (see inside back cover).

Legal and financial support

If you need advice on legal or financial issues, we may be able to refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Connect 13 11 20.

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.

Information resources

Cancer Council produces booklets and fact sheets on more than 40 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit cancerconnect.org.au.

Practical help

Cancer Connect can help you find ways to manage the practical impacts of cancer. This can include connecting you with services, such as accommodation and transport services.

For your community

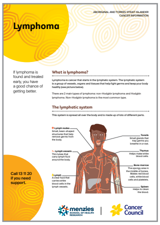
A cancer diagnosis can feel isolating. Cancer Council has developed information for various communities to provide more tailored support.

Aboriginal and Torres Strait Islander peoples – A series of easy-to-understand fact sheets on key cancer topics has been produced together with Aboriginal and Torres Strait Islander peoples.

Easy Read resources – These booklets use pictures and simple words to make the information easier to understand. The series also includes a short video about being told you have cancer.

LGBTQI+ people – Our *LGBTQI+ People and Cancer* booklet answers common questions LGBTQI+ people may have after a cancer diagnosis.

Information in other languages – Resources are available in some community languages. Call 13 11 20 or visit cancerconnect.org.au for details on languages included. If you need an interpreter, call the free interpreting service TIS National on 131 450.



ABORIGINAL AND TORRES STRAIT ISLANDER CANCER INFORMATION

Lymphoma

If lymphoma is found and treated early, you have a good chance of getting better.

What is lymphoma?

Lymphoma is cancer that starts in the lymphatic system. The lymphatic system is a group of vessels, organs and tissues that help fight germs and keep your body healthy (see picture below).

There are 2 main types of lymphoma: non-Hodgkin lymphoma and Hodgkin lymphoma. Non-Hodgkin lymphoma is the most common type.

The lymphatic system

This system is spread all over the body and is made up of lots of different parts.

Call 13 11 20 if you need support.

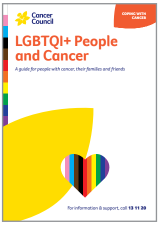
menzies SCHOOL OF HEALTH RESEARCH | Cancer Council

Cancer Council

EASY READ

Feelings and cancer

Visit our website: cancercouncil.com.au/easy-read



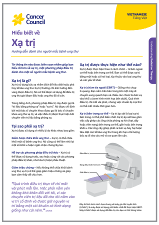
Cancer Council

COPING WITH CANCER

LGBTQI+ People and Cancer

A guide for people with cancer, their families and friends

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



Cancer Council

VIETNAMESE
Tiếng Việt

Hiểu biết về

Xạ trị

Hướng dẫn dành cho người mắc bệnh ung thư

Xạ trị là gì?

Tại sao phải xạ trị?

Xạ trị được thực hiện như thế nào?

"Quá trình điều trị thực tế chỉ mất vài phút mỗi lần. Việc phải nằm yên không khó khăn đối với tôi, vì các chuyên viên trị liệu đã cho tôi nằm vào vị trí cố định và được giữ nguyên vị trí bằng một cái khuôn có hình dạng giống như cái nêm."

If you live in a rural or regional area

Living in rural or regional areas can mean travelling long distances to get to doctors and support services. It can help to:

- get financial help for travel and accommodation (see page 45)
- ask if any appointments can be done using telehealth (your GP may help with this) to reduce the amount of travel you need to do
- join a local cancer support group, where you can share experiences
- keep a diary with treatment details and contacts for your cancer care team.

Useful contacts

Australia has a range of support organisations for people with cancer.

General support organisations

Cancer Connect Supporting everyone affected by cancer	13 11 20 **cancerconnect.org.au**
Beyond Blue Mental health information and support	1300 22 4636 **beyondblue.org.au**
Cancer Australia Australian Government organisation that aims to reduce the impact of cancer	**canceraustralia.gov.au**
Cancer Hub Support for families affected by cancer	1800 945 215 **cancerhub.org.au**
Carer Gateway Australian Government program providing free services and support for carers	1800 422 737 **carergateway.gov.au**
Cancer Voices Australia Represents people affected by cancer	**cancervoicesaustralia.org**
eviQ Evidence-based cancer treatment information	**eviq.org.au**
Finding My Way Online support for people with early-stage cancer	**findingmyway.org.au**
Gather My Crew Helps people coordinate care and support	**gathermycrew.org.au**
Inherited Cancers Australia Information about inherited cancers	**inheritedcancers.org.au**
Lifeline 24-hour crisis support service	13 11 14 **lifeline.org.au**
McGrath Foundation Cancer care nurses who provide clinical, psychosocial and emotional support	**mcgrathfoundation.com.au**

Cancer-type organisations

BEAT Bladder Cancer Australia	**beatbladdercanceraustralia.org.au**
Bowel Cancer Australia	1800 727 336 **bowelcanceraustralia.org**
Brain Tumour Alliance Australia	1800 857 221 **btaa.org.au**
Breast Cancer Network Australia	1800 500 258 **bcna.org.au**
Head and Neck Cancer Australia	1300 424 848 **headandneckcancer.org.au**
Leukaemia Foundation	1800 620 420 **leukaemia.org.au**
Liver Foundation	1800 841 118 **liver.org.au**
Lung Foundation Australia	1800 654 301 **lungfoundation.com.au**
Lymphoma Australia	1800 953 081 **lymphoma.org.au**
Melanoma Patients Australia	1300 884 450 **melanomapatients.org.au**
Myeloma Australia	1800 693 566 **myeloma.org.au**
NeuroEndocrine Cancer Australia	1300 287 363 **neuroendocrine.org.au**
Ovarian Cancer Australia	1300 660 334 **ovariancancer.net.au**
Pancare Foundation	1300 881 698 **pancare.org.au**
Prostate Cancer Foundation of Australia	1800 22 00 99 **pcfa.org.au**
Rare Cancers Australia	1800 257 600 **rarecancers.org.au**

Question checklist

Asking your doctor questions can help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of cancer do I have, and where is it located?
- What stage is the cancer? Has it spread beyond where it first started?
- Will I need any tests and scans?
- Are there lifestyle changes I should try to make before treatment?

Treatment

- What are the treatment options for the type and stage of cancer I have?
- What are the aims of each treatment (e.g. cure, control, symptom relief)?
- What are the potential side effects and risks?
- How soon do I need to start treatment?
- How will treatment affect my daily life?
- Are there any clinical trials that may be suitable for me?
- What is the likely outcome (prognosis) of the cancer?
- Will I need to see other specialists as part of my care?
- Will treatment affect my ability to have children in the future?
- How often will I need check-ups or scans during and after treatment?

Support

- What support services are available for me and my family?
- Who do I contact if I have questions or side effects between appointments?

Costs

- What are the out-of-pocket costs likely to be? Can you provide a written estimate of the doctors' fees, hospital costs and other treatment costs?
- Can I have the test or treatment in the public system? If I have the test or treatment in the private system, what will I have to pay?
- If I have treatment as a private patient, what costs will be covered by my private health insurance policy?
- Does the hospital or doctor have an arrangement with my private health insurer to help reduce my costs (e.g. medical gap scheme)?

Glossary

adjuvant treatment
A treatment given after the main treatment to lower the risk that the cancer will come back.

advanced cancer
Cancer that's unlikely to be cured. In most cases, the cancer has spread to other parts of the body. Treatment may help control the cancer and manage symptoms. Also called secondary or metastatic cancer.

anaesthetic
A drug that stops a person feeling pain during a medical procedure.

benign
Not cancerous or malignant.

cells
The basic building blocks of the body.

chemotherapy
A cancer treatment that uses drugs to kill cancer cells or slow their growth.

genes
Tiny units in cells that direct how the body grows and functions. Genes are inherited from both parents.

grade
A number that indicates how fast the tumour is growing.

hormones
Chemicals that carry messages around the body to help control things like growth.

hormone therapy
A treatment that blocks natural hormones, which sometimes help cancer cells grow.

immunotherapy
Drugs that use the body's own immune system to fight cancer.

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

metastasis (plural: metastases)
See advanced cancer.

neoadjuvant treatment
A treatment given before another treatment to make that treatment more successful.

radiation therapy (radiotherapy)
The use of targeted radiation (usually x-ray beams) to kill or damage cancer cells.

stage
How far a cancer has spread in the body.

surgery (operation or surgical resection)
A procedure to remove or repair part of the body.

targeted therapy
Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

tissue
A collection of cells of similar type that make up an organ or structure in the body.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary.

Reference

1. National Comprehensive Cancer Network (NCCN), *NCCN Clinical Practice Guidelines in Oncology: Distress Management*, Version 2.2025, NCCN, 2025.

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 connect

Cancer Council

For information & support,
call **Cancer Connect 13 11 20**
or visit **cancerconnect.org.au**

TIS TRANSLATING AND INTERPRETING SERVICE

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

National Relay Service

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

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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,
call **Cancer Connect 13 11 20**
or visit **cancerconnect.org.au**

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancer.org.au/tas

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

This booklet is funded through the generosity of the people of Australia.
To support Cancer Council, call 13 11 20 or visit cancerconnect.org.au.