



Cancer Care and Your Rights

A guide for people with cancer,
their families and friends

Practical
and support
information

For information & support, call

13 11 20



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Note to reader

Always consult your doctor about matters that affect your health, a financial adviser or financial counsellor about matters concerning your finances, and a lawyer about legal matters. 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 laws, regulations and entitlements that affect people with cancer may change. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

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



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About this booklet

This booklet is for people starting their journey through the health care system after a cancer diagnosis.

Knowing what you can reasonably expect of the health care system and your treatment team can help you work in partnership with your health care providers and take an active role in your care. This doesn't mean you are making demands of your treatment team – rather, it's about ensuring you have the information and support you need.

Everyone's experience will be different depending on their individual circumstances. We hope this booklet will help you, your family and friends find your way through the health care system.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some terms that may be unfamiliar are explained in the glossary (see page 69). You may also like to pass this booklet to family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health and legal professionals, and people using Cancer Council services.

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



**Cancer
Council**
13 11 20

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Patient rights and responsibilities

Knowing your patient rights and responsibilities may help you feel reassured that you are receiving safe, high quality health care. The *Australian Charter of Healthcare Rights*¹ sets out seven key rights for people needing health care. These rights cover access, safety, respect, partnership, information, privacy, and giving feedback – see pages 6–7 for more details. You have rights and responsibilities whether you are seeking care in the public or private health system.

Q: What are patient rights?

A: Patient rights are rules for people receiving medical care. Some rights are legally enforceable (see opposite); other rights are not protected by laws, but reflect what people can reasonably expect from their care providers.

Q: Why are rights important?

A: Understanding your rights and what you can reasonably expect of your treatment team and the health care system – and what can be expected of you – will help you find your way through the system and take an active role in your care. It's important that you feel comfortable to ask questions.

Care that responds to your needs, preferences and values, as well as the needs of your family and carers, is known as person-centred care. This means that your health care providers will respect your care goals, and involve you in decisions about your treatment and ongoing care. Working in partnership to make joint decisions about your care can lead to better outcomes.

Q: Are rights legally enforceable?

A: Some rights are legally enforceable, which means that laws exist to protect them. There are laws covering discrimination, medical treatment, the conduct of health professionals and the privacy of personal information.

These laws exist to ensure people have the right to safe and competent health care, the right to be free from unlawful discrimination, the right to refuse treatment, and the right to privacy. Health professionals and the health care system have a duty to follow these laws.

While some of the rights set out in the *Australian Charter of Healthcare Rights* may not be legally enforceable, they do reflect fair and reasonable expectations. For example, you may want a second opinion if you're unsure about the treatment a doctor has recommended. This means seeing another specialist for their view about your diagnosis and treatment. It is fair and reasonable to expect that your doctor will refer you to another specialist and share your test results with that person.

Many doctors openly encourage second opinions and help their patients to obtain them. However, some doctors don't, and there is no law that says they have to. Either way, you have a right to ask for a second opinion.

If your doctor is not helpful, you can find a second opinion in other ways. For more information, see *Getting a second opinion*, pages 30–31.

Rights in the Australian health care system

The *Australian Charter of Healthcare Rights*¹ describes your rights when using health care services. The Charter is under review and this information is based on the draft second edition released in January 2019. For more details, visit safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights.



Access

You have a right to receive adequate and timely services and treatment that meet your health care needs. These services will be free if you have a current Medicare card and are treated in a public hospital. You have the right to obtain a second opinion.



Safety

You have a right to receive safe, high quality, evidence-based care in an environment that is safe. If you are worried that something has been overlooked, talk with your health care provider. If required, you should receive instructions about how to safely care for yourself at home.



Partnership

You have a right to be involved in decisions about your treatment and ongoing care in partnership with your health care team. For example, you have the right to accept or refuse any treatment you are offered, and to decide whether to take part in medical research or participate in the clinical training of junior doctors and other students. If you don't want to receive care, you can leave a health facility at any time, at your own risk and liability. You have the right to include family members, friends and carers in your decision-making and meetings with doctors.



Respect

You have a right to have your care needs, preferences and values taken into account, and to be treated with dignity and respect. Services should be free from discrimination, regardless of age, disability, gender, race, religion and sexual preference.

Information

You have a right to receive all the information you need to be able to give informed consent for treatment. Health care providers should clearly explain the risks, benefits and costs of services, tests and treatment options. You can ask questions if you need more information. You can request free interpreter services if English is not your first language. You have the right to access your health information. If something goes wrong, you should be told about it and what is being done to fix it.



Give feedback

You have a right to give appropriate feedback or make a complaint, and for any concerns to be dealt with fairly and promptly.

Privacy

You have a right to privacy. Your personal and health information must be kept private and confidential (except in very limited circumstances). This includes discussions you have with health care providers, and your written and online medical records. You have the right to talk to your doctor in a quiet, private room, and to decline visitors, even during hospital visiting hours.



The *Private Patients' Hospital Charter* sets out the rights and responsibilities of private patients in public and private hospitals. Download a copy from health.gov.au.

Q: What are patient responsibilities?

A: To be effective, health care needs to be a two-way street. If you expect your health care providers to behave in a certain way – for example, to communicate openly – it helps to behave the same way in return. Your hospital or treatment centre might give you information about your responsibilities covering the following three areas.

Being considerate

These responsibilities relate to practical issues, including:

- treating staff and other patients with courtesy, dignity and respect
- being on time for appointments or letting the health service know if you are unable to attend an appointment
- following any policies about visiting hours, using mobile phones, smoke-free areas, etc.

Being honest and open

A key responsibility is to make sure your treatment team has all the information they need to offer the best treatment for you.

Be up-front and provide accurate details about your health. Tell your treatment team if:

- you have a question or problem – it's important that you talk about issues you don't understand or that are troubling you so your team can help
- there are factors in your life that might affect treatment decisions – for example, if you live alone, if you care for an elderly relative or a young family, or if you work or study
- you have side effects or pain – your team may be able to adjust the treatment or offer you medicine to relieve side effects

- you're seeing more than one doctor or another health professional for any part of your care – this includes complementary or alternative therapy practitioners
- you decide not to follow their advice – for example, by not taking the medicine they prescribe
- you are taking any other medicines – this includes prescription and over-the-counter drugs, complementary and alternative medicines, and bush medicines. Tell your treatment team even if you think the medicine is harmless. Some medicines interact with cancer drugs, causing side effects or reducing the effectiveness of the cancer treatment, and this can be harmful.

Being flexible

Your doctor recommends treatment based on your initial test results and your overall health. Depending on how you respond to the treatment you've agreed upon, your doctor may have to reassess the original treatment plan. It's important to be flexible and to accept that your treatment may change. If changes occur, you still have the right to be involved in making decisions about a new treatment plan (see page 27).

It's common to have to wait for tests and treatment in public hospitals. The length of time depends on many factors, including the type of cancer you have, its stage, the treatment you are having, and the hospital's schedule. Hospitals aim to treat people in turn but without waiting for periods of time that would harm treatment outcomes. Waiting for treatment can be stressful – if you are anxious or concerned speak to your doctor or call Cancer Council 13 11 20.



Health care in Australia

The health care system in Australia has two parts: the public health system and the private health system. People can often choose whether to be treated publicly or privately, and many people treated for cancer use a mix of public and private health services. Finding your way through this system can be challenging, particularly when you are dealing with the physical, emotional and financial impacts of cancer.

Public health care

The Australian Government provides free or subsidised medical and hospital services through Medicare to citizens and permanent residents of Australia. Medicare is also available to other people who meet certain requirements (e.g. some overseas visitors).

Under Medicare, you are entitled to free treatment as a public patient in a public hospital, even if you have private health insurance. However, you can't choose your doctor and you might have to wait for treatment.

Medicare also provides benefits for out-of-hospital services, such as visits to general practitioners (GPs), specialists and optometrists, but it doesn't cover dental (with exceptions), ambulance or private home nursing services (see *Paying for treatment* opposite). Some people are able to get a Medicare benefit for allied health services such as physiotherapy or psychology – talk to your GP for more information.

Public hospitals often provide a wider range of services than private hospitals, including emergency departments, specialist surgical and medical units, and allied health services. They usually provide services to patients both in hospital and through outpatient clinics.

Private health care

Many people prefer to be treated privately so they can choose their own doctor or health professional, and don't have to wait as long for treatment. Cancer care delivered in the private system includes:

- consultations with your oncologist, surgeon or GP
- cancer treatments (e.g. surgery, chemotherapy and radiation therapy)
- tests such as blood tests, x-rays and imaging scans
- services by allied health professionals.

Doctors, service providers and hospitals in the private sector can set their own fees. People may take out private health insurance to help cover the cost of hospital treatment as a private patient (see next page).

Paying for treatment

You have a right to know whether you will have to pay for treatment and medicines and, if so, what the costs will be. There may be fees you hadn't considered (e.g. if you have surgery as a private patient, there will be fees for your stay in hospital and for the anaesthetist).

Your doctors and other health care providers must talk to you about likely out-of-pocket costs before treatment starts. This is called informed financial consent.

Many people treated privately are surprised that they have to pay additional costs not covered by Medicare or their health fund. It is important to ask about out-of-pocket costs before treatment.





Visit privatehealth.gov.au/health_insurance/what_is_covered for a detailed list of hospital, specialist and pharmaceutical services covered by Medicare and private health insurance.

Private health insurance

Private health insurance is a contract between you and an insurance company (health fund) where you pay the company to help cover your future health care expenses. The amount you pay (the premium) and what is covered depends on your policy. You can choose to take out hospital cover as well as cover for extras such as dental, optical and physiotherapy treatments. There will usually be a waiting period after you take out a policy before you can claim benefits.

As a privately insured patient, you can choose your own doctor, and you can choose to be treated in a private hospital or as a private patient in a public hospital. You may have to pay some out-of-pocket costs. If you need help resolving a complaint with your health fund, the Commonwealth Ombudsman looks after private health insurance complaints and may be able to help (see ombudsman.gov.au).

Medicare Benefits Schedule (MBS)

The Australian Government sets fees for the medical services it subsidises through Medicare. The Medicare Benefits Schedule (MBS) lists how much Medicare will pay for each subsidised service (known as the Schedule fee). Some doctors charge more than the Schedule fee. The difference between the Schedule fee and the doctor's fee is called the gap fee. If a service is not subsidised by the MBS, you will have to pay the entire fee.

Fees for services in hospital

If you're treated as a public patient, Medicare pays for your treatment, medicines and care while you are in hospital, and for follow-up care from your treating doctor in an outpatient clinic.

For private patients in a public or private hospital, Medicare pays 75% of the Schedule fee for services provided by your doctor. If your doctor charges more than the Schedule fee, your health fund may pay the gap fee or you may have to pay it as an out-of-pocket cost. You will also be charged for hospital accommodation, operating theatre fees and medicines. Private health insurance may cover some or all of these costs, depending on your policy. You may have to pay an agreed amount of the hospital fee (an excess), depending on the type of hospital cover you have. Fees charged by private hospital emergency departments are not covered by Medicare or private hospital cover.

Before being admitted to hospital as a private patient, ask:

- your doctor for a written estimate of their fees (and if there will be a gap), who else will care for you (e.g. an anaesthetist or surgical assistant), and how you can find out what their fees will be
- your private health fund (if you belong to one) what costs they will cover and what you'll have to pay – some funds only pay benefits for services at certain hospitals
- the hospital if there are any extra treatment and medicine costs.

Health funds make arrangements with individual doctors about gap payments. Choosing to use the doctors and hospitals that take part in your health insurer's medical gap scheme can help reduce out-of-pocket costs.

Fees for out-of-hospital services

When making an appointment with a doctor or service provider, ask how much you will have to pay. Some doctors bulk-bill for their services, which is when they bill Medicare directly and accept the Medicare benefit as full payment. This means you don't pay anything for that appointment. Other doctors charge a consultation fee, which means you pay the account at the time of the consultation and then claim the Medicare benefit. The doctor's receptionist can often send the claim to Medicare when you pay the bill.

Generally, Medicare pays:

- 100% of the Schedule fee for GP visits
- 85% of the Schedule fee for visits to specialists
- 85% of the Schedule fee for approved imaging scans and blood tests.

You will have to pay any difference between what the doctor or service provider charges and the Medicare benefit. Private health insurance does not cover the cost of these out-of-hospital medical services.

Medicare also subsidises the cost of radiation therapy in private clinics. How much Medicare pays depends on your treatment plan. Ask your provider for information about out-of-pocket costs.

Medicare Safety Net

The Medicare Safety Net applies to out-of-hospital costs. Once your out-of-pocket costs go over a certain amount (called the threshold), Medicare will pay a higher benefit for eligible services until the end of the year. There are different thresholds depending on your circumstances:

- Individuals do not need to register for the Medicare Safety Net as Medicare automatically keeps a total of your expenses.
- Couples and families need to register for the Medicare Safety Net, even if you are all listed on the same Medicare card. Once you are registered, Medicare combines your medical costs so you are more likely to meet the threshold sooner.
- For more information about the Medicare Safety Net or to download the registration form, visit humanservices.gov.au and search for “Medicare safety net” or call Medicare on 132 011.



Ways to manage costs

- Ask your health care provider for a written quote for fees. If you receive a much higher bill, show them the quote and ask why the bill is higher.
- Ask your GP to refer you to a doctor in the public system.
- Private patients can consider switching to a doctor who charges less.
- You have the right to be treated as a public patient in a public hospital even if you have private health insurance. Before you are admitted, the hospital will ask whether you would like to be treated as a private or public patient.
- Some newer treatment options can be very expensive and may not offer more benefits than traditional approaches. Ask if other treatments would be as effective but cost less.
- If your doctor charges more than the Schedule fee, ask if they will consider an exception in your case.
- If you can't afford treatment, ask your doctor if the costs are negotiable – some doctors may agree to reduce their fees.
- Find out if you can pay in instalments or have more time to pay your bill. Check if you will be charged interest.

Medicines and the PBS

Many drugs – especially chemotherapy, targeted therapy and immunotherapy drugs – are expensive. The Australian Government's Pharmaceutical Benefits Scheme (PBS) subsidises the cost of many prescription medicines for people with a current Medicare card.

Concession cards and allowances

Some PBS medicines are cheaper for people with a Pensioner Concession Card, Commonwealth Seniors Health Card, Health Care Card or Department of Veterans' Affairs Health Card. You will need to show your card to the pharmacist when you get your prescription filled.

People who receive some Centrelink payments may be eligible for a Pharmaceutical Allowance, which can help to cover the costs of prescription medicines. For information and to check if you qualify, visit humanservices.gov.au.

PBS Safety Net

The PBS Safety Net further reduces the cost of PBS medicines once you or your family have spent a certain amount on them each year. This amount is known as the Safety Net threshold. When you reach the threshold, your pharmacist can give you a PBS Safety Net card, and your prescription medicines for the rest of the year will be discounted (or free if you have an eligible concession card). For more information, call the PBS Information Line on 1800 020 613 or visit pbs.gov.au.

Generic medicines

Your pharmacist may ask if you would like a generic brand of your prescribed medicine. Generic medicines contain the same active

ingredients as more expensive brands. The medicine may look different, but it still meets the high standards of quality, safety and effectiveness set by the Therapeutic Goods Administration, which regulates medicines sold in Australia. It is your choice whether to buy the generic or original brand.

Non-PBS prescriptions

Doctors may prescribe a medicine that is not on the PBS. This is known as a private prescription and you will need to pay the full price. It may cost more than PBS medicines and it will not count towards the PBS Safety Net. Private health insurance may cover some or all of the cost of a private prescription. Check with your insurer.



Paying for medicines

- Public patients in hospital do not pay for most medicines, including intravenous chemotherapy drugs, as the cost is covered by the PBS. Talk to your treatment team about whether you have to contribute to the cost of oral chemotherapy drugs.
- If you choose to be treated as a private patient, you may have to contribute to the cost of chemotherapy drugs. Check with your doctor and health fund before starting treatment.
- Some doctors only prescribe PBS medicines to make treatment affordable. Ask your doctor for every option – including private prescriptions – so you can make an informed decision about your treatment.
- You usually have to pay for medicines you take at home. Keep a record of your PBS medicines on a Prescription Record Form, available from your pharmacist, so you know when you've reached the Safety Net threshold.



Key points about health care in Australia

Health care system

You can often choose whether to be treated in the public or private health systems. Many people treated for cancer use a mix of health services.

Paying for treatment

- If you're treated as a public patient, Medicare pays for your care and treatment in hospital.
- You may choose to take out private health insurance to help cover certain medical expenses. Waiting periods may apply before you can claim benefits.
- If you are treated as a private patient, your health care providers should talk to you about how much your tests, treatments, medicines and hospital care will cost. This is called informed financial consent.
- Medicare also provides benefits for out-of-hospital services, such as GP visits and imaging scans. These may be bulk-billed or you may have to pay the bill and then claim the Medicare benefit.
- Once your expenses reach a certain amount (threshold), the Medicare Safety Net subsidises out-of-hospital costs.

Medicines and the PBS

- The Australian Government's Pharmaceutical Benefits Scheme (PBS) subsidises the cost of many prescription medicines.
- The PBS Safety Net also helps with the cost of medicines. Once you reach a certain threshold, your PBS prescriptions for the rest of the year will be discounted or free.



Your health care team

Doctors, nurses and other health professionals offer a range of services to assist you, your family and carers. They can help you find your way through the health care system, from diagnosis through to treatment and recovery.

The table on the next two pages describes the roles of the most common members of the treatment team. Not all of them will be in the hospital or treatment centre, and they may have different titles depending on where you have treatment.

Who can help?

You may think that your specialist is the only member of your treatment team who can answer your questions and address your concerns. It's your right to ask your specialist questions, but there is often limited time in a consultation, and you may want to use that time to talk about your treatment. Other members of your treatment team are often more available than your specialist, and they may be able to help more quickly with any questions and concerns you may have.

Advanced cancer issues

People living with advanced cancer may face additional issues to those discussed in this booklet. Cancer Council has free booklets about advanced cancer, palliative care and end-of-life issues, as well as fact sheets about getting your affairs in order, dealing with debts after death, and appointing an executor. Call **13 11 20** for more information or visit your local Cancer Council website.

Health professionals who can help

General practitioner (GP) or family doctor	Cancer specialist	Cancer care coordinator
<ul style="list-style-type: none"> • assists you with treatment decisions • refers you to specialists and can help arrange second opinions • works with your specialists in providing follow-up care after treatment • continues to see you for day-to-day health care issues • it is important to have a good relationship with a GP who knows you and your medical history • your GP's role may vary depending on where you live – for example, rural patients may have much more to do with their GP than people in urban areas 	<ul style="list-style-type: none"> • may be a medical oncologist, surgeon, radiation oncologist or haematologist • depending on the type of cancer you have, you may need to see several specialists who will look after different aspects of your care • diagnoses the cancer and supervises your treatment, follow-up and overall care • can also answer any questions you have about your treatment • usually works as part of a multidisciplinary team (see page 23) • if you are treated in hospital, junior medical staff such as registrars and resident medical officers, may be able to help you with questions and concerns 	<ul style="list-style-type: none"> • may be called a clinical nurse consultant or clinical nurse specialist • a senior specialist nurse who coordinates your care throughout diagnosis and treatment, and works closely with specialists and other members of the health care team • a reliable source of information and support • larger hospitals may have cancer care coordinators for specific cancer types, while smaller hospitals may have general coordinators • in rural areas, cancer care coordinators may attend with the visiting oncologist • in hospitals that don't have either a cancer care coordinator or a clinical nurse consultant, the nursing unit manager may have a similar role



Social worker	Physical therapists	Other health professionals
<ul style="list-style-type: none">• the primary point of contact for practical issues, such as accommodation, transport, financial support, child care, and home nursing care• assesses what sort of support you need, and identifies ways you can receive this support• will link you with the people and services best able to meet your needs• may provide counselling and emotional support• in some hospitals, may be called a welfare worker	<ul style="list-style-type: none">• physiotherapists help you to move and exercise safely to regain strength, fitness and mobility• exercise physiologists prescribe exercise to help people with medical conditions improve their overall health, fitness, strength and energy levels• occupational therapists offer equipment/aids and advice about getting back to your daily activities	<ul style="list-style-type: none">• psychologists or counsellors help you understand your emotional response to diagnosis and treatment, and come up with strategies for managing your concerns• dietitians may recommend an eating plan for you to follow during treatment and recovery to ensure you meet your nutritional needs; and give you tailored advice on coping with any eating problems you may experience• speech pathologists help you manage any communication and swallowing difficulties



Read our *Understanding Cancer* booklet on the type of cancer you have for more details about the health professionals you may see.



Deciding on specialist care

It is important that you feel comfortable and confident with your choice of specialist because you will have a lot of contact with them and they will influence your care. Some people are happy to leave the choice of specialist to their doctor. However, you have a right to be involved in this decision if you would like to be. You may prefer to choose a specialist based on recommendations from family, friends or colleagues, or from your own research.

Choosing a specialist

Under the Medicare system, you need a referral to see a specialist. This referral can come from a GP or another specialist.

You have the right to be treated as a public patient in any public hospital. If you are treated in the public system, you will be treated by the specialist appointed by the hospital. You might want to research public treatment centres that specialise in the type of cancer you have (see *Specialist centres*, page 24). Public hospitals may give priority to patients in their local area, so you may have to wait longer if you want to be treated in a hospital outside your area.

If you have private health insurance, you can choose to be treated as a private patient, or you can avoid out-of-pocket costs by being treated as a public patient in a public hospital (see pages 11–13).



You can find out about the performance of your local hospitals, including waiting times and infection rates, at myhospitals.gov.au.

“As soon as we met with the brachytherapy specialist, my wife and I looked at each other and more or less knew this was our guy. It was just a feeling – when he described the treatment, we felt confident.” *Derek*

Key issues to consider

There are a few issues to think about when deciding which specialist should be responsible for your treatment. Before visiting your cancer specialist for the first time, take some time to prepare for the appointment (see page 68 for some suggested questions).

Number of patients – Some specialists and treatment centres have particular expertise in treating certain types of cancer because they see a large number of patients and therefore have more experience. For some types of cancer, there is evidence that health professionals who treat a lot of patients have the best treatment outcomes.

Multidisciplinary care – There is evidence that patients do better if their doctor works as part of a multidisciplinary team (MDT). This means health professionals who specialise in different aspects of your care work together to plan treatment.

The MDT often includes a surgeon, a medical oncologist, a radiation oncologist, a cancer care coordinator, a nurse, and allied health professionals, such as a physiotherapist, dietitian and social worker (see pages 20–21). They meet regularly to review cases and consider treatment options. The team also discusses how best to help individuals cope with the physical and emotional effects of cancer.

Specialist centres – Another way to tap into expertise is to see if there are treatment centres that specialise in the type of cancer you have. These centres have many patients and also tend to treat rare cancers or cancers that don't have a typical response to treatment.

Specialist treatment centres have multidisciplinary teams of health professionals experienced in treating particular cancers. They are often teaching centres, which means you might be treated by a junior doctor who is supervised by a specialist. There could be long waiting lists for these centres.

The key principle is that it's your right to ask your GP or other doctors about specialist treatment centres and to be referred to a specialist in one of those centres, even if it's not in your local area.

Your preferences – You may prefer to see all your doctors at the one hospital, even if it is a long way from home, or to attend your local hospital to reduce travel time. It's your right to determine what is most important to you and your doctors should respect your preferences.

How to find a specialist

Ask your GP – Your GP will be able to refer you to a suitable specialist or treatment centre. Your GP should have clear reasons for their choice. You are entitled to ask about those reasons and to receive a clear answer – for example, is it because the specialist has particular skills or simply because they are nearby? You also have the right to ask your GP for a referral to more than one specialist (see *Getting a second opinion*, pages 30–31).

Search online – Check the websites of medical colleges for a list of specialists. For example, you can search for colorectal surgeons on the Colorectal Surgical Society of Australia and New Zealand’s website (cssanz.org). You can also check the registration status of a specialist on the national register of practitioners at ahpra.gov.au.

Contact the treating hospital or centre – The websites of many hospitals allow you to search for a specialist who works at that location. Alternatively, you can call the hospital and ask about specialists who treat the type of cancer you have.

If you live in a rural or remote area

In rural areas, your GP may refer you to a local specialist or treatment centre, or to a visiting oncologist. Depending on the type of cancer, they may recommend you travel to a centre that specialises in a particular treatment.

There are some excellent regional cancer centres in Australia, and some regional specialists treat many cancer patients. However, some regional specialists treat far fewer cancer cases than doctors in metropolitan areas, and there may be a long wait to see the visiting oncologist.

All state and territory governments have a patient travel assistance scheme. If treatment for your cancer type is not available close to home, you may be eligible for financial assistance to help cover the cost of travel to a suitable treatment centre. The scheme may also assist with the cost of accommodation.

For more information, see wiki.cancer.org.au/policy/Patient_travel_assistance_schemes, call Cancer Council **13 11 20** or talk to the hospital social worker.



Key points about your health care team

Who can help?

- A range of health professionals can help you cope with the physical and emotional effects of cancer, including your GP, cancer specialists, nurses and allied health professionals.
- Health professionals usually work together to plan and manage cancer treatment. This is called a multidisciplinary team (MDT).
- You may be referred to a specialist treatment centre that has particular expertise in treating the type of cancer you have.

Choosing a specialist

- Under the Medicare system, you need a referral to see a specialist.
- Your doctor should have clear reasons for referring you to a particular specialist. It is your right to ask about those reasons and to receive a clear answer.
- You can also suggest specialists based on recommendations from other people.
- You can ask to be referred to any specialist regardless of where they are located, however, public hospitals may give priority to patients in their local area.
- Ask the specialist about their experience, such as how many cases of this cancer type they have treated, whether they are a member of a specialist college, and whether they work in an MDT.
- It's your right to choose to have treatment close to home (if it's available) or to be referred out of your local area.



Making treatment decisions

Whether you have just been diagnosed with cancer or have cancer that has spread or come back, you will have to make a number of decisions about your treatment. It can be difficult to decide on the type of treatment to have. Ask your specialist to explain all the options and take as much time as you can before making a decision.

You have the right to accept or refuse any treatment you are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. Becoming informed about your options can help you and your specialist jointly decide on a treatment plan that is right for you.



If you're having trouble deciding on the best cancer treatment pathway, listen to our podcast on "Making Treatment Decisions" at cancercouncil.com.au/podcasts.

Gathering information

Making sure you understand enough about the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. You may feel that everything is happening so fast that you don't have time to think things through. You have the right to delay your decision until you feel you have had enough time to consider all your options. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while.

It is a good idea to have a family member or friend go with you to specialist appointments to join in the discussion, write notes, ask questions or simply listen. If you are confused or want to check anything, it is important to ask your specialist questions. Try to take a list of questions to the appointment (see page 68 for suggestions).

You might like to ask if you can record the consultation – some treatment centres provide recording equipment, or you might have to take your own (many mobile phones have a recording function).

Decision-making steps

Each person's situation is different – not everyone with the same type of cancer will make the same decisions about treatment. It may help to:

- weigh up the advantages and disadvantages of each treatment, and whether it will help you meet your treatment goals
- ask if other treatments are an option (if only one type of treatment is recommended)
- consider how side effects might affect you, especially if they will have an impact on your lifestyle, sexuality, fertility, or ability to work; if you have a partner, it may help to discuss any side effects with them
- find out more about the treatment choices offered to you by speaking to your specialist, cancer care coordinator or Cancer Council 13 11 20; getting a second opinion (see pages 30–31); contacting cancer support groups; and talking to family, friends or people who have had the same cancer
- share your concerns with your doctor or the treating hospital if you're not happy with the information you are given or how it is given (see *Health care complaints*, pages 43–50).

Treatment guidelines

While every case of cancer is different, your specialist should recommend treatment that is based on research. This is called evidence-based medicine. Doctors often follow standards called clinical practice guidelines, which outline the best available treatments for particular cancers. The guidelines may cover:

- tests needed to determine the stage and grade of the cancer
- treatments that are most effective at each stage
- recommended time frames (e.g. how long it is reasonable to wait between receiving test results and starting treatment).

All doctors should be familiar with treatment guidelines, regardless of where they work. Some treatment centres use their own guidelines. Specialists will tailor treatment to suit your situation – this treatment should still meet the recommended best practice guidelines.

Patients are able to read treatment guidelines. Ask your doctor what guidelines they are using – they may use an international guideline if there is not an Australian version. Many guidelines are available online:

- Cancer Australia (canceraustralia.gov.au/publications-and-resources/clinical-practice-guidelines)
- Cancer Council Australia Cancer Guidelines Wiki (wiki.cancer.org.au/australia/Guidelines)
- national optimal cancer care pathways (cancer.org.au/health-professionals/optimal-cancer-care-pathways.html).

👁️👁️ It's important to play an active role in your treatment, because it's your life and body. 🗣️🗣️ Vivien

Getting a second opinion

Finding a specialist and deciding on treatment can be difficult. You have the right to talk to more than one specialist to consider your treatment options or to confirm the recommended treatment. This is called a second opinion, and it may help reassure you that you have explored all of your options.

A second opinion may also be helpful for people who face a choice between high-risk treatment that has a chance of a better outcome, and treatment that has a lower risk with less likelihood for success.

Not everyone will want to get a second opinion. However, some people would like a second opinion but may not ask for one. This may be because they don't realise they can or because they don't want to upset the specialist they've already seen.

Reasons you may want to get a second opinion include:

- peace of mind
- ensuring you receive up-to-date advice and treatment
- getting a different point of view
- joining a clinical trial (see pages 32–33)
- exploring and challenging advice from your first doctor
- not feeling at ease with your first doctor.

“ I wasn't happy with the treatment option recommended by the first specialist my GP referred me to, so I asked for a second opinion. I decided it was my life and my choice. ” Vivien

Finding another specialist

You can seek a second opinion by asking:

- **your specialist** – many are happy to recommend another doctor
- **your GP** – if you don't feel comfortable asking the specialist for a referral for a second opinion, you can go back to your GP
- **treatment centre staff** – one of the nurses at your treatment centre can give you a list of specialists who work at that location. Your GP can then write a referral to the specialist of your choice.



Seeking another opinion

- You have the right to ask for as many opinions as you like.
- Doctors aren't allowed to discriminate against people for requesting a second opinion.
- You don't have to tell your specialist that you are seeking a second opinion, but it might help if you do. Most doctors understand the value of a second opinion and are not offended. They may even be able to help you find someone.
- Some specialists who have a heavy workload don't accept patients for a second opinion.
- Second opinions can take time (to be referred to the new specialist and to get an appointment with them).
- Once you find someone to give you a second opinion, your first specialist should share your test results with them.
- If you are a public patient, you may only be allowed to be on a waiting list to see a specialist at one hospital at a time. Your doctor may also not be able to refer you to another specialist in the same hospital.
- You can get a second opinion even if you have started treatment. You might decide to be treated by the first doctor or you may prefer to be treated by the second specialist.



Marg's story

After I was diagnosed with breast cancer, I asked if there were any clinical trials I could go on.

One was assessing how effective a pain-relieving inhaler was for women having a sentinel node biopsy, which was the procedure I needed.

I felt that the trial was low risk and I had the potential to receive some useful extra treatment. It required an overnight stay in

hospital to have the biopsy and treatment, and to be monitored.

I had to fill out questionnaires about my emotional and physical wellbeing on the day of the trial and the following day. This gave me something to do and I felt that I was actively participating in my own health care.

I don't think I was given the experimental drug, but it was still a positive experience.

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial.

Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. People are recruited to test the new treatment (e.g. a drug, medical device, surgical method or test) to see whether it works and whether any side effects occur.

You may want to join a clinical trial so that you can have treatments that are not available outside of the study. All trials have guidelines on who can participate and there may not always be a trial suitable for your specific situation. If you find a trial you're interested in joining, ask your doctor if you meet the eligibility criteria.

Joining a clinical trial

It is completely voluntary to join a clinical trial. You shouldn't feel pressured to take part or rushed into making any decisions that may affect your health or treatment. Take the time you need to decide whether to join – if you are unsure, you can ask for a second opinion from another specialist or talk to your GP.

Before joining a trial, you need to give informed consent (see also next page). This means you will be given written information about the key facts of the trial so that you can decide whether to participate. You will be asked to confirm in writing (usually by signing a consent form) that you have read and understood the purpose, duration, required procedures, risks and possible outcomes of the research, and agree to take part in the trial. You will be asked to give consent again if the study changes or new information becomes available.

You have rights while participating in a clinical trial, including the right to withdraw at any time without giving a reason. If you do decide to withdraw from a trial, you will not be punished, and you will receive the standard treatment that is currently the best option for you.

► See our *Understanding Clinical Trials and Research* booklet for more information, including how to get involved in a trial, and some practical issues to consider when deciding whether to take part.



Visit australianclinicaltrials.gov.au for more information about clinical trials. To search for current clinical trials, visit australiancancertrials.gov.au, anzctr.org.au or clintrial.org.au.

Giving informed consent for treatment

Your doctor needs your agreement (consent) before performing any medical treatment. To help you make a well-informed decision that's based on your personal values, your doctor is required to give you information about:

- the proposed treatment and its benefits
- other treatment options
- possible side effects, risks and complications
- likely out-of-pocket costs (if any).

Receiving and understanding this information before voluntarily agreeing to treatment (that is, without being pressured to do so) is called informed consent. You will usually be asked to sign a document indicating that you understand the information you are given and agree to treatment. If you are confused or need more information, talk to your doctor. See page 68 for some questions you may want to ask before giving your informed consent to treatment.

Adults can give their informed consent – or refuse it – if they have capacity. Capacity means they can understand and remember the information about the treatment options, make decisions based on this information, and communicate their decision. If you do not have capacity, another person may be able to make decisions for you (see page 37).

Sometimes consent is not needed, such as in a medical emergency (e.g. the treatment is required to prevent death, serious damage to the patient's health or significant pain or distress), or when the patient is unconscious or mentally incapacitated.

Consent from children and young people

As much as possible, involve your child in decisions about their care. Give them age-appropriate information, include them in discussions about their treatment, and encourage them to ask questions. Ensure that the health care team considers your child's health care preferences.

Talk to a lawyer for specific information about consent and children in your state or territory. Australian law generally recognises that people aged 16 and older can make their own health care decisions, and the law requires doctors to obtain their consent before treatment.

As people under the age of 16 are legally considered minors, it's usually up to their parent or legal guardian to consent to health care. However, some states and territories have laws that allow certain minors to make decisions about their own care.

The law also recognises that children become more competent as they grow up, and their consent and input can be sought on a case-by-case basis. For example, a 15-year-old may have more say in their health care than a child aged 11. The young person may be required to show that they understand the nature and possible results of the proposed treatment, and their decision may need to be supported by a doctor.

Advance care planning

Advance care planning involves thinking about your future health care and discussing your treatment goals and preferences for care with your family, friends and treatment team. This helps them understand your goals, values and beliefs, and ensures that your wishes are respected

should you lose the capacity to make your own decisions. Advance care planning can be started at any stage, whether you are feeling well or ill. Making your wishes clear can help give you peace of mind. Everyone has their own individual preferences for medical care and these can change over time.

As part of your advance care planning, you may record your wishes in an advance care directive and appoint a substitute decision-maker.

Advance care directive

The written record of your wishes may be called an advance care directive, an advance care plan or a living will. This includes details of your values, life goals and treatment preferences for doctors, family members and carers to consider if you become unable to communicate or make decisions. You may include details of treatments that you would have or refuse to have, as well as outcomes that you don't want.

If your needs change, you can choose to revise or cancel your advance care directive. Ask your doctor or hospital to place your directive on your medical record. You can also save it online at myhealthrecord.gov.au (see page 40).



Each state or territory has different laws about advance care planning and substitute decision-makers. Talk to a lawyer to obtain specific advice about your situation. For more information about completing an advance care plan, call the Advance Care Planning Advisory Service on **1300 208 582**, or visit advancecareplanning.org.au.

Substitute decision-maker

You can legally appoint someone to make decisions for you if at some point in the future you lose the capacity to make them yourself. This can include decisions about your finances, property and medical care.

A substitute decision-maker should be someone you trust who understands your values and wishes for future care. Depending on where you live, the documents for appointing this person may be known as an enduring power of attorney, enduring power of guardianship or appointment of a medical treatment decision maker.

Default decision-maker

If you lose capacity to give consent for medical treatment and you haven't appointed a substitute decision-maker, consent may be given by a default substitute decision-maker. They may be known as a person responsible, available consenter, statutory health attorney, or medical treatment decision maker. They are usually approached in the following order.

for people under 16	<ul style="list-style-type: none">• the parent or guardian
for people under guardianship (e.g. people with an intellectual disability)	<ul style="list-style-type: none">• the appointed guardian
for people 16 and older	<ul style="list-style-type: none">• the most recent spouse, including a de facto spouse or same-sex partner, with whom the person has a close and continuing relationship• an unpaid carer• a close friend or relative

If no-one is available, a public guardian or a tribunal in your state or territory will make decisions on your behalf.



Key points about making treatment decisions

Information gathering

- It's your right to make decisions about your treatment. Being fully informed about all of your treatment options will help you to decide.
- Take the time you need to consider the advantages and disadvantages of each treatment option.
- Write down questions to ask your specialist, and consider taking someone with you to the consultation for support.
- It can help to talk to more than one specialist to consider other treatment options or to get a different point of view (second opinion).

Informed consent

- Your specialist is required to inform you about the potential benefits and risks of each treatment in a way that you can understand.
- Receiving and understanding all the relevant information before agreeing to treatment is called informed consent.
- A doctor needs your informed consent (agreement) to perform any treatment, unless it's an emergency.

Advance care planning

- It is important to think about your future health care and discuss your wishes with your family, friends and treatment team. This is called advance care planning.
- You can prepare an advance care directive to ensure your family and health care team know your treatment preferences.
- You can appoint a substitute decision-maker in case you do not have the capacity to make decisions at some point in the future.



Protecting your health information

Health professionals will collect a lot of information about you, your health and the treatment you receive. When you are receiving health care, you have a right to privacy and confidentiality. This means, in general, that health professionals can't collect your health information or disclose it to others without your consent.

It's important to note that your rights may vary depending on which state or territory you live in. For specific information, contact the Office of the Australian Information Commissioner (oaic.gov.au), talk to your treatment team, or seek independent legal advice.

Medical records

When you receive health care, the person treating you creates notes. This is called a medical record. A medical record could be handwritten or electronic and it may include:

- personal details (e.g. your name, race, genetic information)
- information or opinions about your health or illness
- scans, tests and the interpretation of results
- recommendations about treatments and medicines
- correspondence to health professionals
- photographs, audio files or video footage.

Every treatment centre you attend will keep a medical record about you, and they will add to that record each time you visit or have tests. A medical record contains personal information, so it's important that you know who can see it, change it and copy it. If you are concerned about the security of your health information, talk to your health provider or ask to see a copy of their privacy policy.

My Health Record

The Australian Government's My Health Record is an online summary of your health information (e.g. imaging scans, test results, a list of medicines, your medical conditions and treatments). It allows you and your health care providers to view summaries of your health information at a glance. Insurers and employers are not able to

access My Health Record. Unless you opted out before 31 January 2019, a My Health Record will automatically be created for you. You have the right to permanently delete your My Health Record at any time. For more information about managing your record, including your privacy and security, visit myhealthrecord.gov.au.

Who owns my medical records?

The treatment centre or health professional who creates a medical record owns and maintains the record. However, Australian law considers ownership and access as separate – so although you don't own the medical record, you generally have a right to gain access to it.

Medical records must be stored and disposed of securely to prevent unauthorised access. Different states and territories may have different requirements about how long doctors and treatment centres must keep your records after your last consultation.

Who can access my medical records?

Medical records are private and confidential. Health professionals directly involved in your care can view your personal and medical information, but only if it's necessary for their work.

Australian privacy standards establish a general rule that health care providers must give you access to the personal information they hold about you when you request it. This includes your medical records. In some limited situations, the organisation has a legal right to refuse you access (see next page).

Giving people access to their medical records:

- allows them to better understand their condition and treatment
- can help ensure the information is accurate
- may make people feel more confident about the health care system.

If you would like to see your medical records, ask your health care provider (e.g. GP, specialist, hospital or treatment centre) for access. You may have to put the request in writing and provide proof of identity, such as a driver's licence or birth certificate.

There is no set time limit for a health care provider to meet a request for medical records. However, the Office of the Australian Information Commissioner recommends that a request should be processed within 30 days.

The health care provider may charge a reasonable fee to copy your record based on the size of the record (public hospitals usually charge around \$30 for a short document), or to recover other costs involved in providing access, but there shouldn't be a fee to request access.

You can also ask for a copy of your medical record to be sent to another health care provider, for example, if you want to change doctors or treatment centres.



You can authorise someone else to see your medical records, such as a relative, interpreter or another health professional. If you make a complaint about your health care, your records may be provided to the health ombudsman or complaints commission in your state or territory.

Why might access be denied?

In some rare situations, you won't be allowed to have a copy of your medical records, such as where another law requires your information to be kept private (e.g. if the information relates to legal proceedings); or there's a serious risk that giving you access to the information could harm someone. If your health care provider refuses to let you see your medical record, they must let you know the reasons.

How can I change my medical records?

If you think your medical records are inaccurate, out-of-date, incomplete, irrelevant or misleading, you can ask for changes. You may be asked to make this request in writing.

If a treatment centre refuses to change your medical record because they think it is correct as it is or that your suggested changes are not appropriate, it must provide a written explanation for the decision. You can also ask them to include a short statement with your record, which explains that you think the information is incorrect.

If you disagree with the treatment centre's decision, you can make a complaint to the Office of the Australian Information Commissioner (call 1300 363 992 or visit oaic.gov.au) or to the health ombudsman or complaints commission in your state or territory (see page 47).



Health care complaints

You have the right to give feedback or make a complaint about any aspect of your health care, and to receive a prompt response. This applies whether you are treated in a public or private hospital or treatment centre, or if you see a practitioner in a private clinic. Complaints will be managed differently depending on the type of concern, and the state or territory you live in.

Importance of feedback

The safety of Australia's health care system requires the active participation of health professionals, patients and carers. Your feedback allows you to be a part of improving health care by supporting what is being done well, highlighting what can be done better, and improving safety. You can provide feedback through:

Compliments – Everyone likes a compliment when a job is done well. Positive comments show health professionals that you value their service and standard of care.

Suggestions – General feedback allows minor problems or difficulties to be dealt with to make things smoother for patients. Often health professionals are so busy treating people that they may overlook practical issues that are easy to solve and can improve everyone's experience of treatment.

Complaints – If health care services have not met your expectations, negative feedback is important. It can help services and health professionals identify and improve service gaps or problems in treatment, communication, processes and behaviour.

How to give feedback or complain

All health care facilities should have procedures for patients to provide feedback and complaints. Check with the cancer care coordinator, nursing unit manager or social worker. Some hospitals have a patient representative or patient advocate who looks after patient concerns. You can usually find their details on the hospital's website.

Raising the issue may mean you get a different view of why something occurred, and talking about it may make you feel better. You can also ask a friend or a relative to raise an issue on your behalf.

If you have a problem with a particular person, it is often best to talk to them face-to-face or on the phone, as this makes it easier for the situation to be sorted out immediately. However, you may prefer to write a letter, for example, if you find it difficult to discuss your concerns with the person involved or feel the issue has been ignored after raising it in person. Remember that putting feedback in writing means you will have to wait for a response.

Health professionals are bound by a strict code of conduct to maintain confidentiality about any complaints you lodge.



If you feel unable to provide feedback or complain immediately, you can still raise your concerns at a later date. Keep in mind the complaints organisation in your state or territory may not assess complaints after a certain time frame, and there are strict time limits for medical negligence complaints (see page 49).

Steps for resolving a health care issue

- 1** Identify the problem and what you would like to happen to resolve it.
- 2** Talk to your specialist, a nurse or other health professional so they have the chance to resolve the issue immediately. A quick conversation may help to sort out a simple misunderstanding.
- 3** If your complaint is about a particular person and you don't want to talk to them directly – or you have spoken to them and the issue remains unresolved – speak to the cancer care coordinator, nursing unit manager or social worker at your hospital or treatment centre.
- 4** If you're not happy with the response from a health professional, or if you want to talk to someone neutral, contact the hospital's independent patient representative, complaints officer or patient advocate.
- 5** If you're not satisfied with the patient representative's investigation, contact the hospital's quality assurance department or the clinical governance unit of your area health service. Smaller or private hospitals may not have a patient representative or quality assurance department – contact the nursing unit manager or general manager.
- 6** If you're still not happy with the outcome – or you don't want to raise the issue with the health care facility – contact your state or territory health complaints organisation (see page 47) or the Australian Health Practitioner Regulation Agency (see page 48). If you have a serious complaint that you want to take to a health complaints organisation, you may wish to obtain independent legal advice.

Making a formal health care complaint

To make a formal complaint, you need to contact your state or territory health complaints organisation (see table opposite). It can be helpful to check if there are any time limits or other conditions you have to meet. Complaints should be in writing and can often be made by filling in an online form.

If you are unable to make the complaint yourself, then a relative, friend, guardian or health professional may be able to lodge the complaint on your behalf.

In most cases, you will be assigned a case officer, who may provide a copy of the complaint to the health care provider and ask them to give their version of events. Your case officer may also obtain your medical records or other relevant information from the health care provider, with your consent.

Once the case officer has completed their assessment, the relevant state or territory ombudsman or commissioner will write to tell you how they will deal with your complaint. They may decide to refer it to mediation or conciliation, which is when the parties meet to try to agree to a resolution. Public health and safety issues are referred elsewhere within the ombudsman or commission's office for formal investigation.

Serious cases against a health practitioner may result in prosecution, and some cases can be referred to a registration board or another organisation – see page 48 for information about the Australian Health Practitioner Regulation Agency and registration boards.

Health complaints organisations

Australian Capital Territory	ACT Human Rights Commission (Health Services Commissioner) 02 6205 2222 hrc.act.gov.au/health
New South Wales	Health Care Complaints Commission 1800 043 159 hccc.nsw.gov.au
Northern Territory	Health and Community Services Complaints Commission 1800 004 474 hcsc.nst.gov.au
Queensland	Office of the Health Ombudsman 133 646 oho.qld.gov.au
South Australia	Health and Community Services Complaints Commissioner 08 8226 8666 or 1800 232 007 hcsc.sa.gov.au
Tasmania	Health Complaints Commissioner Tasmania 1800 001 170 www.healthcomplaints.tas.gov.au
Victoria	Health Complaints Commissioner 1300 582 113 hcc.vic.gov.au
Western Australia	Health and Disability Services Complaints Office 08 6551 7600 or 1800 813 583 hadsco.wa.gov.au

Health professional registration

To help protect the public's safety, the Australian Health Practitioner Regulation Agency (AHPRA) and 15 National Boards regulate the health practitioners listed below. Health practitioners must meet certain standards before they can be registered and accredited with a National Board. This helps ensure that only trained and competent health professionals practise within these professions.

AHPRA works together with the National Boards to investigate complaints about health practitioners. If you have concerns about the health, performance or conduct of a registered health practitioner, you can complain to AHPRA (ahpra.gov.au).

Registered health practitioners*

It is unlawful for a person to pretend to be a registered health practitioner. You can check that your health practitioner is registered at ahpra.gov.au.

- Aboriginal and Torres Strait Islander health practitioners
- Chinese medicine practitioners
- chiropractors
- dental practitioners
- medical practitioners (GPs and specialists)
- nurses and midwives
- occupational therapists
- optometrists
- osteopaths
- paramedics
- pharmacists
- physiotherapists
- podiatrists
- psychologists
- radiation practitioners

** Includes students enrolled in an approved program of study or undertaking clinical training placements.*

Unregistered health practitioners

Allied and complementary health practitioners who are not legally required to be registered with a National Board are known as unregistered health practitioners or general health service providers. They may choose to join a professional association that sets education and practice standards, but membership is voluntary. In some states unregistered health practitioners are required to follow a Code of Conduct. If you have an issue with an unregistered practitioner, talk to them first. If you're not satisfied with the outcome, you can lodge a complaint with their professional association (if they are a member), or with a health complaints organisation (see page 47).

Medical negligence

Health professionals have a duty to treat patients with reasonable care and skill. If you receive an injury or suffer loss that was caused by inadequate treatment or care, you may be able to make a claim for compensation (medical negligence claim). Inadequate treatment may include failure to diagnose or treat promptly, failure to advise you of risks of procedures, or giving you the wrong medicine. Medical negligence claims about cancer diagnosis and care are uncommon.

In most states and territories, the time limit for lodging a complaint is generally three years from the date the injury occurred. Proving negligence can be difficult – you may have to attend court, and the process can be expensive. If you think you may have a claim, it's important to obtain legal advice from a lawyer who specialises in medical negligence. To find a suitable lawyer, contact the Law Society in your state or territory.



Key points about patient feedback

Why give feedback

- Patient feedback helps to improve health care.
- You have the right to give feedback about any aspect of your health care and to receive a prompt response.

How to give feedback

- If your issue is with a particular person, try talking with them first, as there may have been a simple misunderstanding.
- If you're not happy with the response, check with your health care facility about their procedures for patients to provide feedback. You may want to send a written complaint or talk to the patient representative.
- Health care providers are bound by a strict code of conduct to maintain confidentiality regarding any complaints.
- You can make a formal complaint to your state or territory health complaints organisation or AHPRA.

Health professional registration

- Many health professionals are required to be registered and accredited by a National Board.
- Unregistered health practitioners (also known as general health service providers) are not legally required to be registered with a National Board but may choose to join a professional association.

Medical negligence

- Health professionals have a duty to treat patients with reasonable care and skill. If you experience an injury caused by inadequate treatment or care, you may be able to claim compensation (medical negligence claim).



Legal, financial and workplace concerns

During or after cancer treatment, you may have concerns about insurance policies, financial issues and work. This chapter provides an introduction to these topics. For more information, see our *Cancer and Your Finances* booklet or call Cancer Council 13 11 20. You may also want to consider obtaining independent legal and financial advice about any issue covered in this chapter.

Insurance

You may have taken out personal insurance policies (e.g. income protection or total and permanent disability) before your diagnosis. You may also have insurance through your superannuation. It's important to make a claim as soon as possible, because there may be time limits that apply. If you think you should be covered but your claim is denied, get in touch with the Australian Financial Complaints Authority (afca.org.au). You can also call Cancer Council 13 11 20 to see whether we can connect you with a lawyer for assistance.

If you're not making a claim, usually you do not need to inform the insurer about your cancer diagnosis until you renew your policy or change your level of cover. However, it is a good idea to check your insurance policy to see what it says about disclosing health issues. If you're taking out a new policy you are generally required to provide your medical history, including your cancer diagnosis. Insurance companies are allowed to refuse cover, but only on reasonable grounds. This does not include private health insurance – it is unlawful to be denied health insurance because of health issues, but there may be a waiting period before pre-existing conditions are covered.

► See our *New insurance policies* fact sheet.

Travel insurance

Getting travel insurance can be a major concern for people with cancer or who have had cancer. Insurance companies may view you as more of a risk. They may believe that you're more likely to get sick and require treatment while you're travelling, need to return home for treatment, or cancel your trip due to illness.

In general, you should be able to buy travel insurance for things that are not related to your cancer (like lost luggage and cancelled flights). 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. If you have to disclose any pre-existing health conditions, be honest – a claim may be denied if you withhold information.



How to get travel insurance

- Apply for a policy well before your departure date.
- Shop around – the terms and conditions may vary.
- Ask your specialist or GP to write a detailed letter outlining your condition.
- If you are travelling overseas, check whether there is a reciprocal health care agreement between Australia and the country you are visiting that covers some of the costs of medical treatment. Visit humanservices.gov.au and search for “reciprocal agreements”.
- Some credit cards offer free travel insurance if you use the card to pay for some or all of the trip. Read the fine print.
- If you are denied travel insurance, ask the insurer to provide reasons in writing.

Legal, financial and workplace support

Cancer Council's Legal, Financial, Small Business and Workplace Referral Service may be able to help if you or someone in your family is affected by cancer, and you need financial, legal or workplace advice. We can connect you with professionals to assist you with credit and debt issues, insurance claims and disputes, early access to superannuation, managing workplace issues, and transitioning to retirement. Call **13 11 20** to find out what services are available in your area and whether you are eligible for this assistance.

Financial issues

If you're in financial stress, several options are available. A financial counsellor can help you to budget and work out a plan to manage your finances. To find a counsellor in your area, call 1800 007 007 or visit financialcounsellingaustralia.org.au.

Dealing with debts

If you are struggling with debts, such as your mortgage or credit card bills, talk to your credit provider about your financial situation and your options. These may include:

- extending the time you have to repay the debt
- reducing or pausing repayments for a short time
- changing to interest-only repayments for a specified period
- renegotiating your interest rate.

If you're not satisfied with the response you receive, you can complain through the free external dispute resolution scheme run by the Australian Financial Complaints Authority (afca.org.au).

If you're having trouble paying your utility bills, such as electricity, gas, water, phone or internet, talk to your provider. They can help you find ways to avoid disconnection and penalty fees.

For more information about dealing with debt and other financial matters, visit the Australian Securities and Investments Commission's consumer website at moneysmart.gov.au.

➤ See our *Dealing with debts* fact sheet.

Accessing superannuation

If cancer causes financial issues, talk to your superannuation fund about applying for an early release of your superannuation savings on the grounds of severe financial hardship. Before you decide to access your super early, get financial advice about how this will affect your retirement and find out whether there are any insurance policies attached to your superannuation account that you could claim on.

➤ See our *Superannuation and cancer* fact sheet.

Applying for government benefits

Centrelink offers a range of payments that may be available to people with cancer, including Sickness Allowance, Mobility Allowance, and the Disability Support Pension. You may also be eligible for the Pensioner Concession Card or the Health Care Card, which can reduce your expenses. Centrelink benefits may be income and asset tested or have other eligibility requirements. Medicare also has reimbursement programs for people who need certain medical supplies, such as breast prostheses and continence aids. For more information and to check eligibility requirements, visit humanservices.gov.au or talk to your social worker.

Workplace issues

If you are employed or hope to return to work after treatment, you might wonder how cancer will affect your work life. You may be concerned about your leave entitlements, discrimination, changing your working hours, or unfair dismissal. Some of the issues described here differ between states and territories, and they may depend on the industry you work in. You may need to obtain specific advice about your situation from a lawyer who specialises in employment matters.

➤ See our *Cancer, Work & You* booklet.

Taking leave

All full-time employees except casuals are entitled to a minimum of 10 days of paid personal leave each year. This leave can be taken when you are unwell or need to care for an immediate family member. Part-time employees receive this entitlement on a pro rata basis. Employees can take as much personal leave as they have accumulated, though your employer can ask you to provide evidence of your illness.

If you need to take more time off, you may be able to combine personal leave with annual leave or long service leave, or ask your manager if you can take unpaid leave. For more information about your leave entitlements and what to do if you are prevented from taking leave you have a right to, visit fairwork.gov.au.

Discrimination

In general, discrimination in the workplace due to cancer and treatment is unlawful. This includes denying you a promotion, demoting you to a lower paid job, sacking you or refusing to hire you for a reason related to your cancer.

If you think you're being discriminated against, try talking with your employer and follow your workplace's grievance handling policy. If you're not happy with the response, you can lodge a formal complaint with the discrimination agency in your state or territory or the Australian Human Rights Commission (humanrights.gov.au).

If you have been dismissed from your job or experienced other disadvantage due to your cancer diagnosis, you may also be able to lodge a complaint with the Fair Work Commission (www.fwc.gov.au).

Contact these organisations to see which one is most appropriate for your situation before you lodge a complaint. Most complaints are resolved through mediation or conciliation, which is an informal type of resolution. If mediation doesn't work, you may go to an administrative tribunal or to court for a legal judgment that must be followed.

Special arrangements

Australian laws require an employer to take reasonable steps to accommodate the effects of an employee's illness and help you perform your job. They can only refuse your request to provide these arrangements if the changes would cause unjustifiable hardship to their business or, in some cases, on reasonable business grounds.

Some examples of flexible working arrangements are:

- making minor changes to your work duties
- allowing you to work from home some or all days
- providing you with additional equipment
- allowing you to vary your hours, work part-time or job share.

If your employer refuses your request, you may be able to seek assistance from the Fair Work Ombudsman, Fair Work Commission or the discrimination agency in your state or territory.

Unfair dismissal

An employer can't pressure you to resign or dismiss you because you have cancer. If you have been dismissed from your job, you may be able to lodge an unfair dismissal claim with the Fair Work Commission. You must lodge claims within 21 days of being dismissed and meet some other conditions (see www.fwc.gov.au for eligibility requirements).

State and territory discrimination agencies

ACT Human Rights Commission	hrc.act.gov.au
Anti-Discrimination Board of NSW	antidiscrimination.justice.nsw.gov.au
Northern Territory Anti-Discrimination Commission	adc.nt.gov.au
Anti-Discrimination Commission Queensland	adcq.qld.gov.au
Equal Opportunity Commission (SA)	eoc.sa.gov.au
Equal Opportunity Tasmania	equalopportunity.tas.gov.au
Victorian Equal Opportunity & Human Rights Commission	humanrightscommission.vic.gov.au
Equal Opportunity Commission (WA)	eoc.wa.gov.au



Key points about legal, financial and workplace concerns

Insurance

- You may have insurance policies that cover you when you are diagnosed with cancer.
- Insurance companies (excluding health insurers) are allowed to refuse cover for new policies, but only on reasonable grounds.
- Travel insurance can be a major concern for people with cancer or who have had cancer. It should be possible to get a basic plan to cover lost luggage, theft and cancelled flights.
- Some travel insurers don't cover medical expenses for people who have had cancer. You can ask them to tell you in writing why they refused cover.

Financial issues

- If cancer causes financial issues, you may consider accessing your superannuation.
- The Department of Human Services (Centrelink) offers benefits and pensions to some people with cancer. Medicare also offers reimbursement schemes for some products and equipment.
- If you have cancer and are struggling with debts, such as your home loan or credit cards, talk to your lenders about your situation.
- A financial counsellor can help you to budget and work out a plan to manage your debts.

Workplace issues

- If you are working, you can talk to your employer about taking leave or changing your work arrangements during treatment and recovery.
- It is against the law for employers to discriminate against you, pressure you to resign or dismiss you because you have cancer.



Rights of carers

A carer is someone who provides unpaid care and support to a person who needs this help because of an illness or disability. Carers have a vital but often demanding role providing physical and emotional support to people with cancer. Knowing your rights as a carer can help you deal with the treatment team, and make medical and financial decisions.

- ▶ See our *Caring for Someone with Cancer* booklet and listen to our “Cancer Affects the Carer Too” podcast.

Talking to the treatment team

As a carer, you're part of the health care team. One of your key roles is to help the person you care for communicate with their treatment team and make decisions about their care. The person needs to give written consent to allow you to do this, and this consent should be included in their medical record. At times, you may also need to speak on behalf of the patient. It is your right to take on this advocacy role if that is what the person you care for would like.



Getting ready for medical appointments

- Talk with the person you care for and make a list of questions to ask the doctor (see page 68 for suggestions).
- Call the receptionist to check what you have to take, such as test results or scans.
- Prepare a list of medicines that the person is taking. Include the dose and any side effects.
- Record any recent changes in the person's condition or symptoms so you can tell the doctor about them.

Making decisions

The person you care for may give you the power to make decisions on their behalf if they lose the capacity to make their own decisions. This can include decisions about finances and medical care. It is important that you have a discussion ahead of time about how much treatment the person wants for the cancer, what matters most to them when making treatment decisions, and whether you're able to carry out their wishes.

If the person you are caring for becomes incapable of making their own decisions and has not given you the power to make decisions on their behalf, the medical practitioner will approach the default substitute decision-maker. See *Advance care planning*, pages 35–37, for more information.

Rights of same-sex partners

The law recognises the role of same-sex partners in medical decision-making. Sometimes, medical staff may not be fully aware of this and they may seek a decision from another member of the patient's family before approaching the person's domestic partner.

To ensure your rights as the domestic partner are protected, you may want to speak to the treating doctor to confirm that you

are the default substitute decision-maker for medical decisions (see page 37).

You or your partner may be concerned about you being recognised as the decision-maker. If so, consider asking your partner (when they still have capacity) to appoint you as their enduring guardian, enduring power of attorney or medical treatment decision maker.

Workplace issues for carers

Many people who care for someone with cancer are also employed. Sometimes people find it difficult to balance the needs of both roles. You may need to take time off work or to stop working for some time.

► See our *Cancer, Work & You* booklet.

Taking time off work

All full-time employees except casuals are entitled to a minimum of 10 days of paid personal leave each year. This can be used if you are unwell or if you are providing care to a member of your immediate family or household. Part-time employees receive this entitlement on a pro rata basis. Employees can take as much personal leave as they have accumulated, though your employer can ask you for basic facts about why you need time off.

In addition, full-time and part-time employees are entitled to two days of paid compassionate or bereavement leave when an immediate family member is seriously ill or injured, or dies. Casual employees are also entitled to this leave, but it is unpaid.

If you've used all of your paid personal leave, you are entitled to two days of unpaid carer's leave each year. Both casual and permanent employees are entitled to this leave, which must be used to provide care or support to a member of your immediate family or household.

If you need to take more time off work, you may be able to use annual leave or long service leave, or apply for leave without pay (if your employer allows this). For more information about leave entitlements, visit fairwork.gov.au.

Special arrangements

You have the right to ask your employer to make flexible working arrangements to help you manage your work and caring responsibilities. They can only refuse to provide these arrangements if the changes would cause serious unjustifiable hardship to their business or, in some cases, on reasonable business grounds.

Some examples of flexible working arrangements are:

- allowing you to work from home some or all days
- changing your start, finish or break times
- allowing you to vary your hours, work part-time or job share
- varying the amount of unpaid or paid leave you can take and when you can take it.

Discrimination

Discrimination at work because of your caring responsibilities is against the law. Your caring responsibilities cannot be held against you when you are applying for a job. You also have the right to the same opportunities for promotion, transfer or training, and the same benefits as other employees.

Making a complaint

If you feel you have been discriminated against because of your caring responsibilities, you may have the right to make a complaint to the Australian Human Rights Commission (humanrights.gov.au), the Fair Work Commission (www.fwc.gov.au), or the human rights, equal opportunity or anti-discrimination agency in your state or territory (see page 57). See pages 55–57 for further information on making a complaint about discrimination in the workplace.

Financial assistance for carers

Caring for someone with cancer can cause financial difficulties. The Department of Human Services (Centrelink) supports carers with a range of payments. These include the Carer Payment and Carer Allowance. For more information about financial assistance for carers, and to check eligibility requirements, call 132 717 or visit humanservices.gov.au.

Support for carers

Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful. It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with your caring role.

Local support services – The Australian Government’s Carer Gateway provides practical information and resources for carers, and a service finder to help carers connect to local support services, including respite care. Call 1800 422 737 or visit carergateway.gov.au.

“ I joined a tai chi class organised through the Carers Association and also attended their support workshops and relaxation sessions. I found the encouragement from other carers gave me the confidence boost I needed. ” *Isabella*

Respite options – Respite care is available to give you a break. Contact a Commonwealth Respite and Carelink Centre for information on local carer support services and respite options that may suit you. Call 1800 052 222 during business hours or call 1800 059 059 for emergency respite support outside business hours.

Cancer Council telephone support group – Cancer Council offers a national telephone support group for carers. It runs twice a month. For more information about how you can speak with other people in a carer role, call 13 11 20.

Carers Associations – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. They also run local support groups and offer short-term counselling through the National Carer Counselling Program. Call 1800 242 636 or visit carersaustralia.com.au.

Young Carers – For information and support tailored for carers under 26, call 1800 242 636 or visit youngcarersnetwork.com.au.

Consumer advocacy

Advocacy means speaking out on behalf of others to achieve positive change. Cancer advocates lobby the government and key organisations to convince them to reduce cancer risks and improve services. Many people affected by cancer get involved with advocacy. For more information, call Cancer Council **13 11 20** or visit cancervoicesaustralia.org.



Key points about carer rights

Treatment issues

- The person you care for needs to give written consent so the treatment team can talk to you about their care.
- The person you care for may give you the power to make decisions about their care if they lose the capacity to make their own decisions. It is important that you understand their treatment goals and personal values, and consider whether you will be able to carry out their wishes.

Workplace issues

- You may be able to use a range of leave if you need to take time off work to care for someone in your family or household. This could include personal leave, annual leave, long service leave and unpaid leave.
- You can request flexible working arrangements to help you manage your work and caring responsibilities. Employers are legally obliged to consider all reasonable requests.
- Discrimination at work because of your caring responsibilities is against the law.
- If you've been discriminated against, you may be able to make a complaint to the Australian Human Rights Commission, the Fair Work Commission or the discrimination agency in your state or territory.

Support for carers

- The Department of Human Services (Centrelink) supports carers with a range of payments, including the Carer Payment and Carer Allowance.
- There are specific support services for carers of all ages, such as counselling and respite services and support groups.



Support and information

Useful websites

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

Cancer

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Optimal Care Pathways	cancerpathways.org.au

Health care

Australian Commission on Safety and Quality of Health Care	safetyandquality.gov.au
Department of Health	health.gov.au
Department of Human Services	humanservices.gov.au
Healthdirect Australia	healthdirect.gov.au
My Health Record	myhealthrecord.gov.au
MyHospitals	myhospitals.gov.au
Pharmaceutical Benefits Scheme	pbs.gov.au
PrivateHealth.gov.au	privatehealth.gov.au

Regulatory and complaints organisations

Australian Financial Complaints Authority	afca.org.au
Australian Health Practitioner Regulation Agency	ahpra.gov.au
Australian Human Rights Commission	humanrights.gov.au
Commonwealth Ombudsman	ombudsman.gov.au
Fair Work Commission	www.fwc.gov.au
Fair Work Ombudsman	fairwork.gov.au
Office of the Australian Information Commissioner	oaic.gov.au

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 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 (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



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.

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.





Question checklist

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

Choosing a specialist

- Have you treated a lot of people with this type of cancer?
- What stage is the cancer and what does it mean?
- Do you specialise in treating this type of cancer? If not, could you recommend someone who does?
- Do you work in a multidisciplinary team? Who else is in the team?
- What hospitals or treatment centres do you work or operate in?
- Are you a member of a specialist medical college? If so, which one?
- I'm thinking of getting a second opinion. Can you recommend anyone?

Treatment choice, side effects and informed consent

- What are my treatment options? What is the aim of each treatment?
- What treatment do you recommend? What is the expected outcome of the treatment?
- Are there other treatments that you aren't recommending? Why?
- What should I expect if I don't have treatment?
- How long will treatment take? Will I have to stay in hospital?
- If this particular treatment does not work, are there other options?
- What is the likely success rate of any surgery or treatment?
- What are the risks and possible side effects of each treatment?
- What is the chance that these complications or side effects will occur?
- What will be done to prevent these side effects?
- Are the side effects immediate, temporary or long-lasting?
- What follow-up care can I expect after treatment?
- Will I need to take medicines long-term after treatment?

Financial impacts

- Are there any out-of-pocket costs not covered by Medicare or my private health cover?
- Can the cost be reduced if I can't afford it?
- Will I be able to work while having treatment?



Glossary

advance care planning

When a person thinks about their future health care and discusses their wishes with their family, friends and health care team. The written record of these wishes may be known by different names, such as an advance care directive, advance care plan, or living will.

advocacy

Campaigning, speaking out and making recommendations for positive change on behalf of oneself or other people.

allied health professional

A tertiary-trained professional who works to support a person's medical care. Examples include a psychologist, social worker, occupational therapist, physiotherapist and dietitian.

benefit

The amount paid by an insurer for an insured service.

bulk-bill

When a doctor bills Medicare directly and accepts the Medicare benefit as full payment.

capacity

Having the ability to understand and think things through to make decisions.

clinical trial

A research study that tests new approaches to prevention, screening, diagnosis or treatment, to see if they are better than current approaches.

code of conduct

A list of professional rules that health care providers must follow so that patients receive safe, fair and ethical health care.

complementary therapy

A supportive treatment used alongside conventional treatment. It may improve general health, wellbeing and quality of life, and help people cope with cancer symptoms and treatment side effects.

conciliation

See mediation.

consent

When you agree to something.

enduring power of attorney/

enduring power of guardianship

A legal document prepared by a lawyer that lets a person appoint someone they trust to act on their behalf if and when they become unable to make decisions for themselves. May cover financial, property, lifestyle and treatment decisions.

evidence-based medicine

When health care providers make decisions based on research that shows how well a particular treatment works.

excess

The amount you pay towards your hospital admission before your private health insurer pays a benefit.

gap fee

The difference between the Schedule fee set by Medicare and the doctor's fee.

grade

A number that describes how similar cancer cells look to normal cells.

informed consent

Receiving and understanding all relevant information, such as potential risks, before agreeing to or declining medical treatment.

informed financial consent

Receiving and understanding all relevant information about the likely cost of treatment.

inpatient

A patient who stays in hospital while having treatment.

insurance

A contract between a company and an individual that guarantees a payment in the case of covered loss, accidents or death.

mediation

An informal type of resolution using a mediator or negotiator who communicates between two parties to settle differences and problems. Also called conciliation.

medical negligence

When a health care provider is proven to have breached their duty of care to a patient, causing injury or personal loss.

medical record

Notes about a person's health care history (e.g. scan and test results and doctors' recommendations).

multidisciplinary care

A system where all members of the treatment team collaborate to discuss a patient's physical and emotional needs, as well as any other factors affecting their care. The team meets to review cases and decide on treatments.

National Board

A board authorised by the government to oversee the registration and professional standards of health care practitioners.

out-of-pocket costs

The difference between what you are charged, and the amount Medicare or your health fund will pay.

outpatient

A patient who receives medical treatment without being admitted to hospital.

patient responsibilities

Expectations of patients to treat their treatment team with respect, honesty and consideration.

patient rights

Rules and guarantees for people receiving medical care. Some rights are legally enforceable; other rights are what you can reasonably expect from your care and are not enforceable.

personal leave

Leave that can be taken when an employee can't attend work because they are sick or injured, or need to provide care or support to a member of their immediate family due to an illness, injury or unexpected emergency. Also known as sick or carer's leave.

power of attorney

A document that gives a person the ability to act on your behalf on financial and legal matters.

pre-existing condition

An illness or injury that existed before applying for an insurance policy.

private health insurance

An insurance policy that covers some medical expenses. Patients with private hospital cover can choose their own doctor and whether they want to be

treated in a private or public hospital. People can also take out general treatment cover for extras such as dental, optical and physiotherapy treatments.

public guardian

A legal official who can be appointed to make important health and lifestyle decisions on behalf of another person.

registered health professional

A health care provider, such as a doctor, nurse or pharmacist, who needs to be registered and approved by a government registration board before working in that field.

registrar

A hospital doctor who is training to be a specialist.

resident medical officer

A hospital doctor who has not undertaken specialist training.

respite care

Alternative care arrangements that allow the carer and person with cancer a short break from their usual care arrangements.

Schedule fee

Medicare's recommended fee for a medical service.

specialist

A doctor with qualifications and skills in a particular branch of medicine (e.g. an

oncologist is a doctor who specialises in the study and treatment of cancer).

stage

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

substitute decision-maker

A person who makes decisions on your behalf if you become incapable of making them yourself. The documents to appoint this person may be called an enduring power of attorney, an enduring power of guardianship or appointment of medical treatment decision maker.

unfair dismissal

When an employee is terminated from a job and the dismissal is considered to be harsh, unjust or unreasonable.

unregistered health practitioner

A health care provider who is not legally required to be registered with a government registration board. Also known as general health service provider.

Can't find a word here?

For more cancer-related words, visit:

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

References

1. Australian Commission on Safety and Quality in Health Care, *Australian Charter of Healthcare Rights – draft second edition*, as at January 2019. Available url: safetyandquality.gov.au/wp-content/uploads/2019/02/Australian-Charter-of-Healthcare-Rights-DRAFT-second-edition.pdf. (Viewed: 8 March 2019)



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 cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

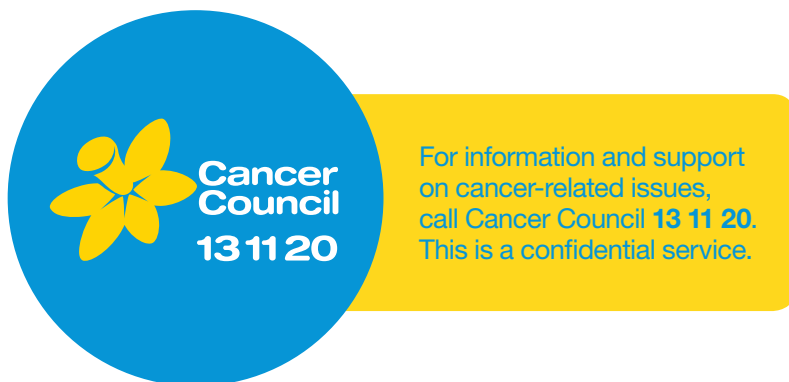
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



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

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



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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