



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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Introduction

For many people, a cancer diagnosis is the start of a long and often complicated journey through the health care system. Navigating through this system can be challenging, particularly when you are dealing with the physical and emotional effects of cancer.

This booklet outlines what you can reasonably expect of the health care system and your treatment team. It also includes some basic information about insurance and workplace rights, and practical issues such as paying for treatment, finding a specialist and accessing community services.

The information in this booklet is about working in partnership with your health care providers and taking an active role in your care, if you wish to do so. This doesn't mean you are making demands of your treatment team – rather, it's about feeling comfortable asking questions and ensuring your needs are met.

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. You may also like to pass this booklet to your family and friends for their information.

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



**Cancer
Council
13 11 20**

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Health care in Australia

This chapter provides a general overview of the health care system in Australia. It includes information about:

- the differences between public and private health insurance
- how to pay for health care in and out of hospital
- medicines and the Pharmaceutical Benefits Scheme (PBS).

Types of health insurance

Public (Medicare)

Medicare is insurance provided by the government that gives citizens and permanent residents of Australia access to medical and hospital services. It is also available to people who meet certain other requirements (e.g. some overseas visitors).

Under Medicare, you are entitled to free inpatient treatment in a public hospital, even if you have private health insurance. However, you can't choose your own doctor and you might have to wait for treatment. Medicare also provides benefits for outpatient 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.

Public dental services

Free or subsidised dental care is available to people who meet certain eligibility criteria, for example, you may need to hold a particular concession card. Visit your state or territory health department's website for information.

Private

Private health insurance is a contract between you and an insurance company where you pay the company to cover your medical expenses. The amount you pay (the premium) and what is covered depends on your policy.

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. See *Public or private treatment*, page 21.

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



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 – for example, if you have surgery as a private patient, there will be fees for your stay in hospital and for the anaesthetist.

Your doctors must talk to you about likely out-of-pocket expenses before treatment starts. This is called informed financial consent. For more information, call Cancer Council 13 11 20 and ask for a free copy of *Cancer and Your Finances*, or download a digital version from your local Cancer Council website.

Medicare Benefits Schedule (MBS)

Medicare sets fees for medical services. The list of fees is called the Medicare Benefits Schedule (MBS). Some doctors charge more than the Schedule fee. The difference between the Schedule fee and the doctor's fee is called the gap fee.

Before being admitted to hospital, you should ask:

- your doctor for an estimate of their fees (and if there will be a gap), who else will care for you 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.

Fees for services in hospital

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

For private patients in a public or private hospital, Medicare pays 75% of the Schedule fee for services and procedures that your doctor provides. If your doctor charges more than the Schedule fee, your health fund may pay the gap fee or you may have to pay it yourself. You will also be charged for hospital accommodation and items such as operating theatre fees and medicines. Private health insurance may cover some or all of these costs, depending on your policy. You may also have to pay an excess to your health fund, depending on the type of hospital cover you have.

Fees for out-of-hospital services

A lot of cancer care is delivered outside hospital, such as consultations with your oncologist, surgeon or GP, and tests, such as blood tests, x-rays and scans.

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. Other doctors charge a consultation fee, which means you pay the account at the time of the consultation and claim the benefit through Medicare. You can often make this claim when you pay the bill – the doctor's receptionist can process it through EFTPOS.

Medicare pays 100% of the Schedule fee for GP visits and 85% of the Schedule fee for visits to specialists – you pay the extra 15% of the specialist's fee. If the doctor charges above the Schedule fee, you will pay a gap fee on top of the 15%.



Keeping costs in check

- Ask your health care provider for a written quote for fees. If you receive a much higher bill, you can show them the quote and only pay that amount.
- Even if you have private health insurance, you don't have to use it – you can be treated as a public patient in a public hospital to reduce your out-of-pocket costs. Before you are admitted, the hospital will ask whether you would like to be treated as a private or public patient.

What if I can't afford treatment?

You have some options if treatment is too expensive:

- If your doctor charges more than the Schedule fee, ask if they will consider an exception in your case.
- Ask if costs are negotiable – some doctors may agree to reduce their fees.
- Find out if you can pay in instalments, or ask for more time to pay your bill. Check if you will be charged interest.
- Private patients can consider switching to a doctor who charges less.
- Ask your GP to refer you to a doctor in the public system.

Medicare Safety Net

The Medicare Safety Net subsidises out-of-hospital costs, such as medical appointments and tests, once your expenses exceed a certain amount (called the threshold). There are different thresholds depending on your circumstances. Once you reach the threshold, you may receive a higher Medicare benefit for eligible expenses for the rest of the calendar year.

Individual patients do not need to register for the Medicare Safety Net as Medicare automatically keeps a total of your expenses. You can contact Medicare to register as a family or couple and combine your medical costs so you are more likely to meet the threshold sooner. For more information about the Medicare Safety Net or to register as a family or couple, visit humanservices.gov.au/customer/services/medicare/medicare-safety-net.

Medicines and the PBS

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

Concession cards and allowances

Some PBS medicines are cheaper for people with the following cards:

- Pensioner Concession Card
- Commonwealth Seniors Health Card
- Health Care Card
- Department of Veterans’ Affairs health card.

You will need to show your eligible card to the pharmacist when you get your prescription filled.

People who receive certain Centrelink payments may be eligible for a Pharmaceutical Allowance, which can help to cover the costs of prescription medicines. For information and to check whether you qualify, visit humanservices.gov.au/customer/services/centrelink/pharmaceutical-allowance.

PBS Safety Net

The PBS Safety Net further reduces the cost of PBS medicines once you or your family have spent a certain amount. When you reach the Safety Net 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.

Generic medicines

You can ask your pharmacist to supply you with a generic brand of your prescribed medicine if one is available. Generic medicines contain the same active ingredients as more expensive brands. The medicine may look different, but it meets the high standards of quality, safety and effectiveness set by the Therapeutic Goods Administration, which regulates medicines sold in Australia.

Non-PBS prescriptions

Doctors may prescribe a medicine that is not on the PBS. Prescriptions for these medicines are known as private prescriptions. They may cost more than PBS medicines and they do 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

- Ask if your hospital or treatment centre charges a fee for chemotherapy drugs and whether you will have to pay.
- If you have private health insurance, ask whether you have to contribute to the cost of chemotherapy drugs.
- Some doctors prescribe only 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.
- Keep a record of your PBS medicines on a Prescription Record Form, available from your pharmacist. Take the form with you each time you get a prescription filled, so the pharmacist can record it.



Key points

- There are two types of health insurance: public (Medicare), which is provided by the government; and private, which is a contract between you and an insurer to cover certain medical expenses.
- Your treatment team should talk to you about how much treatment and medicines will cost. This is called informed financial consent.
- Some doctors charge more than the Medicare Benefits Schedule fee for services. Your health fund may pay the difference (gap fee) or you may have to pay it.
- If you're treated as a public patient, Medicare pays for your care and treatment in hospital, and for follow-up care from your doctor.
- For private patients in a public or private hospital, Medicare pays 75% of the Schedule fee for services and procedures.
- A lot of cancer care is delivered outside hospital, e.g. visits to your doctors and some tests. Medicare pays 100% of the Schedule fee for GP visits and 85% of the Schedule fee for visits to specialists out of hospital. The remaining 15% is paid by you.
- Once your expenses reach a certain amount (threshold), the Medicare Safety Net subsidises costs.
- The Australian Government's Pharmaceutical Benefits Scheme (PBS) subsidises the cost of many prescription medicines.
- The PBS Safety Net helps with the cost of medicines. Once you reach a certain threshold, your prescriptions for the rest of the year will be discounted or free.



Rights and responsibilities

This chapter explains what patient rights and responsibilities are and why they are important. The information is based on the Australian Charter of Healthcare Rights, which was developed by the Australian Commission on Safety and Quality in Health Care and endorsed for nationwide use in 2008.

The Charter sets out seven key patient rights – see pages 14–15.

For specific information about your rights in the workplace and other legal and financial matters, see *Other rights issues* (pages 49–58), or call Cancer Council 13 11 20 to request free booklets and fact sheets.

Q: What are patient rights?

A: Patient rights are rules and guarantees for people receiving medical care. Some rights are legally enforceable (see opposite); other rights are what you can reasonably expect from your care and are not legally enforceable.

Rights and responsibilities affect people seeking care in both the public and private health care systems.

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 navigate the system and take an active role in your care.

Q: Are rights legally enforceable?

A: Some rights are legally enforceable, which means that laws exist to protect them. There are laws against discrimination and laws governing the provision of 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 medical care, the right to be free from discrimination, the right to refuse treatment and the right to privacy. They create obligations for health professionals and the health care system.

While some of the rights 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 31–32.

Rights in the Australian health care system



Access

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



Safety

The care you receive should be safe and of high quality. After discharge from hospital, you should receive instructions about how to care for yourself at home so you have a safe recovery.

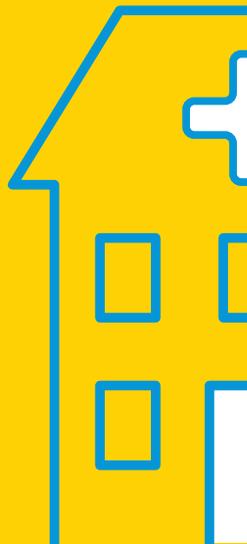
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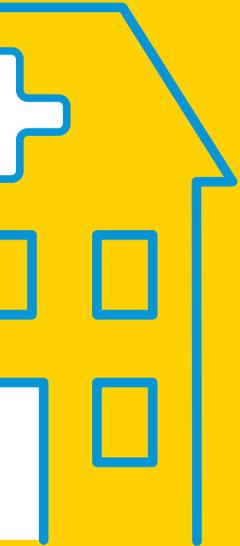
You have a right to give a compliment or make a complaint, and for any concerns to be addressed.



Respect

You should be shown respect, dignity and consideration, and receive services free from discrimination, regardless of your age, gender, sexual preference, religion or culture.





Communication

Services, treatment options, risks and costs should be clearly explained to you. The communication should be appropriate and on a regular basis. You can ask questions if you need clarification. You can request free interpreter services if English is not your first language.

Privacy

Your personal information must be kept private and confidential (except in very limited circumstances). This includes your written medical records.



Participation

You can take part in decisions about your health care. For example, you can decide if you want to be treated by a particular health care practitioner; take part in medical research; or participate in the clinical training of junior doctors and medical students. If you don't want to receive care, you can leave a health facility at any time, at your own risk and liability.



Source: [safetyandquality.gov.au/wp-content/uploads/2012/01/Charter-PDF.pdf](https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Charter-PDF.pdf). Viewed: 3 May 2016.

Q: What are patient responsibilities?

A: To be effective, health care is more than a one-way street. If you expect your health care providers to behave in a certain way – for example, to communicate openly – it helps to provide the same in return. Your hospital or treatment centre might give you a brochure about your responsibilities, which may cover the following three areas.

Being honest and open

A key responsibility is to make sure your treatment team has all the information they need to offer treatment that is best for you. Be up-front with your team and give them accurate details about your health. Tell your treatment team if:

- you have a question or problem – it's vital that you communicate any issues that 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 a young family or an elderly relative, or if you work or study
- you have side effects or pain – your treatment team may be able to change the dose of your medicine or offer you medicine to relieve side effects
- you're seeing more than one doctor or another health professional – this includes complementary or alternative therapy practitioners

- you are taking any other medicines – this includes prescription and over-the-counter drugs, and complementary and alternative 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
- you decide not to follow instructions – for example, by not taking prescribed medicine.

Being considerate

There are some basic responsibilities that relate to practical issues, including:

- treating staff and other patients with courtesy, dignity and respect
- being on time
- letting the health service know if you are unable to attend an appointment.

Being flexible

Your doctor plans your treatment based on your initial test results. You will then have tests to check your response to treatment, and 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.



Who can help?

Doctors, nurses and other health professionals care for you and can help you find your way through the health care system, from diagnosis through to treatment and recovery.

This chapter describes the roles of people who may be in your 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.

Your specialists

Depending on the cancer type and treatment you have, several specialists may plan and manage your treatment, including a surgeon, a medical oncologist, a radiation oncologist, a haematologist or a palliative care specialist. They can also answer any questions you have about your treatment. The doctors caring for you usually work as part of a multidisciplinary team (MDT, see page 23).

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, so it is best to use that time to talk about your treatment.

Other members of your treatment team are often more accessible than your specialist, and they may be able to help you with questions and concerns more quickly. If you are treated in hospital, it may be helpful to talk to resident medical officers and registrars, who can ask your specialist for information.



Consider taking a list of questions when you visit your doctor. Call **13 11 20** and ask for the *Questions for your doctor* fact sheet, or download it from your local Cancer Council website.

Cancer care coordinator or clinical nurse consultant

The cancer care coordinator or clinical nurse consultant is a senior specialist nurse who monitors patients throughout their diagnosis and treatment, and works closely with specialists. They are a reliable source of information and support.

There may be cancer care coordinators for specific cancer types in large hospitals, while smaller hospitals may have general coordinators. In rural areas, cancer care coordinators may visit 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

The social worker is the primary point of contact for practical issues that affect life outside hospital, such as accommodation, transport, financial assistance, child care and home nursing care. Many social workers also provide emotional support and counselling. They ensure you can access the information and assistance that's available in your local community, and will link you with people and services who are best able to meet your needs.

Your general practitioner (GP)

It is important to have a good relationship with a GP who knows you and your medical history. When you are discharged from hospital, your treatment team will usually provide you with information to give to your GP, and your specialists should send test results to them.

You can discuss treatment options with your GP, who can also arrange a second opinion if required. 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.

Other health professionals

A range of health professionals can help you cope with the physical and emotional effects of cancer. These people include:

- **dietitians** – specialise in diet and disease, and recommend an eating plan for you to follow during treatment and recovery
- **psychologists or counsellors** – provide emotional support by listening to problems and offering strategies for dealing with them
- **physiotherapists** – help you to move and exercise safely to regain strength, fitness and mobility
- **occupational therapists** – offer equipment/aids and advice about getting back to your daily activities.



Cancer Council produces booklets about many different types of cancer. Call **13 11 20** and ask for free copies, or download digital versions from your local Cancer Council website.



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 have influence over your care. This chapter describes points to consider when choosing a specialist, and outlines your rights when making a decision.

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. Some people are happy to leave the choice of specialist to their GP. However, you have a right to be involved if you would like to be. You may prefer to choose a specialist based on recommendations from other people, such as family, friends or colleagues.

Public or private treatment

You are entitled to be treated as a public patient in a public hospital. If you are treated in the public system, you can be referred to any specialist regardless of where they are located. You can have a say in where you are treated by researching a public treatment centre that may specialise in the type of cancer you have (see *Specialist centres*, page 24). Keep in mind that public hospitals may give priority to patients in their local area, so you may have to wait longer if you want to be treated by a specialist outside your area.

If you have private health insurance, you can be treated as a private patient in a private facility, or you can avoid out-of-pocket expenses by being treated in a public hospital. See pages 5–8 for more information about paying for cancer care.

**Do you specialise
in this type of
surgery?**

**Can I talk to
someone who has
had this surgery?**

**Have you treated
a lot of people
with this type
of cancer?**

**Do you work in a
multidisciplinary
team?**

**Which hospitals or
treatment centres
do you work or
operate in?**

**Are you a member of
the relevant section
of a specialist college
(e.g. for breast cancer, the
Royal Australasian College
of Surgeons breast section)?**

Questions you may want to ask the surgeon or oncologist

A cancer diagnosis and treatment often means many medical appointments. Before visiting the doctor, take some time to prepare for the appointment.

Key issues in choosing a specialist

There are a few issues to consider when deciding which specialist should be responsible for your treatment.

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 outcomes.

Multidisciplinary care – There is evidence that patients have better outcomes if their doctor works as part of a multidisciplinary team (MDT). This means health professionals work together to plan treatment and manage care.

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 and a dietitian. They meet regularly to review cases and consider treatment options.

The team also discusses how best to help the patient cope with the physical and emotional effects of cancer.

Visit canceraustralia.gov.au/affected-cancer/treatment/treatment-team for tips on communicating with your treatment team.



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 rarer cancers or cancers that don't have a typical response to treatment.

You may not be aware of the treatment centres that specialise in the type of cancer you have. Ask your GP for suggestions. If they're not familiar with specialist centres, they may be able to refer you to someone who is.

The key principle is that it's your right to ask 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.

Specialist treatment centres 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.

How to find a specialist

Ask your GP – If your GP has already referred you to a specialist or treatment centre, you should ask on what basis they have referred you – is it because the specialist has particular skills or simply because they are nearby?

Your GP should have clear reasons for referring you to a particular specialist, and you are entitled to ask about those reasons and to receive an answer. You also have the right to ask your GP for a referral to more than one specialist.

Search online – Check the websites of cancer organisations for a list of specialists. For example, you can search for colorectal surgeons on the Bowel Cancer Australia website.

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.

Rural patients

In rural areas, your GP may refer you to a local specialist or treatment centre, or to a visiting oncologist.

There are some excellent regional cancer centres in Australia, and some specialists in these areas 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.

If treatment for your cancer type is not available close to home and you must travel for treatment, you may be eligible for financial assistance to pay for travel to a suitable treatment centre. Accommodation costs may also be covered.

To find out about assistance programs in your area, call Cancer Council **13 11 20** or visit ruralhealthaustralia.gov.au, search for 'PATs' and click on 'Patient Assisted Travel Schemes'.



Key points

- Under the Medicare system, you need a referral to see a specialist. This referral can come from a GP or another specialist. You can be involved with this choice if you prefer.
- If you need or want to be treated in the public system, you can be referred to any specialist regardless of where they are located. Public hospitals may give priority to patients in their local area.
- If you have private health insurance, you can be treated as a private patient in either a private or public hospital.
- You may want to ask the specialist about their experience, such as how many cases of this cancer type they have treated and whether they are a member of a specialist college.
- Some specialists and treatment centres have particular expertise in treating certain types of cancer because they see a large number of patients.
- Health professionals often work together to plan and manage cancer treatment and care. This is called a multidisciplinary team (MDT).
- Some treatment centres tend to specialise in diagnosing and treating a particular type of cancer.
- Your doctor should have clear reasons for referring you to a particular specialist. You are entitled to ask about those reasons and to receive an answer.
- 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. Rural areas may have a local specialist, a treatment centre or a visiting oncologist.



Making treatment decisions

When you are diagnosed with cancer, you have to make a number of decisions about your treatment. This chapter sets out your rights in being involved in treatment decisions. It also outlines how you can become informed so that you and your specialist can decide on an appropriate treatment plan that offers the greatest chance of the best possible outcome.

Gathering information

Sometimes it is difficult to decide on the type of treatment to have. Making sure you understand enough about your illness, the treatment and its side effects will help you to make your own decisions.

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. For most cancers, there's no urgency to decide about treatment straightaway.

Many people like to have a family member or a friend go with them to the specialist appointment to take part in the discussion, take notes or simply listen. If you are confused or want clarification, you can ask for further explanation. It may also be helpful to write down any questions you have and take them to the appointment.

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).



CAN.recall is a smartphone app that features questions to ask your oncologist or surgeon, and it includes the ability to record the answers. Visit www.rarecancers.org.au/page/1086/can-recall-app to download the app.

Decision-making steps

If you are concerned that you need to make a quick decision about your treatment, ask your specialist if it's okay to take more time to consider your options.

- Weigh up the advantages and disadvantages of each treatment.
- Consider how side effects might affect you, especially if they will have an impact on your lifestyle. If you have a partner, it may help to discuss any side effects with them.
- If only one type of treatment is recommended, ask if other treatments are an option.
- 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 31–32); and talking to family, friends or people who have had the same cancer.
- If you're not happy with the information you are given – or how it is given – share your concerns with your doctor or the treating hospital or centre.

Giving informed consent

Your doctor is required to inform you about the benefits and risks that are relevant to you. Receiving and understanding all of this information before voluntarily agreeing to treatment (that is, without being pressured to do so) is called informed consent. Adults can give their informed consent – or decline it – if they can understand, remember and make choices about the information provided.

Before giving informed consent to treatment, you could ask:

- What are the treatment options?
- Are there any clinical trials I could join?
- What are the expected outcomes of each option, including complications and side effects?
- What is the chance that each outcome will occur?
- What methods can be used to prevent or relieve side effects?
- Are there other treatments that you aren't recommending? Why?
- What will happen if I don't have treatment?

Sometimes consent is not needed, such as in a medical emergency.

Capacity

Your ability to make decisions is called capacity. If there is a chance you might ever lose the capacity to give consent, you may consider advance care planning (see next page), which can involve appointing someone to make medical, financial and legal decisions for you (substitute decision-maker). The documents for appointing this person may be known as an enduring power of attorney, an enduring guardian or a power of guardianship.

Person Responsible

If you lose capacity to give consent and you haven't appointed a substitute decision-maker, consent may be given by a Person Responsible. 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. intellectually disabled people)	<ul style="list-style-type: none">the appointed guardian
for people 16 and older	<ul style="list-style-type: none">the appointed substitute decision-maker, e.g. enduring guardian or enduring power of attorneythe most recent spouse, including a de facto spouse or same-sex partner, with whom the person has a close and continuing relationshipan unpaid carera close friend or relative

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

Advance care planning

Advance care planning involves thinking about your future health care and discussing your wishes with your family, friends and treatment team. The written record of your wishes may be called an advance care plan, an advance care directive or a living will.

Visit advancecareplanning.org.au/resources for specific information about advance care planning in your state or territory.

Consent and children

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 patients 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 that 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 consequences of the proposed treatment, and their decision may need to be supported by a medical practitioner.

Talk to a lawyer for specific information about consent and children in your state or territory.

Getting a second opinion

Finding a specialist and deciding on treatment can be difficult. It may help 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 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 seek a second opinion. However, some people would like a second opinion but may not ask for one, perhaps because they don't realise they can or because they don't want to upset the specialist they've been referred to.

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 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 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 don't accept patients for a second opinion because they have a heavy workload.
- 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 that person.

Treatment guidelines

While every case of cancer is different, your specialist should recommend treatment that has a strong research base. This is called evidence-based medicine.

Guidelines are developed by institutions and experts to provide information about different types of cancer. They are regularly reviewed and updated in line with the latest clinical evidence.

The guidelines may cover:

- what tests are needed to determine the stage and grade of the cancer
- the treatments that are most effective
- the urgency of treatment, for example, how long it is reasonable to wait between receiving test results and starting treatment
- timely and appropriate access to tests and 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 the treatment guidelines, but guidelines aren't available for every type of cancer. Treatment guidelines for breast cancer, gynaecological cancers and lung cancer can be found at canceraustralia.gov.au/clinical-best-practice. You can find guidelines for other cancer types on Cancer Council Australia's Cancer Guidelines Wiki at wiki.cancer.org.au/australia/guidelines.

Taking part in a clinical trial

Doctors conduct clinical trials to test new or modified treatments to see if they are effective. Research shows that people who take part in clinical trials generally have better outcomes than those treated outside of clinical trials.

This section explains some aspects of clinical trials, but more detailed information is available in Cancer Council's booklet *Understanding Clinical Trials and Research*. Call 13 11 20 for a free copy, or download a digital version from your local Cancer Council website.

How to find a clinical trial

If you would like to take part in a clinical trial, you can talk to your specialist, who may be running a suitable trial or know of one being run elsewhere. If not, they may be able to help you find one. Some hospitals have clinical trials or research nurses who can help.

Trials are available only in select treatment centres, so you might have to travel to a different location to take part.

If you hear or read in the media about a clinical trial, ask your doctor for more information. Remember that trials have guidelines on who can participate, and you may not be eligible to join – for example, the trial may be for people with other types of cancer.

Up-to-date information on clinical trials can also be found online.

Information on clinical trials

- Australian New Zealand Clinical Trials Registry anzctr.org.au
- Australian Cancer Trials australiancancertrials.gov.au
- Cancer Trials Australia cancertrialsaustralia.com
- Your local Cancer Council website may also have information about trials.

What happens in a randomised controlled trial?

If you join a randomised controlled trial, you will be selected at random to receive the best existing treatment (the control) or a promising new treatment. Some people are reluctant to join a clinical trial because they worry they'll be randomised into the control group rather than the group receiving the new treatment. The control group is the standard care, so you will still be receiving evidence-based treatment.

You have to give consent to take part in a clinical trial, and you have rights while participating, including the right to withdraw from the trial at any time; withdrawing won't jeopardise your cancer treatment. If you are unsure about joining a clinical trial, ask for a second opinion from an independent specialist or talk to your GP.

“ The trial I was on ran initially for three years, but my involvement only lasted a year and a half. I had to have check-ups every three months – a physical examination and blood tests. ” Julie



Key points

- You will have to make many decisions about your treatment. Being informed about the treatment and its side effects will help you to decide.
- Take the time to consider all of your treatment options. If you are concerned that you need to make a decision quickly, ask your specialist if it's okay to take more time.
- Write down questions to ask your specialist, and consider taking someone with you to the consultation. You may record the conversation or take notes.
- Your specialist is required to inform you about the potential benefits and risks of treatment. Receiving and understanding all the relevant information before agreeing to a procedure is called informed consent.
- A doctor needs your consent (agreement) to perform any treatment, unless it's an emergency. People under 16 usually need a parent or guardian to consent on their behalf, but this can depend on the individual situation.
- You may want to think about your future health care and discuss your wishes with your family, friends and treatment team. This is called advance care planning.
- It can help to talk to more than one specialist to consider other treatment options or to confirm a recommended treatment (second opinion).
- For some types of cancer, there are evidence-based guidelines covering issues such as what tests are needed and how urgent treatment is.
- Doctors conduct clinical trials to test new or modified treatments to see if they are more effective than the best existing treatment.



Medical records and other privacy issues

Health professionals will collect a lot of information about your health and the treatment you receive. A medical record contains personal information, so it's important to know who can see it, change it and copy it. This chapter covers your rights in relation to your medical records and other privacy issues, such as talking about sensitive matters with health professionals.

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 are treated for a medical condition, either in or out of hospital, the person treating you creates notes about your health. This is called a medical record.

A medical record could be handwritten or electronic and it will include notes about:

- services provided
- scans, tests and the interpretation of results
- recommendations about treatments
- personal details (e.g. genetic information)
- correspondence to health professionals.

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.

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 can request access to it.

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?

Australian privacy standards establish a general rule that organisations are required to provide you with access to personal information (such as medical records) held about you.

This standard has been developed because 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.



You can authorise someone else to see your medical records, such as a relative, interpreter or another health professional. Your records may also be provided to the health ombudsman if you make a complaint about your health care. See page 44 for more information.

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 fee to copy your record (public hospitals usually charge about \$30), but there shouldn't be a fee to just look at the record.

Why might access be denied?

Rarely, you won't be allowed to have a copy of your medical records because:

- another law requires your information to be kept private (e.g. if the information relates to legal proceedings)
- there's a risk that the information could harm you or someone else, such as a relative, treatment staff or other patients.

Who can change my medical records?

You can ask for changes to your medical records if you think the records are inaccurate, irrelevant or misleading. You should 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. If you disagree with the decision, you can make a complaint to the Office of the Australian Information Commissioner or to the health ombudsman or complaints commission in your state or territory (see page 45).

Other privacy issues

When you are having treatment, you have a right to privacy and confidentiality. Some privacy issues that may affect you include:

- If you're being treated in a public hospital, you have the right to talk to your doctor in a quiet, private room. You can also decide who should be included in the meeting.
- You can decline visitors, even during hospital visiting hours.
- In some treatment centres, trainee doctors and medical students observe consultations and are involved in cancer care under the supervision of a specialist. You should be informed if they will be involved, and you are entitled to refuse or limit their involvement.
- You can ask your doctor or treatment centre to mail information to you in unmarked envelopes.

If you're concerned about your privacy, talk to your treatment team or hospital social worker.



Commenting on health care

You have the right to provide feedback on and complain about any aspect of your health care, and to receive a prompt response.

This chapter describes the importance of both positive and negative feedback. It outlines the different ways you can give feedback or make a complaint. This information is relevant whether you are treated in a public or private hospital or treatment centre, or if you see a practitioner in a private clinic.

Importance of feedback

Your feedback allows you to be a part of improving health care by reinforcing what is being done well and highlighting what can be improved. You can provide feedback in the following ways:

- **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 inefficiencies to be addressed to make things smoother for patients. Often health professionals are so busy treating people that they overlook practical issues that are easy to solve and can improve your experience of treatment.
- **Complaints** – Negative feedback is important if health care services have not met your expectations. It helps services and health professionals to identify and improve service gaps or problems in treatment, communication and behaviour.

How to give feedback or complain

All health care facilities should have procedures for patients to provide feedback. Check with the nursing unit manager, cancer care coordinator, social worker, patient representative or patient advocate.

Raising the issue may mean you get a different perspective on why something occurred, and talking about it may make you feel better. You can also have another person, such as a friend or a relative, 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 addressed immediately. A quick conversation may help to resolve a simple misunderstanding.

However, you may prefer to write a letter, for example, if you find it difficult to discuss your concerns 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. However, the ombudsman may not assess complaints after a certain time frame, and there are strict time limits for medical negligence complaints (see page 47).

Steps for making a complaint

- Talk to your specialist, a nurse or another health professional so they have the chance to resolve the issue immediately.
- 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.
- If you're not happy with the response from a health professional, or if you want to talk to a neutral party, contact the hospital's independent patient representative, complaints officer or patient advocate.
- If you're not satisfied with the patient representative's investigation, you can elevate your complaint to the hospital's quality assurance department, or to the clinical governance unit of your area health service. As smaller or private hospitals may not have a patient representative or a quality assurance department, you can contact the nursing unit manager or general manager.
- If you're still not happy with the outcome – or if you don't want to raise the issue with the health care facility concerned – contact your state or territory's health ombudsman (see page 45).
- If you have a serious complaint that you want to take to the health ombudsman or complaints commission, you may wish to obtain independent legal advice.

Health ombudsman

To make a formal complaint, you need to contact your state or territory health ombudsman or relevant complaints commission (see table opposite).

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.

Complaints should be made in writing and can often be made via an online form.

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 ombudsman or commissioner decides how to manage 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 practitioner may result in prosecution, and some cases can be referred to a registration board or another organisation – see page 46 for information about registration boards.

State/territory	Ombudsman or commission
Australian Capital Territory	ACT Human Rights Commission 02 6205 2222 hrc.act.gov.au
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 hcsccl.nt.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 (toll-free country SA) hcsccl.sa.gov.au
Tasmania	Health Complaints Commissioner Tasmania 1800 001 170 www.healthcomplaints.tas.gov.au
Victoria	Office of the Health Services Commissioner 1300 582 113 health.vic.gov.au/hsc
Western Australia	Health and Disability Services Complaints Office 08 6551 7600 or 1800 813 583 (country WA free call) hadsco.wa.gov.au

Registration boards

The health professionals listed in the table below are required to be registered and accredited nationally through professional registration boards. These boards are responsible for ensuring that only trained and competent health professionals practise in their profession. The Australian Health Practitioner Regulation Agency (AHPRA) oversees the work of the registration boards – see ahpra.gov.au.

All registration boards have a process for handling complaints. If you have an unresolved problem with a registered health professional, you should contact the relevant registration board.

Registered health professionals

- Aboriginal and Torres Strait Islander health practitioners
- Chinese medicine practitioners
- Chiropractors
- Dentists
- GPs and specialists
- Nurses
- Occupational therapists
- Optometrists
- Osteopaths
- Pharmacists
- Physiotherapists
- Podiatrists
- Psychologists
- Radiation practitioners

Unregistered health practitioners

Allied and complementary health professions may be self-regulated. This means practitioners are not legally required to be registered, but they can choose to join a professional association that sets education and practice standards. These practitioners may be called ‘accredited’.

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 the health ombudsman or complaints commission.

Medical negligence

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

In most states and territories, the time limit for lodging a complaint is 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, contact the Law Society or Institute in your state or territory to find a lawyer who specialises in medical negligence.

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. For more information about advocacy, call Cancer Council 13 11 20 or visit cancervoicesaustralia.org.



Key points

- You have the right to comment on or complain about any aspect of your health care and to receive a prompt response. Patient feedback helps to improve health care by reinforcing what is being done well and highlighting what can be improved.
- All health care facilities should have procedures for patients to provide feedback. Check with the nursing unit manager, cancer care coordinator, social worker, patient representative or patient advocate.
- If your issue is with a particular health professional, it is usually best to talk to them face-to-face or on the phone, especially if there has been a simple misunderstanding.
- Health care providers are bound by a strict code of conduct to maintain confidentiality regarding any complaints.
- You can complain to your state or territory health ombudsman or complaints commission.
- Many health professionals are required to be registered and accredited nationally through professional registration boards. Allied and complementary health care providers may be self-regulated.
- 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).
- Advocacy means speaking out on behalf of others to achieve positive change. People may try to make changes by advocating to key organisations and governments.



Other rights issues

Other issues you may face during or after cancer treatment include:

- purchasing and claiming on insurance policies
- access to superannuation, reimbursements, benefits and pensions
- dealing with debts
- your rights in the workplace
- concerns you may have about advanced cancer and end of life.

This chapter provides an introduction to these topics. For more information, including what to do if insurance claims are rejected, delayed or reduced, you can refer to Cancer Council's booklet *Cancer and Your Finances* and fact sheets about workplace, legal, financial and insurance issues. For free copies, call 13 11 20, visit your local Cancer Council website, or talk to your hospital social worker. You may also want to consider obtaining independent legal and financial advice about any issues covered in this chapter.

Insurance

You may have taken out personal insurance policies, such as income and mortgage protection, or life or trauma insurance, before you were diagnosed with cancer. Usually this will mean 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. Insurance companies are allowed to refuse cover, but only on reasonable grounds. This does not include health insurance – it is unlawful to be denied health insurance.

Travel insurance

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.

Travel insurance policies can cover the basics, such as lost luggage and cancelled flights, as well as overseas medical expenses and death or disability cover. If you have to disclose any pre-existing health conditions, be honest – a claim may be denied if you withhold information.



Applying for 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 so you can access 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.

Superannuation

If cancer causes financial issues, you may consider accessing your superannuation or claiming on insurance policies that might be attached to your superannuation account.

Cancer Council produces fact sheets that provide state- and territory-specific information about superannuation. Call 13 11 20 and ask for free copies, or download digital versions from your local Cancer Council website.

Reimbursements, benefits and pensions

The Department of Human Services offers a range of payments to people with cancer via Centrelink. These include:

- **Sickness Allowance** – for people aged 22 or older who can't work or study due to illness
- **Mobility Allowance** – for people who can't use public transport without substantial assistance due to illness and who need to travel for work or study
- **Disability Support Pension** – for people with a medical condition that means they are unable to work.

Medicare has reimbursement programs for people who require certain medical supplies, such as prostheses or stoma accessories.

For more information about reimbursements, benefits and pensions, see humanservices.gov.au or visit a Centrelink or Medicare office.

Dealing with debts

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

- extending your loan term
- reducing or pausing repayments
- changing to interest-only repayments
- renegotiating your interest rate.

If you're not satisfied with the response you receive from your lender, you can complain via a free external dispute resolution scheme, such as those provided by the Financial Ombudsman Service Australia (fos.org.au) or the Credit and Investments Ombudsman (cio.org.au). The Australian Securities and Investments Commission's MoneySmart website has information about making complaints – visit moneysmart.gov.au/tools-and-resources/how-to-complain.

A financial counsellor can help you to budget and work out a plan to manage your debts. Visit financialcounsellingaustralia.org.au to find a counsellor in your area.

Call Cancer Council 13 11 20 and ask for a free *Dealing with debts* fact sheet, or download it from your local Cancer Council website.



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 a way to avoid disconnection and penalty fees.



Carmen's story

I'd been complaining to my doctor for about six months about a pain in my hip. At first, she told me there was nothing wrong with me because I had a lot of scans and tests and all the results came back negative.

Eventually, I had a colonoscopy and the doctor found a polyp. I found out it was bowel cancer the day after my birthday.

I'd been working in the finance industry for a while and I had a lot of responsibility. The company had been sold about two months earlier, so I was already concerned about my job.

I went into work after the doctor told me I had cancer and talked to my boss, who said he'd do anything to stand by me. I was very lucky in that regard.

I took sick leave to have surgery to remove part of my bowel. When I was well enough to have chemo, I worked part-time

from home when I felt up to it. Overall, I worked this way for nine months during my treatment and recovery.

Once chemo was finished, I went back to work full-time. By then, the office had moved from near my home to the city, which meant I had a longer distance to travel each day. I don't know how I did it all, but I did.

I didn't have as much responsibility when I first went back, but I didn't care at the time because I just wanted to recover from my illness. I was able to schedule my check-ups in the morning before going to work. At one point, I had to go back to hospital as I had a blocked bowel, but work was flexible and understanding.

There have been lots of changes at work, but now I'm back in the same role I had before I had cancer, and everything's going really well.

Workplace issues

If you are employed or hope to return to work after treatment, you might wonder how cancer will affect your job. You may be concerned about your leave entitlements, discrimination at work, unfair dismissal or your right to flexible working hours.

Some of the issues described here differ between states and territories, and they may depend on the industry you work in. For more specific information, call 13 11 20 or visit your local Cancer Council website, where you can download the booklet *Cancer, Work & You* and fact sheets about employment issues, including compensation for work-related cancer.

Taking leave

All full-time employees except casuals are entitled to 10 days of paid personal leave each year, including sick leave. Part-time employees receive this entitlement on a pro rata basis. If you need to take more time off, you may be able to take unpaid leave or make another arrangement with your employer.

Discrimination

Being discriminated against at work because you have cancer is against the law. Examples of discrimination include being prevented from taking leave that you are entitled to and being sacked for a reason related to your cancer diagnosis.

If you think you're being discriminated against, you can lodge a complaint with the Australian Human Rights Commission (humanrights.gov.au) or the anti-discrimination,

equal opportunity or human rights agency in your state or territory (see table, next page).

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. Tribunals are less formal than courts, and you may not need legal representation. A tribunal has the power to make a legal judgment that must be followed.

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

Cancer Council's Pro Bono Program offers free legal and financial assistance to eligible people. Call **13 11 20** to find out if you qualify.



Special arrangements

Your employer may need to make arrangements to help you manage your work responsibilities while you are having or recovering from treatment. They can only refuse to provide these arrangements if the changes would cause serious hardship to their business. Some examples of flexible 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.

State/territory	Agency
Australian Capital Territory	ACT Human Rights Commission 02 6205 2222 hrc.act.gov.au
New South Wales	Anti-Discrimination Board of NSW 02 9268 5544 or 1800 670 812 (regional NSW only) www.antidiscrimination.justice.nsw.gov.au
Northern Territory	Northern Territory Anti-Discrimination Commission 1800 813 846 adc.nt.gov.au
Queensland	Anti-Discrimination Commission Queensland 1300 130 670 adcq.qld.gov.au
South Australia	Equal Opportunity Commission (08) 8207 1977 or 1800 188 163 (country callers) eoc.sa.gov.au
Tasmania	Equal Opportunity Tasmania 1300 305 062 equalopportunity.tas.gov.au
Victoria	Victorian Equal Opportunity & Human Rights Commission 1300 292 153 humanrightscommission.vic.gov.au
Western Australia	Equal Opportunity Commission (08) 9216 3900 or 1800 198 149 (country callers) eoc.wa.gov.au

Advanced cancer issues

If you have cancer that has spread or come back, you may live for many years. However, some people with advanced cancer want to outline their wishes for end-of-life care. Making plans may give you peace of mind and help you to make your wishes clear to your family, friends, carers and health care providers.

- You have a right to make treatment decisions as long as you have capacity (see page 29), including decisions about accessing palliative care services, and stopping or refusing treatment. You can also request that treatment continue as long as it could be of benefit.
- You can appoint someone to make decisions for you and/or create an advance care plan (see page 30). Each state and territory has different laws and types of documents.
- You can make a will that details how you want your assets and belongings (your estate) distributed after you die.
- You can indicate where you would prefer to die (e.g. at home, or in a hospice or hospital).

Not everyone needs information about advanced cancer issues, and it can be confronting to consider these topics. Cancer Council has free booklets about advanced cancer, palliative care and end-of-life issues, as well as state- and territory-specific fact sheets about getting your affairs in order, dealing with debts after death and appointing an executor. Call 13 11 20 to request information, or visit your local Cancer Council website.



Key points

- You may have insurance policies, such as income and mortgage protection, or life or trauma insurance, when you are diagnosed with cancer. Insurance companies (excluding health insurers) are allowed to refuse cover, 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 insurers don't cover medical expenses for people who have had cancer. You can ask for the reasons for a refusal of cover in writing.
- If cancer causes financial issues, you may consider accessing your superannuation or claiming on insurance policies that are attached to your superannuation account.
- The Department of Human Services (Centrelink) offers benefits and pensions to people with cancer. Medicare also offers reimbursement schemes for some products and equipment, such as stoma accessories and prostheses.
- 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.
- If you are working, you can talk to your employer about taking leave and changing your work arrangements during treatment and recovery.
- People with advanced cancer may consider outlining their wishes for end-of-life care.



Rights of carers

A carer is someone who helps and supports a person through a disability or illness. Carers have a vital but often demanding role providing physical and emotional support to people with cancer.

This chapter sets out your rights as a carer in dealing with the treatment team, and making medical and financial decisions. It also covers your rights at work and the types of support you can access.

Talking to the treatment team

One of your key roles as a carer will be to help the person you care for communicate with their treatment team and make decisions about their care. The person needs to provide their 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 be an advocate for the patient. It is your right to take on this role if that is what they would like.



Medical appointments

- Prepare for appointments by talking with the person you care for and making a list of questions to ask the doctor.
- Call the receptionist to check what you have to take, such as test results or scans.
- Take a list of any medicines and doses that the person is taking.
- Keep a diary of the person's health issues or symptoms, or help them to keep their own diary.

Making decisions

Financial decisions

The person you care for may give you the power to act on their behalf on all financial matters if they lose the capacity to make their own decisions. This is usually called an enduring power of attorney.

Medical decisions

As a carer, you may be appointed by the patient or asked by the treatment team to make medical decisions for the person with cancer if they lose capacity. While this is called different things in different states and territories, it is often called a power of guardianship or an enduring guardian. Call your local Cancer Council on 13 11 20 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 Person Responsible for medical decisions (see page 30).

If you or your partner have any concerns about you being recognised as the decision-maker, consider asking your partner to appoint you as their enduring guardian or enduring power of attorney (when they still have capacity).

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 can approach the substitute decision-maker (see pages 29–30).

Workplace issues for carers

This section provides a snapshot of some of the issues faced by working carers. For specific information about carers' rights at work, call 13 11 20 to request a copy of the *Cancer, Work & You* booklet, or contact Carers Australia by calling 1800 242 636 or visiting carersaustralia.com.au.

Carer's leave

All full-time employees except casuals are entitled to receive 10 days of paid personal leave each year, which includes sick leave and carer's leave. Part-time employees receive this entitlement on a pro rata basis. 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 injured or dies. Casuals are not paid for this type of leave.

All employees, including casuals, are also entitled to two days of unpaid carer's leave per year, or more time if their employer agrees. This unpaid leave can be used when the employee has used up their paid personal leave.

For more information about carer's leave, visit fairwork.gov.au and search for 'sick and carer's leave'.

Discrimination

Discrimination at work because of your caring responsibilities is against the law and is prohibited under the Disability Discrimination Act and the Fair Work Act. 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 to the same benefits as other employees.

Special arrangements

Your employer may need to make arrangements to help you manage your work and caring responsibilities. They can only refuse to provide these arrangements if the changes would cause serious hardship to their business. Some examples of flexible 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.

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 (fwc.gov.au), or the human rights, equal opportunity or anti-discrimination agency in your state or territory (see page 56).

See pages 54–55 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 supports carers with a range of payments via Centrelink. These include:

- **Carer Payment** – for carers who provide full-time assistance in the home of the person with cancer. It is subject to income and assets tests
- **Carer Allowance** – for carers who provide a significant amount of assistance, either in their own home or in the home of the sick person. The allowance is not income and assets tested. You may be eligible if you are working or receiving another type of benefit
- **Carer Supplement** – for people who receive the Carer Payment, Carer Allowance or other benefits. It is automatically paid annually as a lump sum
- **Carer Adjustment Payment** – for people providing full-time care to a sick child under seven years of age.

For more information about financial assistance for carers, visit humanservices.gov.au/customer/subjects/payments-carers.

Cancer Council's booklet *Caring for Someone with Cancer* has more information about being a carer. Call **13 11 20** and ask for a free copy, or download it from your local Cancer Council website.



Support for carers

There are specific services for carers of all ages to help support their physical and mental wellbeing:

- 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. Call 1800 422 737 or visit carergateway.gov.au.
- The National Carer Counselling Program provides short-term professional counselling. It is run by local Carers Associations. For details, call 1800 242 636 or visit carersaustralia.com.au and click on 'How We Work'.
- Cancer Council runs a telephone support group for carers of people with cancer. Call 13 11 20 for details.
- The Young Carers Program provides services for people aged up to 25 who are caring for a person with cancer. Call 1800 242 636 or visit youngcarers.net.au.
- Commonwealth Respite and Carelink Centres provide free and confidential information about respite options and support services for carers. Centres are located throughout Australia – call 1800 052 222 to find your nearest centre.



Key points

- A carer is someone who helps and supports a person through a disability or illness.
- The person you care for may give you the power to act on their behalf on all financial matters after they lose the capacity to make their own decisions. In some areas of Australia, this is called an enduring power of attorney.
- You may be appointed to make medical decisions for the person with cancer. This is managed differently in each state and territory.
- Working carers are people who have caring responsibilities in addition to paid casual or permanent employment. For information about carers' rights at work, call **13 11 20** to request a free copy of *Cancer, Work & You*.
- All employees are entitled to two days of unpaid carer's leave on top of any available paid leave.
- If you feel you have been discriminated against because of your caring responsibilities, you may make a complaint to the Australian Human Rights Commission, the Fair Work Commission or the anti-discrimination, human rights or equal opportunity agency in your state or territory.
- The Department of Human Services (Centrelink) supports carers with a range of payments, including the Carer Payment, Carer Allowance and Carer Supplement.
- There are specific support services for carers of all ages, such as counselling and respite services and support groups.



Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

In these support settings, people often feel they can speak openly and share tips with other people who have gone through a similar experience.

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

Ask your nurse or social worker about support groups that are available in your area, or call Cancer Council 13 11 20.

Types of support services

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

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as cancerconnections.com.au.

Cancer Council resources

Many of the issues in this booklet are complex, and some of your rights will be governed by laws in your state or territory. For this reason, it's best to contact your local Cancer Council to ask about the booklets and fact sheets relevant to your situation. Call 13 11 20 to talk to a consultant, who can send you free copies. Digital versions of these resources are also available from your local Cancer Council website, although availability may vary across states and territories.

Booklets and fact sheets cover issues such as:

- emotions
- workplace rights, discrimination and work-related cancers
- treatments, such as chemotherapy and radiotherapy
- complementary therapies
- caring for someone with cancer
- superannuation, insurance and financial issues
- advanced cancer
- palliative care
- end-of-life issues, such as getting your affairs in order and dealing with debts after death.

Cancer Council also produces booklets about more than 20 types of cancer. For copies, call 13 11 20 or visit your local website.

“ I started having relationship issues when I was going through chemo, and my partner left me three months after it finished. Cancer Council really supported me through that and referred me to a counsellor. ” *Carmen*



Useful websites

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

Cancer Council Australia.....	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Connections.....	cancerconnections.com.au
Australian Health Practitioner Regulation Agency.....	ahpra.gov.au
Australian Human Rights Commission.....	humanrights.gov.au
Cancer Voices Australia.....	cancervoicesaustralia.org
Carer Gateway.....	carergateway.gov.au
Carers Australia	carersaustralia.com.au
Credit and Investments Ombudsman.....	cio.org.au
Department of Health.....	health.gov.au
Department of Human Services (includes Centrelink and Medicare)	humanservices.gov.au
Fair Work Commission	fwc.gov.au
Fair Work Ombudsman.....	fairwork.gov.au
Financial Ombudsman Service Australia.....	fos.org.au
National Health and Medical Research Council.....	nhmrc.gov.au
Office of the Australian Information Commissioner.....	oaic.gov.au
PrivateHealth.gov.au	privatehealth.gov.au
Young Carers	youngcarers.net.au



Glossary

advance care plan

A legal written document that records your medical treatment wishes that can be used if you are unable to speak for yourself due to illness or injury. Also called a living will or advance care directive.

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 with others in a treatment team to support a person's medical care. Examples include psychologists, social workers, occupational therapists, physiotherapists and dietitians.

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 topics and make decisions.

clinical trial

A research study that tests new and better treatments to improve people's health.

code of conduct

Professional rules that health care providers must follow so that patients receive safe, fair and ethical health care.

complementary therapies

Treatments that are used in conjunction with conventional treatment. They might improve general health, wellbeing and quality of life, and help people cope with side effects of conventional cancer treatment.

conciliation

See mediation.

consent

When you agree to something.

enduring guardian

The person you appoint to make medical decisions on your behalf if you lose capacity.

enduring power of attorney

A document that gives a person the ability to act on your behalf on financial, legal and medical matters after you lose capacity.

evidence-based medicine

Where health care providers make decisions based on research studies that measure 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 Medicare Benefits Schedule fee and the doctor's fee.

grade

A score that describes how quickly a tumour is likely to grow.

haematologist

A doctor who specialises in studying and treating diseases of the blood, bone marrow and lymphatic system.

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 expenses of treatment.

inpatient

A patient who stays in hospital while having treatment.

insurance

A contract between a company and a person that guarantees a payment in the case of covered loss, accident or death.

mediation

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

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.

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.

Person Responsible

A person who, under law, can make decisions on behalf of a patient who cannot make their own decisions and has not appointed someone to act on their behalf.

power of attorney

A document that gives a person the ability to act on your behalf on financial, legal and medical 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 health insurance can choose their own doctor and whether they

want to be treated in a private or public hospital.

prosthesis

An artificial replacement for a lost body part.

public guardian

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

public health insurance (Medicare)

Health care insurance provided free of charge to citizens and permanent residents of Australia.

registered health professional

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

registrar

A hospital doctor who is training to be a specialist.

registration board

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

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 break from their usual arrangements.

Schedule fee

Medicare's recommended fee for a medical service.

specialist

A doctor with qualifications and skills in a particular branch of medicine.

For example, 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.

stoma

A surgically created opening to the outside of the body.

substitute decision-maker

A person who makes decisions on your behalf if you become incapable of making them. The documents for appointing this person may be called an enduring power of attorney, an enduring guardian or a power of guardianship.

unfair dismissal

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

unregistered health practitioner

A health care provider who is not legally required to be registered with a government registration board.

Can't find a word here?

For more cancer-related words, visit:

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



How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

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

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council 13 11 20

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

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

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

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

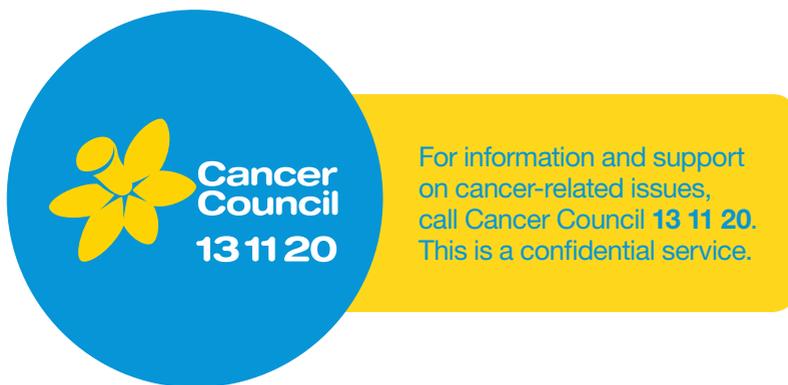
Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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



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



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.*